Promises and Perils:

Supported Decision-Making, Legal Capacity and Rights

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Contents

Introduction

"Capacity is not an off-switch to a person's rights and freedoms"[1]

Historically, when an individual has been found to lack decisional capacity, frequently being individuals with disabilities, States who are signatories of the Convention on the Rights of Persons with Disabilities[2] (henceforth "States") have responded with guardianship regimes that authorise third-party decision-makers, in specific situations, to make decisions *on behalf* of individuals. These guardianship regimes exist across various jurisdictions and have been subject to various reforms. However, in a General Comment released by the United Nations Committee on the Convention on the Rights of Persons with Disabilities (2014) (the "Committee"), the very existence of these regimes has been challenged.[3]

At the turn of the 21st century, the balance between paternalism and autonomy, in respect of individuals who lack capacity,[4] was brought to the fore when proposals for a comprehensive international convention to protect the rights and dignity of individuals with disabilities was examined.[5] A representative for New Zealand summarised the shift, stating:[6]

> "…at one time guardianship was seen as a benign way to protect people with disabilities; now it is seen as an intrusion into people's basic human rights."

This proposal led to the United Nations Convention on the Rights of Persons with Disabilities 2006 (the "CRPD").[7] The CRPD was the first international instrument to specifically address

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[1] *Wye Valley NHS Trust v Mr B* [2015] EWCOP 60.
[2] Convention on the Rights of Persons with Disabilities [CRPD]. Available at <www.un.org/disabilities/documents/convention/convoptprot-e.pdf>.
[3] United Nations Committee on the Rights of Persons with Disabilities *General Comment No. 1. Article 12: Equal recognition before the law*, CRPD/C/GC/1 (2014) at [7].
[4] Wayne Martin "Capacity, Incapacity and Human Rights: A CRPD Perspective" (speech to Keele University, Newcastle, 15 February 2017); David B Wexler and Bruce J Winick *Essays in Therapeutic Jurisprudence* (Carolina Academic Press, North Carolina, 1991) at 68.
[5] United Nations "History of United Nations and Persons with Disabilities – The first millennium decade" <https://www.un.org/development/desa/disabilities/about-us/history-of-united-nations-and-persons-with-disabilities-the-first-millennium-decade.html>.
[6] Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities *Report of fifth session the Ad Hoc Committee* (UN Enable, A/AC.263/2005/2, 4 February 2005) [Ad Hoc Committee].
[7] CRPD, above n 2.

the rights of persons with disabilities, utilising the active participation of the disability rights movement,[8] the CRPD culminated decades of work by the United Nations to change attitudes towards people with disabilities.[9] As one of the fastest negotiated treaties in the United Nations ("UN") framework, there was a strong push for immediate implementation among disability advocates to ensure equality for all individuals with disabilities.[10] Through its resolution, the CRPD made paramount the autonomy of all individuals, promoting an awareness of disability as both a human rights matter and a matter for development.[11]

Despite this, an individual's right to self-determination remained contingent on mental capacity tests, which operate as a threshold for the exercise of legal capacity. The General Comment No. 1 of 2014 (the "General Comment") encourages a radical paradigm shift, both culturally and systematically, from this position.[12] At its core, the General Comment denotes that respect for "universal legal capacity" requires guardianship regimes to be abolished and replaced with support-based regimes that centralise an individual's "will and preferences".[13] Individuals will be entitled to as much support as required to allow them to exercise their legal capacity. This recognises that every individual - with or without disabilities - has the same non-derogable right to make their own legally-binding decisions.[14]

This dissertation will challenge the General Comments conclusion that substitute decision-making, as a guardianship regime, must be abolished for States to comply with the CRPD. It will be shown that supported decision-making, by itself, is not a viable framework for all cases. In Part I, Chapter I will unpack the CRPD, specifically Article 12 and outline the General Comment. Chapter II considers the legal landscape and the extent to which New Zealand's guardianship regimes do, and could, comply with the CRPD and the General Comment.

[8] International Disability Alliance "How ten years of the CRPD have been a victory for disability rights" (6 December 2016) <internationaldisabilityalliance.org/blog/how-ten-years-crpd-have-been-victory-disability-rights>.
[9] United Nations, above n 5.
[10] Piers Gooding "Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law" (2013) 20 Psychiatry, Psychology and Law 431 at 442 and 446.
[11] Lucy Series and Anna Nilsson "Article 12 CRPD: Equal Recognition before the Law" in I Bantekas, MA Stein and D Anastasiou (ed) *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, Oxford, 2018) at 391.
[12] UN Committee, above n 3.
[13] At [17].
[14] *Report of the Special Rapporteur on the rights of persons with disabilities* (Human Rights Council, A/HRC/37/56, March 2018) at [28].

Chapter III will frame the modern understanding of disability and the limits of the social model that is promoted by the General Comment, identifying the "hard cases". Within the context of these hard cases, Chapter IV will operationalise the General Comment in practice, assessing the extent to which the limited retention of substitute decision-making is necessitated in practice and then endorsed by the CRPD and the General Comment. Chapter V will theorise this limited retention within a rights-based approach, rejecting a complete focus on an individual's right for choice to show that the denial of legal capacity, in decision-specific cases, does not equate to the denial of an individual's legal personhood and recognition before the law. In light of this, Part II will consider the steps New Zealand could undertake ahead of its review by the Human Rights Committee at the end of 2019, appreciating the need for both supported and substitute decision-making regimes in a rights-respective society.

I. The United Nations Convention on the Rights of Persons with Disabilities (CRPD)

The CRPD is an innovative human rights treaty, with explicit social development dimensions that advocate for a universal minimum standard to be applied to all individuals.[15] It was introduced after previous human rights treaties proved unsuccessful in addressing the rights of individuals with disabilities and is designed to provide the basis for a coherent framework of action.[16] New Zealand became a signatory to the CRPD in 2007 and ratified it in 2008.[17]

The CRPD's preamble affirms the importance of autonomy, independence and freedom of choice,[18] identifying the right to legal capacity as a component of the right to equal recognition before the law.[19] In light of this, an individual's right in decision-making is recognised through Article 12 of the CRPD, the right of all individuals to have equal recognition before the law.

A. The normative content of Article 12

Article 12 – Equal recognition before the law

1. States Parties reaffirm that persons with disabilities have the *right to recognition* everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy *legal capacity on an equal basis* with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the *support* they may require in exercising their legal capacity.
4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and

[15] United Nations "Convention on the Rights of Persons with Disabilities (CRPD)" <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
[16] Andrew Byrnes and others "From Exclusion to Equality, Realizing the rights of persons with disabilities (United Nations, Handbook for Parliamentarians on the Convention on the Rights of Persons with Disabilities, 2007) at 5.
[17] CRPD, Article 45.
[18] Lana Kerzner and Michael Bach *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* (Law Commission of Ontario, 2010) at 8 and 140.
[19] CRPD, Article 12(3).

preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.

5. […]

Article 12 reconceptualises capacity for individuals with disabilities to participate in decision-making, bringing into the CRPD a direct and explicit statement of the rights of individuals with disabilities.[20] Consequently, States are obliged to provide individuals with support for the exercise of legal capacity, an obligation not previously seen in international human rights law.[21]

1. The General Comment

The General Comment was adopted in 2014 following five years of debate to clarify several interpretive issues regarding Article 12,[22] concluding with an alternative, support-based model for decision-making.[23] Additionally, the General Comment advocates for a rights-based model that is underpinned by the social model of disability (discussed below at (3)),[24] to overcome societal-based barriers that lead to substitute decision-making and rights violations against individuals with disabilities.[25]

2. The radical approach to legal capacity

At its core, the General Comment explores how legal capacity and substitute decision-making operate. It concludes that all substitute decision-making frameworks must be abolished to "ensure full legal capacity is restored to persons with disabilities on an equal basis with others."[26] By extension, the Committee states the right to have decisions recognised in law can

[20] *Report of the Special Rapporteur on the rights of persons with disabilities,* above n 14, at [24] and [74].
[21] Anna Arstein-Kerslake "Restoring Voice to People: Realizing the Right to Equal Recognition Before the Law of People with Cognitive Disabilities" (PhD, Law, National University of Ireland, 2014) at 2.
[22] Lucy Series and others *The Mental Capacity Act 2005, the Adults with Incapacity (Scotland) Act 2000 and the Convention on the Rights of Persons with Disabilities: The Basics* (online loose-leaf ed, Thirty Nine Essex Street) at [10].
[23] UN Committee, above n 3, at [3].
[24] CRPD, Article 1.
[25] Theresa Degener "Disability in a Human Rights Context" (2016) 5 MDPI 1 at 3–5.
[26] UN Committee, above n 3, at [2].

no longer be premised on traditional accounts of mental capacity.[27] Under the General Comment, every individual retains the right to exercise their legal agency regardless of their mental status, even if they require considerable support to do so.[28] Support "must respect the rights, will and preferences of persons with disabilities and should never amount to substitute decision-making"[29] and can only be provided with the consent of the individual.[30]

Finally, the General Comment identifies the higher rate of individuals with disabilities subject to and failing mental capacity tests means capacity laws disproportionately affect individuals with disabilities, discriminating against them.[31] The Committee's interpretation is an attempt to radically realign legal frameworks so individuals with disabilities are seen as autonomous and equally recognised before the law.

3. Disability and the social model

Disability is described generally as an impairment on the functioning processes of an individual as a result of a disease.[32] Under the medical model, disability and impairment are conjoined factors intrinsic to an individual.[33] The CRPD rejects this medicalised understanding, recognising disability as 'an evolving concept' resulting from interactions between individuals and societal barriers, endorsing a social model of disability.[34] Disability, therefore, is caused by barriers present in the socio-political environment where an individual resides,[35] reinforcing that impairments from disabilities can be eliminated by the removal of social barriers and attitudes that reflect how society is ordered.[36] In acknowledging this shift, the General Comment disbands disabilities from impairments, isolating impairments on an individual's legal capacity as "social oppression".[37]

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[27] UN Committee, above n 3 at [4].
[28] At [17].
[29] UN Committee, above n 3, at [4].
[30] *Report of the Special Rapporteur on the rights of persons with disabilities,* above n 14, at 7.
[31] Anna Arstein-Kerslake, above n 21, at 62.
[32] *World Report on Disability* (World Health Organisation and World Bank Group, 2011) at 3-5.
[33] UN Committee, above n 3, at [23].
[34] CRPD, preamble.
[35] UN Committee, above n 3, at [14].
[36] Brent Hyslop "Supported Decision-Making and Dementia"(Masters of Bioethics and Health Law, University of Otago, 2017) at 35-36; Dan Goodley, Bill Hughes, Lennard Davis *Introducing social and disability* (Palgrave Macmillan, New York, 2012) at 2-3.
[37] Tom Shakespeare and Nicholas Watson "The social model of disability: an outdated ideology?" (2002) 2 Journal Research in Social Science and Disability 9 at 12.

4. Legal capacity

Legal capacity is the standard by which an individual and their decisions will be respected in law. Under the CRPD, legal capacity is twofold, engaging legal standing (an individual's recognition before the law) and legal agency (the ability to act within a legal framework to enforce rights held).[38] The right to self-determination, therefore, is framed as an exercise of legal agency, a human rights basic.[39] The General Comment declares, first, "legal capacity is a universal attribute inherent in all persons by virtue of their humanity,"[40] and second, that legal capacity is an essential aspect of the right to recognition as a person before the law.[41]

In the medical context, legal capacity is exercised as informed consent. When an individual does not possess mental capacity, the authority granted by the individual's decision is questioned. Consequently, acts by health professionals remain illegal, subject to the doctrine of necessity, the "best interests" standard under Right 7(4) of the Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 (the "Code") or any other relevant statutory provision. Where an individual holds decisional capacity, the principle of self-determination overrides all other duties, including the sanctity of life and a doctor's duty of care.[42]

Under New Zealand law, an individual's right to exercise their legal agency is commensurate to the gravity of the decision and mental capacity thresholds.[43] Following ratification of the CRPD, New Zealand interpreted Article 12(2)'s reference to "legal capacity" in line with the United Kingdom's common law.[44] This holds "every adult is presumed to have […] capacity

[38] Jacinta Douglas and others "Factor that Underpin the Delivery of Effective Decision-making Support for People with Cognitive Disability" (2015) 2 Research and Practice in Intellectual and Developmental Disabilities 37 at 37; Office of the United Nations High Commissioner of Human Rights (OHCHR), "Legal Capacity" (Background Conference Document for the Sixth Session of the Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities, 1–12 August 2005).

[39] Piers Gooding and Eilionóir Flynn, "Querying the call to introduce Mental Capacity Testing to Mental Health Law: Does the Doctrine of Necessity Provide an Alternative" (2015) 4 L 245; see also Malcolm Parker "Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making" (2016) 13 Bioethical Inquiry 381 at 385.

[40] UN Committee, above n 3, at [8].

[41] At [14]–[15].

[42] *Lake v Medical Council of New Zealand* HC Auckland HC123/96, 23 January 1998.

[43] Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, Right 7(3) and (4) [HDC Code]. Right 7(3) holds: 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 (own emphasis).

[44] HDC Code Right 7(4); Protection of Personal and Property Rights Act 1988, s 5.

but it is a presumption that can be rebutted".[45] Right 7(2) and (3) of the Code codify this presumption on a case-by-case basis,[46] making the right to self-determination conditional on an individual holding certain functional capabilities, including the capacity to retain and understand information, use and weigh that information and communicate a decision.[47]

The General Comment strongly reiterates that "a person's status as a person with a disability or the existence of an impairment (including a physical or sensory impairment) must never be grounds for denying legal capacity".[48] This rejects regimes that deny an individual's capacity solely because they have a disability (the status approach). New Zealand has instead adopted functional tests of mental capacity to assess an individual's ability to perform certain functions.[49] Functional tests are perceived as "disability neutral" because they apply to both people with, and without, disabilities.[50] For example, s 9 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017 codifies the functional capabilities above and applies where an individual is impaired from addiction, or where they are under the influence of impairing substances.[51]

Despite being the most CRPD compliant, the General Comment cites the disproportionate application of mental capacity tests to individuals with disabilities as discriminatory, rendering it only facially neutral.[52] Accordingly, New Zealand's linking of legal capacity to mental capacity renders the law non-compliant under the General Comment's interpretation of Article 12.

5. The status of the General Comment

Under rule 47 of the *Rules of Procedure* for the CRPD, General Comments are made "with a view of promoting [the Conventions] further implementation".[53] As a definitive legal

[45] *Re T (Adult: Refusal of Treatment)* [1992] 4 All ER 649 at 661.
[46] HDC Code, Rights 7(2) and (3).
[47] *Re C (Adult: refusal of treatment)* [1994] 1 WLR 290; [1994] 1 All ER 819.
[48] UN Committee, above n 3, at [9].
[49] Hyslop, above n 36, at 27.
[50] George Szmukler, "Capacity", "best interests", "will and preferences" and the UN Convention on the Rights of Persons with Disabilities (2019) World Psychiatry 18 at 35.
[51] Substance Addiction (Compulsory Assessment and Treatment) Act 2017, s 7.
[52] UN Committee, above n 3, at [9].
[53] Committee on the Rights of Persons with Disabilities *Rules of Procedure* CRPD/C/1/Rev.1 (10 October 2016), Rule 47.

interpretation for the application of treaties,[54] General Comments aid Courts in deciding the meaning of statutory provisions that have their origins in international treaties.[55] Whilst not binding on New Zealand courts unless directly incorporated into domestic law, international treaties should be construed to give effect to international obligations where possible.[56] As a signatory of the CRPD, New Zealand will be under pressure to implement the General Comment.

B. Summation

In consequence of the CRPD and the subsequent General Comment, New Zealand will need to review their current legal structure for decision-making. The following sections consider how New Zealand's law does and could comply with the General Comment's interpretation of the CRPD.

[54] Judy McGregor, Syliva Bell and Margaret Wilson "Human rights in New Zealand: Emerging Faultlines" (Bridget Williams Books, Wellington, 2016) at 39; Helen Keller and Leena Grover, 'General Comments of the Human Rights Committee and their Legitimacy' in Keller and Ulfstein (ed) *UN Human Rights Treaty Bodies* (Cambridge University Press, Cambridge, 2012) 116 at 124.

[55] Andrew Butler and Petra Butler (ed) *The New Zealand Bill of Rights Act: A Commentary* (online ed, LexisNexis) at [3.6.21]. Note that while there have been a large number of references to the International Convention on Civil and Political Rights by New Zealand Courts, reference to the General Comments and jurisprudence of the Human Rights Committee has been significantly less frequent.

[56] *Attorney-General v Chapman* [2011] NZSC 110 at [4]; see also New Zealand Bill of Rights Act 1990, long title. New Zealand law must be construed, where possible, to give effect to its international obligations: *Hamed v R* [2011] NZSC 101 at [36].

II. The Legal Landscape

A. The decision-making options

Compliance with Article 12 now centres on two distinct approaches in law. States must choose, so the General Comment states, between non-compliant substitute decision-making regimes and supported decision-making regimes.[57] This distinction is delineated by the General Comment's conclusion that substitute decision-making regimes must be abolished and replaced with supported decision-making alternatives."[58]

1. Substitute decision-making

The General Comment outlines the common characteristics of substitute decision-making as follows:[59]

(a) Legal capacity is removed from a person;
(b) A substitute decision-maker can be appointed, with or without the will of the individual; or
(c) Any decision made by the substitute decision-maker is based on the "best interest" test.

Substitute decision-making regimes allow authorised third party's to undertake decision-making processes for individuals who lack decisional capacity. Under this substitution, decision-makers should make the decision the individual would have made themselves, had they held capacity.[60] However, there is no overriding obligation to prioritise an individual's will and preferences.

2. Supported decision-making

In comparison to substitute decision-making, supported decision-making regimes explicitly keep the locus of decision-making with the individual, comprising various formal and informal

[57] UN Committee, above n 3, at [3]; Wayne Michael Martin and others *The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK* (University of Essex, Essex Autonomy Project Position Paper, June 2016) at 11.
[58] UN Committee, above n 3, at [24].
[59] At [23].
[60] *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [44]–[45], per Lady Hale.

support options[61] that give primacy to an individual's will and preferences.[62] In the context of the General Comment, supported decision-making involves an appointed third party (the "supporter") assisting an individual to identify and implement their will and preferences.[63] Any decisions made on behalf of an individual are excluded.[64] Crucially, supported decision-making frames legal capacity as autonomous decision-making that empowers individuals to govern their lives free from the interference of others.[65] This espouses freedom of choice through independent decision-making, a focus that is not yet fully recognised in New Zealand's law.

B. New Zealand's law

New Zealand's key legal guardianship regime, the Protection of Personal and Property Rights Act 1988 (the PPPRA) and Right 7(4) of the Code are "substitute decision-making regimes".[66] Whilst it is unfair to say all decisions made under these regimes breach the CRPD, the very existence of substitute decision-making alternatives make both regimes non-compliant with the General Comment.

This section will consider the extent to which PPPRA and the Code currently comply with the support paradigm promoted in the General Comment and the universal right to self-determination.

1. Protection of Personal and Property Rights Act 1988

The PPPRA aims to protect and promote the personal and property rights of adults who "are not fully able to manage their own affairs"[67] and has been New Zealand's dominant guardianship regime for over 30 years. Like the common law, s 5 of the PPPRA presumes every person "until the contrary is prove[n]" holds the capacity to:[68]

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[61] UN Committee, above n 3, at [21].
[62] At [25].
[63] Martin, above n 4.
[64] Jeanne Snelling and Allison Douglass "Legal capacity and supported decision-making" in Iris Reuvecamp and John Dawson (ed.) *Mental capacity law in New Zealand*. (Thomson Reuters, Wellington, 2019) 163 at 168.
[65] Hyslop, above n 36, at 13.
[66] See this dissertation, Part I, I (a)–(c).
[67] Protection of Personal and Property Rights Act 1998, s 1 (long title).
[68] Section 5(a) and (b).

(a) understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; and
(b) to communicate decisions in respect of those matters.

Akin to the common law, this presumption is revoked when an individual wholly or partly lacks capacity, placing the individual under the court's jurisdiction.[69] An application can also be made to place an individual under the court's jurisdiction when they lack capacity.[70] In these cases, the PPPRA empowers the Family Court to make personal orders,[71] including appointing a welfare guardian (WG) to make decisions on an individual's behalf.[72] In exercising their jurisdiction, the court's primary objectives are "to make the least restrictive intervention possible in the life of the person"[73] and to "enable or encourage an individual to develop and exercise their capacity to the greatest extent possible".[74]

The PPPRA implicitly incorporates aspects of the support model. For example, an appointed lawyer must, "as far as practicable", explain the nature of the application to the individual and "ascertain and give effect to that person's wishes".[75] Similarly, an appointed WG must encourage an individual "to act on his or her own behalf to the greatest extent possible".[76] In consequence, a WG's predominant consideration is promoting an individual's welfare and best interest.[77] Both WG's and the court must encourage an individual "to develop and exercise such capacity as that person has to understand the nature and foresee the consequences of decisions relating to the personal care and welfare of that person, and to communicate such decisions".[78]

Under the PPPRA an individual's interests can be centralised, however, their "will and preferences" are not the overriding concern and are subordinate to a decision made in an individual's "best interests". Therefore external factors can be considered, especially if the

[69] Section 6.
[70] Section 7.
[71] Section 10.
[72] Section 12.
[73] Section 8(a).
[74] Sections 8(a) and 8(b).
[75] Section 74(1).
[76] Section 18(4)(a).
[77] Section 18(3).
[78] Section 18(3).

health of an individual is seriously compromised,[79] or if risk to the individual or others would arise if the individual's will and preferences are respected, or if an individual is so impaired that capacity can never be held. Furthermore, the PPPRA's implicit recognition of support does not equate to a "presumption" for supported decision-making, rendering it non-compliant with the CPRD per the General Comment.[80]

2. Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 (the Code)

The Code is a rights-based instrument, declaring ten specific consumer rights and reciprocal duties for healthcare providers.[81] Aspects of the Code arguably reflect the spirit of the CRPD by promoting the rights of consumers and a system of accountability. Under Right 7(1) health and disability services can "only" be provided if that consumer makes an informed choice and gives informed consent. This is subject to an exception where any statute, the common law or another provision of the Code provide otherwise.[82]

Right 7(2) explicitly considers legal capacity, stating a consumer "retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence".[83] Therefore, a spectrum of competence is contemplated and reiterated under the requirement for informed consent under right 7(1). Furthermore, exceptions to an individual having capacity are considered by the definition of "consumer" extending to include a person entitled to give consent on behalf of a consumer.[84]

Finally, if an individual lacks capacity and no-one entitled to consent on their behalf is available, Right 7(4) allows health services to be provided if they are "in the best interests of the consumer" and "reasonable steps have been taken to ascertain the views of the consumer" and either:[85]

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[79] Snelling and Douglass, above n 64 at 175; see also *R v R* [2004] NZFLR 797 at [75] per Miller J.
[80] Alison Douglass "Supported Decision-making" in A Douglass *Mental Capacity: Updating New Zealand's Law and Practice* (New Zealand Law Foundation, Dunedin, 2016) 44 at 54.
[81] Snelling and Douglass, above n 64, at 173.
[82] HDC Code, Right 7(1).
[83] Right 7(3).
[84] Clause 4 of the HDC Code specifies that for the purposes of Right 7(1) a "consumer" includes a person entitled to give consent on behalf of that consumer.
[85] HDC Code, Right 7(4)(c)(i)-(ii).

a. 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
b. 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.

The Code, therefore, establishes a patient-centric approach by requiring, whenever possible, a genuine attempt to ascertain a patient's views. However, no guidance is provided on what reasonable steps must be taken to obtain a consumer's views and in turn, a presumption for substitute decision-making remains.

C. Summation

Whilst the above regimes indicate an ability for New Zealand's law to accommodate the support paradigm, the provisions for support are merely implicit. Whilst not surprising, given both regimes predate the CRPD, modernising the law to introduce an explicit support framework into New Zealand is encouraged. Supported decision-making has been shown to facilitate therapeutic benefits, including benefits to recovery in cases where the individual has been involved in decision-making,[86] as well as providing for the development of alternative communication and cultural approaches that will allow for the diverse nature of New Zealand's socio-political environment to be accommodated.[87] These benefits compel the inclusion of supported decision-making as far as possible, however, legal reform must be conscious of cases where the different avenues of support are unsuccessful, requiring instead substitute decision-making. If the law fails to appreciate these hard cases it will ultimately fail.[88]

[86] Wexler and Winick, above n 4, at 73.
[87] At 76.
[88] Charles Foster *Choosing Life, Choosing Death: The Tyranny of Autonomy in Medical Ethics and Law* (Hart Publishing, Oregon, 2009) at 10.

III. Disability and the "Hard Cases"

In abolishing substitute decision-making, supported decision-making must apply irrespective of the nature and extent of an individual's disability.[89] This blanket approach is examined below to recognise the inherent tensions that will arise when the complexities of disability and impairment are actualised. In appreciating that support will assist some individuals capacity for decision-making, especially where impairments mean an individual must communicate through alternative means, a strong case is made for situations where support is not successful.[90]

A. The "hard cases"

The social model of disability has become widely promulgated to recognise the impact of social environments on individuals with disabilities.[91] The General Comment proposes that by mitigating social barriers, an individual can exercise their legal capacity through self-regarding decisions. However, the General Comment's assumption that it is always possible to support individuals with disabilities in decision-making is misleading and not practical in "hard cases".[92] These "hard cases" are described below.

1. Organic impairment resulting in extreme medical disability

The unconditional rejection of substitute decision-making by the Committee is contentious for individuals with profound cognitive impairment, a complete inability to communicate, or whose disability has meant they are unable to express, from birth, a will or preference.[93] The social model relies on disability and impairment being wholly explained by social barriers, which are subsequently mitigated through support. In consequence, the General Comment's disability framework fails to acknowledge the organic nature of various disabilities and impairments. For example, the molecular processes of dementia mean its organic pathology[94] cannot be remedied by socio-political modifications, therefore, an individual's decision-

[89] Snelling and Douglass, above n 64, at 171-172.
[90] See generally Renata Kokanovic and others *Options for Supported Decision-Making to Enhance the Recovery of People Experiencing Severe Mental Health Problems* (Melbourne Social Equity Institute, University of Melbourne, Melbourne, 2017) at 20 and 47-48.
[91] Snelling and Douglass, above n 64, at 164-165.
[92] Foster "Choosing Life", above n 88, at 10-11.
[93] Snelling and Douglass, above n 64, at 170.
[94] Hyslop, above n 36, at 36.

making capabilities will not be enhanced through support.[95] This reveals the social model's inability to apply to all disabilities, asking, how will the support paradigm respond to individuals who, after all reasonable avenues of support are exhausted, cannot exercise their decisional capabilities?[96] This dissertation poses an alternative rights-based regime that is conscious of these situations.

2. Identifying will and preferences

The proposed elimination of substitute decision-making regimes restricts the action that can be taken when an individual cannot express a will or preference. Or when, due to disability since birth, an individual never held or expressed a will and preference. Article 12(3) requires all actions to respect the "rights, will and preferences" of the individual. Where an individual's will and preferences cannot be ascertained, a representative may make decisions based on their "best interpretation" of an individual's will and preferences from the available evidence.[97] In giving effect to this provision, decision-makers will likely continue to operate from an objective standard due to a lack of available evidence.[98] In consequence, "best interpretation" and "best interests" are likely to align and coextensively become substitute decision-making, indicating all that has changed is the language used to describe the decision-making paradigm. This contention was recognised by the Chair in the preparatory notes of the CRPD when it was stated that "in actual practice, 100% support would equate to personal representation".[99]

3. Competing will and preferences

The General Comment believes an individual's "will" and "preferences" can co-exist, routinely conflating the two concepts. This is not plausible. The "paradoxical nature" of anorexia nervosa, for example, means an individual may hold a will to live whilst simultaneously maintaining a preference not to eat.[100] In parallel, the courts summary in *Department of*

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[95] Szmukler, above n 50, at 39.

[96] Series and others, above n 22, at [49]-[52].

[97] UN Committee, above n 3, at [21]; Canadian Association for Community Living *Response to Draft General Comment No. 1 on Article 12 UN Committee on the Rights of Persons with Disabilities* (26 February 2014) at 483.

[98] Smulzker, above n 48, at 36-37.

[99] Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities *Daily Summary of Discussions* (UN Enable, 3 February 2006, morning session per the Chair).

[100] See Finn Skårderud "Eating one's words, part II: The embodied mind and reflective function in anorexia nervosa—theory" (2007) 15 European Eating Disorders Review 243 at 250.

Corrections v All Means All[101] (a case about a prisoner's hunger strike) recognised that the goal of a hunger strike is to undertake a protest, with death a possible but unwanted outcome.[102] In these situations, an individual's will and preferences cannot mutually exist and in consequence, will fail to provide effective guidance for decision-making.

Furthermore, variations in disabilities can mean an individual's previously held preferences can change. Dementia, for example, results in progressive, irreversible cognitive decline[103] that can mean an individual's will and preferences could drastically change, severing their personality chain and destroying the psycho-emotional continuity between their present self and past self.[104] Correspondingly, paranoid schizophrenia involves episodic psychosocial impairments which may cause frequent fluctuations in an individual's will and preferences.[105] This severance inquires whether State's must hold an individual bound to their old will and preferences, or accept a new, albeit momentary, preference expressed following exacerbations of a disability?

4. Respecting an individual's will and preferences and "serious adverse consequences"

In *Hutt Valley DHB v MJP*,[106] MJP was in the advanced stages of dementia and subject to an application under the PPPRA. Whilst not having nor wanting support at home, MJP expressed strong wishes to return home and care for herself. If MJP's will to remain at home was accepted she would have been left to personally care for her personal hygiene, household management and food intake. Support services such as an in-house nurse and meals on wheels[107] could help mitigate the evidence that showed MJP struggled "with initiation, with follow-through of tasks and with executive functions", especially concerning eating and drinking and taking her

[101] *Department of Corrections v All Means All* [2014] 3 NZLR 404.
[102] At [41].
[103] Hyslop, above n 36, at 17.
[104] See Jesse Wall and Jonathan Herring "Autonomy, Capacity and vulnerable adults: filling the gaps on the Mental Capacity Act" (2015) 35 *Legal Studies* 698 at 703-705, 710.
[105] Hyslop, above n 36, at 17-18.
[106] *Hutt Valley District Health Board v. MJP* [2012] NZFLR 458.
[107] CRPD, Article 25(b) requires State Parties to provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons.

medication.[108] The mitigation of these factors is likely to be crucial to MJP's right to health and may be included under her right to health services under article 25(b) of the CRPD.[109]

If MJP maintained she did not want in-house support, this preference would conflict, in practice, with her wish to live at home.[110] If no in-house support was provided, or the demands of MJP's healthcare increased so that support provisions were no longer sufficient, a gap in the support model is highlighted where an individual's choice is harmful to themselves or others. In *MJP*, Moss J made personal orders for dementia level care and the necessary medical treatment, recognising MJP's need for interactive care and ongoing treatment.[111] This conclusion would not be possible under the support paradigm because support cannot be provided against an individual's will,[112] especially in cases where it overrides their will and preferences. In consequence, the support paradigm would have left MJP to live in squalid conditions at the expense of her disability.

B. Summation

The aforementioned "hard cases" challenge the General Comment's belief that an individual can never lack capacity, recognising times where support may fail to aid an individual's ability to exercise their legal agency. In these cases, reliance on a support framework will pose unanswerable and unguided tasks for supporters. Therefore, the General Comment's support paradigm cannot provide a functional basis for a workable rights-based framework in New Zealand. The remainder of this section will consider the claims made by the General Comment and their impact in practice. Most pointedly, it will consider whether substitute decision-making should be abolished and completely replaced by supported decision-making.

[108] *Hutt Valley*, above n 100, at [10].

[109] Health and Disability Commissioner *Opinion 11 HDC00647 – GP, Dr C* (10 June 2013). The Commissioner opined that Dr C failed to provide appropriate care and support for her patient by not continuing to assess the patient who had Huntington's disease and lived in isolation.

[110] UN Committee, above n 3, at [21]. Paragraph 21 indicates that an individual must be provided with support but must also be entitled to reject the provision of any support.

[111] At [16].

[112] At [19]. The UN Committee state "some persons with disabilities only seek recognition of their right to legal capacity on an equal basis with others, as provided for in article 12, paragraph 2, of the Convention, and may not wish to exercise their right to support, as provided for in article 12, paragraph 3."

IV. Operationalising the General Comment

This section will consider the operational difficulties promoted by the wholesale paradigm shift from substitute decision-making to supported decision-making. It will first consider the General Comment's claim that substitute decision-making regimes are discriminatory. It will make a case for the retention of mental capacity and consider how legal capacity, alongside the right to equal recognition before the law, is framed by the General Comment. An alternative framing that is realistic to the hard cases experienced by individuals with disabilities will be suggested, concluding that supported decision-making, in the context of hard cases, is at best an enigmatic, and at worst specious, concept.[113]

It is important to note the General Comment's stipulation that substitute decision-making must be abolished is not endorsed in the CRPD. The CRPD does not mention substituted, nor supported, decision-making explicitly. During the drafting of the CRPD, the co-ordinator asked of Article 12 "whether the article should focus on supported decision-making and not permit substitute decision-making?"[114] A conclusive response was not reached, instead a compromise was formed that whilst supported decision-making was important, substituted decision making should neither be encouraged nor abolished.[115] Despite this history, the General Comment adopts an absolutist position to abolish substitute decision-making, revisiting the posed question to answer in the affirmative.

A. Are New Zealand's guardianship laws discriminatory?

Freedom from discrimination based on disability directly correlates to the right of individuals with disabilities to be "treated on an equal basis with others".[116] The General Comment makes

[113] Michelle Browning, Christine Bigby and Jacinta Douglas "Supported Decision Making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice" (2014) 1 *Research and Practice in Intellectual and Developmental Disabilities* 34 at 34.

[114] Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities *Report of seventh session the Ad Hoc Committee* (UN Enable, A/AC.265/2006/2, 13 February 2006); Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities *Daily Summary of Discussions* (UN Enable, 3 February 2006). The coordinator repeatedly pressed the question of whether substitute decision-making should not be permitted.

[115] Ad Hoc Committee on a Comprehensive and Integral International Convention on Protection and Promotion of the Rights and Dignity of Persons with Disabilities *Daily Summary of Discussions* (UN Enable, 18 January 2006).

[116] John Dawson "A realistic approach to mental health laws compliance with the UNCRPD" (2015) 40 Intl J L & Psychiatry 70 at 71.

the bold empirical claim that mental capacity tests are discriminatory towards individuals with disabilities, due to their disproportionate application.[117] In practice, this impugns systems that are facially neutral but whose law discriminates against individuals with disabilities in application or effect.[118] In addition to removing disability as a legitimate reason to deny legal capacity, the General Comment also provides that legal capacity cannot be denied due to impairments in decision-making ability.[119] This section will show that while it is undeniable that capacity laws can, and often do, discriminate based on disability, "discrimination", as a legal concept does not mean all differential treatment constitutes discrimination. Rather, the law is concerned with unjustified differential treatment that disadvantages individuals.[120]

The General Comment's framing of discrimination is at odds with the International Covenant on Civil and Political Rights (the "ICCPR") and the subsequent United Nations Convention on the Rights of Individuals to be free from Discrimination.[121] The latter states 'not every differentiation of treatment will constitute discrimination, if the criteria for such differentiation are reasonable and objective and if the aim is to achieve a purpose which is legitimate under the Covenant'.[122] Accordingly, claims of discrimination entail a multifaceted analysis that cannot be answered by analysing the extent to which the law applies to one group of individuals over another. Guardianship laws in this way can be analogised to rules that prevent a blind individual from operating a vehicle,[123] or an individual impaired by their level of intoxication from operating a motor vehicle.[124] These laws are likely to disproportionately apply to individuals who suffer from disabilities, namely blindness and alcoholism, yet are not considered to be disproportionate or discriminatory.

When impairments are objectively considered, an intervention cannot always be seen as discriminatory. Instead, it is the type of intervention and the circumstances in which it occurs

[117] UN Committee, above n 3, at [9].
[118] Series and others, above n 22, at [6].
[119] UN Committee, above n 3, at [9]; Hyslop, above n 36, at 28.
[120] Dawson, above n 116, at 71; see also Mary Donnelly "From Autonomy to Dignity: Treatment for Mental Disorders and the Focus for Patient Rights" (2008) 26 Law in Context 37 at 38.
[121] International Covenant on Civil and Political Rights.
[122] United Nations Human Rights Committee CCPR *General Comment No, 18: Non-discrimination* HRI/GEN/1/Rev.9 (10 November 1989) at 13.
[123] Dawson, above n 116, at 73.
[124] Land Transport Act 1998, ss 11-12.

that may result in disadvantage and discrimination.[125] A convincing theory of discrimination would indicate, therefore, that it is not improper discrimination to treat individuals differently when relevant differences exist between their situations and accommodation of these differences is not reasonable. This recognises, in light of the support paradigm, that difference must be assessed after adequate support and reasonable accommodation has been provided.[126] Where support is not conducive to an individual's interests or fails to plausibly aid their decisional capacity, the Committee's claim that all individuals can retain their legal capacity may itself result in disadvantage and indeed be harmful. This is due to the Committee's failure to recognise objective differences in the functional capabilities of individuals when support mechanisms fail, requiring instead the "equal treatment of those who are not equal".[127] The scope of this disadvantage is considered throughout this section to recognise the need for the limited retention of substitute decision-making for hard cases.

B. Retaining mental capacity tests

The General Comment states mental capacity approaches are "flawed" because they presume "to be able to accurately assess the inner-workings of the human mind".[128] The General Comment further denies the use of decisional capacity because it is not "naturally occurring" and therefore cannot fairly deny an individual's decision-making.[129] This is an inaccurate ideological claim. As Hyslop states, "the fact that something is not naturally occurring does not mean it is not a useful concept".[130] The criminal law's use of mens rea, for example, also engages mental functioning standards to assess an individual against a mental criterion. These tests are an evaluative line that decides the validity of an individual's decisions within a legal framework, albeit its circumstantial nature. Mental capacity thresholds operate as this line in the medical sphere, mediating circumstances where an individual cannot exercise the functional processes of mental capacity and therefore require a third party decision-maker.

[125] Anne Plumb "UN Convention on the Rights of Persons with Disabilities: out of the frying pan into the fire? Mental health service users and survivors aligning with the disability movement" in H Spandler, J Anderson J and B Sapey (ed) *Madness, distress and the politics of disablement* (Policy Press, Bristol, 2015) 183 at 195.
[126] Dawson, above n 116, at 74.
[127] *Austin v Commonwealth* (2013) 215 CLR 185 at [247].
[128] UN Committee, above n 3, at [15].
[129] At [14]; Hyslop, above n 36, at 49.
[130] Hyslop, above n 36, at 49.

C. The limits of "will and preferences"

An individual's will and preferences are promoted as the guiding factors for decision-making under the General Comment. However, there are strong risks involved in adopting a legal regime that requires complete adherence to an individual's will and preferences in all circumstances.

1. Distinguishing will and preferences

In their basic forms, there is a recognisable difference between an individual's "will" and their "preferences". An individual's will is habitual, "reasonably stable" and likely to be well established.[131] Alternatively, an individual's preferences may fluctuate and at times, based on the situation, conflict with their will. Therefore, when an individual's preferences conflict with their will, a threshold question of what short term interest can override the long term will of the individual is engaged.[132] In these situations, the General Comment's promotion of an individual's will and preferences, as guides for decision-making, will leave supporters in a decisional deadlock if the individual is unable to provide further guidance on these matters.[133]

For example, in *A Local Authority v E and Others,* a 32-year-old woman (E) suffered from anorexia nervosa, alcohol and opiate dependence and an unstable personality disorder.[134] On an application to consider whether E could be forcibly fed, the court reasoned the anorexia nervosa disease had impacted E's reasoning process and the "real E" would have wanted to live.[135] In this case, the court had to assume E's "will" to be that she wanted to live, despite her immediate preference that she did not want to eat. Expanding this analysis, it is evidenced that substitute decision-making will be required when supporters are unsure of an individual's will and preferences, or the will and preferences of the individual do not indicate a mutually compatible outcome.

[131] Szmukler, above n 50, at 38.
[132] Wall and Herring, above n 104, at 708.
[133] Melvyn Freeman and others "Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities" (2015) 2 Lancet Psychiatry 844 at 845-846.
[134] *A Local Authority v E & Others* [2012] EWHC 1639 (COP).
[135] At [129]–[133].

2. Indiscernible preferences

The hard cases analysis recognises a class of disability impairments, for example, permanent cognitive impairments from severe hypoxic brain injury or when an individual is in a coma, that indicate the support paradigm will fall short in aiding *all* individuals with disabilities. In these hard cases, the will and preferences of an individual will be indiscernible unless intuited from a prior life story. The Committee provides some guidance for these situations, endorsing the use of advance directives to allow an individual to plan prospectively for situations where "they may be unable to communicate their wishes to others."[136] Paradoxically, the Committee also concludes that an individual retains legal capacity at all times.[137] This inconsistency contests the claim that the denial of decisional capacity also denies individuals recognition before the law.

With regards to the legal capacity debate, it can be presumed that where advanced directives exist, any wishes expressed at a time of wellness will override those stated during an "acute, severe exacerbation of mental illness".[138] Again, however, little guidance is provided for situations where an advance directive has not been completed, or when individual's wishes to revoke their advance directive (an exercise that currently requires capacity).[139] This is made increasingly difficult by the General Comment's requirement that an individual must voluntarily accept any support provided,[140] despite the duties of reasonable care and skill owed by healthcare providers to individuals in the medical sphere.[141] The inherent ambiguity in these situations is likely to mean, in practice, that other duties owed to an individual will take precedence over the individual's right to self-determination in acute circumstances. In consequence, State's will be at risk of having to reject parts of the General Comment, risking their international law compliance.

3. "Respect" for the rights, will and preferences of an individual

Article 12(4) of the CRPD requires States to provide "respect for the rights, will and preferences" of an individual. Where an individual's will and preferences are known, Peter

[136] UN Committee, above n 3, at [17].
[137] At [18].
[138] Freeman and others, above n 133, at 843 and 846.
[139] See HDC Code, Right 7(4) and (5); Foster "Choosing Life", above n 88, at 155. An advance directive must relate to the circumstances the patient faces at the time to operate as decisive evidence. Advance directives are not able to apply to requests for, or authorisation of treatment, under New Zealand law.
[140] UN Committee, above n 3, at [29(g)].
[141] HDC Code, Right 4.

Jackson J in *Wye Valley NHS Trust v Mr B*[142] ruled an individual's "wishes and feelings" should not be ignored because they are not objectively assessed to be in the individual's best interests.[143] This aligns with the requirement under New Zealand's guardianship laws that substitute decision-makers must consider the expressed interests of an individual in reaching a "best interests" determination, embracing a patient-centric approach.[144] Debates about respect for an individual's rights, will and preferences, **therefore,** do not arise because New Zealand's legal approach is not patient-centric, instead, it is the weight that is given to the views of individuals who lack capacity within the decision-making framework that is contentious.

The General Comment presumes an individual's will and preferences will be made paramount and upheld in all cases. Therefore, it will never be justified, on the contrary, to override the will of an individual based on an assessment of their decision or its impact (to the extent these are lawful).[145] However, interpreting "respect" to mean complete adherence is contentious. "Respect" as Martin et al. explains is something stronger than consider, but less than an obligation to be bound by.[146]

The Committee's absolute obligation to uphold the will and preferences of an individual is especially contentious where an individual's decision is harmful to themselves or others, or risks compromising their autonomy in the future. Recognising this, a recent decision by the European Court of Human Rights has endorsed a less restrictive obligation, indicating the will and preferences of an individual cannot always be determinative of decisions taken in their name.[147] "Respect" in this case required a:[148]

> …balance between the respect for the dignity and self-determination of the individual and the need to protect the individual and safeguard his or her interests, especially

[142] *Wye Valley*, above n 1.
[143] At [16].
[144] HDC Code, Right 7(4)(c)(i); PPPRA, s 6(1)(b).
[145] Series and others, above n 22, at 16. The authors note, despite the lack of comment by the UN Committee, that where an individual's will and preferences constitute an illegal action, no person will be forced to realise them.
[146] Martin and others, above n 57, at 40.
[147] *A.-MV v. Finland* [2017] ECHR 273. This case was decided in light of the draft Mental Capacity Amendment Bill, which provides a regulation-making power to establish a 'supported decision-making scheme'. For a broader discussion, see Alex Keene and others *Mental Capacity Report: Compendium* (Essex Chambers, Issue 76, May 2017) at 20-24.
[148] *A-MV v Finland* at [90].

> under circumstances where his or her individual qualities or situation place the person in a particularly vulnerable position.

Legal tensions are likely to increase when the right to self-determination is considered paramount for both individuals who have capacity and for those who do not. In the hard cases, as recognised in *Superintendent of Belchertown State Sch. v. Saikewicz*,[149] a substitute decision-maker may be integral to "respecting the dignity and worth" of a patient's life.[150] In *Saikewicz*, the court recognised that the well-being and dignitary interest in avoiding suffering for a 67-year-old patient, with the mentality of a three-year-old, necessitated a third party decision-maker. This aligns with CRPD's purpose to "ensure the full and equal enjoyment of all human rights" including the right to healthcare[151] and an adequate standard of living and social protection[152], as a means to "promote respect for [an individual's] inherent dignity".[153] Respect, therefore, requires consideration of an individual's will and preferences, however, these cannot be determinative factors and must be considered alongside other rights and interests.

4. Summation

The proposed gaps in the General Comment risk forcing supporters and individuals who lack decisional capacity into practical impasses. Equally, supporters who are left to endorse the will and preferences of an individual, regardless of the outcome, are unlikely to gain satisfaction from the role and may face rejection by the practising clinician.[154] This will risk a potential decrease in individuals volunteering to be supporters, of the standard of support and the further promotion of support and rights principles.[155]

D. When does support become substitution?

The Committee acknowledges, despite its conclusion, that in some circumstances it will not be 'practicable to determine the will and preferences of an individual'.[156] In these cases, a

[149] *Superintendent of Belchertown State School v Saikewicz* 373 Mass. 728 (1977).
[150] Norman L Cantor *Making Medical Decisions for the Profoundly Mentally Disabled* (The MIT Press, Massachusetts, 2005) at 39.
[151] CRPD, Article 25.
[152] Article 28.
[153] Article 1 (purpose).
[154] Kokanovic and others, above n 90, at 39.
[155] At 37-38 and 40-44.
[156] UN Committee, above n 3, at [20] – [21].

supporter must undertake a "best interpretation" of an individual's "will and preferences" as a last resort.[157] The problems with this test are twofold.

First, "last resort" is an important, yet crucially underdeveloped threshold that risks leaving supporters and individuals in a practical and theoretical lacuna. This is because the support paradigm, when underpinned by the social model of disability, overlooks the external constitutive elements of disability and capacity. Consequently, supporters are left to practically consider how much support they must provide before accepting they are in a situation of last resort. In parallel, a theoretical inquiry asks, to what extent can an individual be regarded as personally capacious if they are completely reliant on relationships with others to make decisions?[158]

Second, the General Comment's requirement for supporters to undertake a "best interpretation" is vague and potentially unanswerable when the will and preferences of an individual are unknown or conflict?[159] It equally assumes a supporter will be able to tell a coherent story of who an individual is.[160] As Emily Jackson states, where an individual has never had any discernible will or preferences, the "legal fiction" of coming to the 'best interpretation' of their will and preferences will veil the reality that decisions can only be made based on what others believe to be in an individual's interests.[161]

Supported decision-making in "hard cases" risks granting unregulated authority to a supporter, which may have serious adverse risks for individuals where this authority is exercised ostensibly. Supporters can impute indeterminate preferences onto an individual and in consequence, are likely to form a decision that cannot itself be evaluated. Given the epistemic uncertainty and unequal power dynamic in supported decision-making, the potential threats to an individual's right to healthcare and well-being are increasingly concerning.[162] In

[157] At [21].
[158] Lucy Series "Relationships, autonomy and legal capacity: Mental capacity and support paradigms" (2015) 40 International Journal of Law and Psychiatry 80 at 84.
[159] See *Re E (Medical Treatment Anorexia)* [2012] EWHC 1639 (COP).
[160] Kerzner and Bach, above n 18, at 65.
[161] Emily Jackson, "From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment" (2018) 81 The Modern Law Review 247 at 274.
[162] Series, above n 158, at 83.

consequence, individuals who lack decisional capacity may be left within an imagined framework that relies on their unknown or conflicting perspectives.

It must be asked, therefore, whether total support based on an individual's perceived will and preferences is better at promoting rights in comparison to a substitute decision-making regime? A conscious reading of the aforementioned situations contends that, in the hard cases, support will become substitution and that frameworks which fail to consider this may place individuals with disabilities into a fabricated framework. Legal reform, therefore, must consider how the limited retention of substitute decision-making can be regulated within a framework of support.

E. Decision-making under the CRPD

The tension between substitute decision-making and supported decision-making, as a dichotomy, is an unhelpful premise promoted by the General Comment. This section will show that support for the limited retention of substitute decision-making can be found in CRPD itself.

1. Article 12(4) safeguards

The General Comment frames substitute decision-making as one of the States most paternalistic arms and while the extent of this paternalism is being challenged, protection by the State is arguably reflected in the CRPD. Under Article 12(4) of the Convention, States must provide "appropriate and effective safeguards" to prevent abuse in accordance with international human rights law.[163]

The Committee contemplates safeguards that prevent abuse, conflicts of interest, or undue influence.[164] Perhaps unsurprisingly, given the social model underpinnings of the CRPD, the Committee only recognise the aforementioned external processes. This reasoning is incompatible for hard cases, acknowledging that whilst supported decision-making regimes reject the laws paternalistic origins, they risk providing less protection in consequence.[165] A holistic reading of the CRPD frames Article 12(4) within proportionality and duration requirements,[166] implying a greater depth to the safeguards than a primary purpose of ensuring

[163] CRPD, Article 12(4).
[164] UN Committee, above n 3, at [22].
[165] Douglass "Supported Decision Making", above n 80, at 2.20.
[166] CRPD, Article 12(4).

support for the exercise of a person's "rights, will and preferences", as promoted by the General Comment.[167]

(a) Proportionality of response

The CRPD clearly states "safeguards shall be proportional to the degree to which such measures affect the person's rights and interests."[168] This is difficult to reconcile with the General Comment's statement that "[at] all times, including in crisis's, the individual autonomy and capacity of persons with disabilities to make decisions must be respected."[169] A proportional response would require, as Snelling and Douglass frame, consideration of whether, under exceptional circumstances, limited actions contrary to an individual's will and preferences, maybe the most proportionate way of protecting the full range of rights and freedoms reaffirmed under the CRPD.[170]

Exceptional circumstances include situations where an individual's disability removes them from the context of reality, making them a danger to themselves. In a case under the PPPRA, *Mr HK* suffered from paranoid schizophrenia and refused to consent to urgent tooth extraction for a severe infection.[171] Mr HK's denial was based on the delusion that after becoming a Sunni Muslim in 1981, he gained a 'mentor' and Muslim doctor (Dr S), who is 400 years old. Mr HK believed Dr S would take away his teeth and arrange for others to grow back, whilst also believing his teeth were "majestic" and would "last centuries".[172] By completely adhering to Mr HK's delusions, Mr HK would be at serious risk of further medical complications and serious discomfort. This appears incompatible with the intentions of Article 12(4).

The court recognised their dual obligations to respect the wishes of Mr HK whilst providing the least restrictive intervention possible,[173] an important acknowledgement in cases where the right to self-determination is exercised under a delusion.[174] Despite medical advice to remove

[167] UN Committee, above n 3, at [20].
[168] CRPD, Article 12(4).
[169] UN Committee, above n 3, at [18].
[170] Snelling and Douglass, above 64, at 173.
[171] *Re HWK* [2012] NZFC 9497 at [2]–[3].
[172] At [24].
[173] At [25].
[174] Bruce J. Winick, "Competency to Consent to Treatment: The Distinction between Assent and Objection" in David B Wexler and Bruce J Winick (ed) *Essays in Therapeutic Jurisprudence* (Carolina Academic Press, North Carolina, 1991) 41 at 61.

an additional three teeth that did not have any discernible decay, the Court's treatment order restricted extraction to Mr HK's decayed teeth.[175] The court reasoned that the limited extraction was likely to be what Mr HK would have decided had he held capacity.[176] In this case, the court's analysis indicates how respect for Mr HK's will can be included within a consideration of the need to protect his rights and interests in healthcare and bodily integrity. This resulted in a proportional and rights-respective response despite the court's role as a substitute decision-maker.

(b) Temporal Limitations

The CRPD's temporal consideration requires safeguards to apply for the shortest time possible, implying a contemplation of a coercive element.[177] This is at odds with the General Comments interpretation that support should be applied for as long as required and to the extent that is required.[178] In practice, support provisions will likely have limitations concerning resources, the commitment of the involved parties and the need for constant review of the support provisions. The CRPD itself recognises that disabilities are "evolving", therefore in situations where an individual is a danger to themselves or others, or where support mechanisms are no longer effective, an individual may need protection by the State.

For instance, in *Re H,*[179] H suffered from bulimia and was reported to have strong suicidal ideations which created considerable problems for her caregivers and subsequently the police.[180] It appears implausible to expect H's supporters to continue to support her "for as long as required" where the support poses risks to supporters. Additionally, the involvement of the police indicates the support being provided to H is no longer beneficial to her care and as a result, she is at risk of becoming involved with the criminal law. In these circumstances, it appears possible that coercive measures may be required.

In light of the above, interpretations of Article 12(4) must engage with the plurality of the safeguard requirements to ensure its beneficial operation in practice.[181] This recognises that

[175] *Re WHK*, above n 163, at [33].
[176] At [27] and [32].
[177] Martin, above n 2.
[178] UN Committee, above n 3, at [24].
[179] *Re H* [1996] NZFLR 998.
[180] At 1000.
[181] Martin and others, above n 57, at 39.

proportional and potentially coercive safeguards may be required, in exceptional circumstances, to protect an individual's full range of rights and interests, despite this action being contrary to their will and preferences.

F. Dignity of risk

The safeguards emphasised above directly conflict with the Committee's endorsement of individuals with disabilities right to experience the "dignity of risk", the right to make mistakes and take risks.[182] The Victorian Government Framework for Recovery-orientated Practice has recognised that dignity of risk involves "optimising informed choice and consumer-led decision making"[183], conditioning the notion of "dignity" on an individual's functional ability to contemplate their choice and accept any consequences that may follow.[184] Where an individual cannot undertake a conscious appreciation of risk, assigning this dignity to their choice appears stretched, converting risks into unapprehended consequences.

Fundamental to the undertaking of risk, and for capacity assessments, is the ability to understand the information that is at the core of the decision. Only then can the choice be informed and led by the consumer, such that it is dignified. In *A NHS Trust v K*, K suffered from a mental disorder and refused to believe she had cancer, subsequently refusing all forms of treatment.[185] There was no evidence K had expressed a will or preference regarding treatment. If K did not obtain any treatment, she would likely "endure a year of unpleasant symptoms and a protracted period of pain and indignity before death".[186] An honest reflection of the facts indicates it was K's impairment governing her choice, not K herself. It is difficult to reason, therefore, that allowing K's decision to risk increased pain and death was a decision that enhanced her dignity.

Legal reform must not conflate the "dignity" attached to risk-taking behaviours, with the individual suffering the preventable consequences of their decision. To do so would impose on individuals responsibility for risks when they are unable to contemplate the totality of such

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[182] UN Committee, above n 3, at [22].

[183] Victorian Department of Health and Human Services *Framework for Recovery-orientated Practice* (2011).

[184] Charles Foster "Human Dignity in Bioethics and Law" (Hart Publishing, Oregon, 2011) at 65; Elionóir Flynn and Anna Arstein-Kerslake "Legislating Personhood: Realising the Right to Support in Exercising Legal Capacity" (2014) 10 Intl J L in Context 81at 96.

[185] *A NHS Trust v K* [2012] EWHC 2922.

[186] At [16].

risks to begin with. In practice, there is little dignity in a decision made by a person who is so impaired that they are unaware of or cannot understand their actions.[187] Without full consideration of the obligations of the State to establish safeguards for the reality of hard cases, the responsibilisation from and associations of dignity within legal regimes will be thwarted.[188] Regimes will risk allowing individuals to cause themselves, and others, great harm on the basis that they cannot process what they are doing and are yet able to make their own choices based on their will and preferences.[189]

G. The responsibility paradigm

The basic tenet of decision-making assumes an individual consciously undertakes responsibility for certain outcomes and thereby absolves others of responsibility for those outcomes.[190] The support paradigm claims that provided "supporters" stand in an appropriate relationship with an individual, supporters can satisfy the ordinarily "internal" competence criteria of the individual.[191] Consequently, supporters operate as a "prosthetic" through which a decision is made, authentically prescribing the decision to the disabled individual,[192] complicating the distribution of responsibility.

Whilst the support paradigm allows for formal recognition of decisions made with support; New Zealand's legal reform would be underdeveloped if it ignored questions of where the ultimate responsibility for decisions lies.[193] In facing hard cases an honest appraisal will recognise that, while traces of an individual may be present in the decision, the decision is being made by a third party. In the legal sense, making it clear that decisions are made by another ensures the application of duties, including fiduciary and rights-based duties, towards an individual. For this reason, the law must recognise situations where support becomes substitution and then, where substitute decision-making is utilised, that a third party, not the

[187] See Wall and Herring, above n 104, at 716-717 on the difference between a "richly autonomous decision" versus a "weak autonomous decision"; Victorian Branch of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) *Enabling supported decision-making* (PP PPP, May 2018) at 1-2.
[188] Dawson, above n 116, at 74.
[189] Wall and Herring, above n 104, at 698.
[190] Matthé Scholten and Jakov Gather "Adverse consequences of article 12 of the UN Convention on the Rights of Persons with Disabilities for persons with mental disabilities and an alternative way forward" (2017) 44 Med Ethics 226 at 229-230; Winick, above n 161, at 69.
[191] Anita Silvers and Leslie Pickering Francis "Thinking about the Good: Reconfiguring liberal metaphysics (or not) for people with cognitive disabilities" (2009) 40 Metaphilosophy 475 at 481; Series, above n 158, at 85.
[192] Series, above n 158, at 85.
[193] At 91.

individual, is making the decision. This will become increasingly important when the plurality of rights owed to an individual are considered and balanced.

H. Tensions with other rights

By focusing solely on the will and preferences of an individual, as an expression of an individual's autonomy, the General Comment is likely to become inconsistent with other rights of the individual. The full articulation of the "will and preferences" obligation in Article 12(4) is recalled here to recognise that the CRPD gives a prominent place to respect for an individual's rights, as well as their will and preferences.[194] Key rights included in the CRPD are considered below.

1. Right to enjoyment of the highest attainable standard of health – Article 25, CRPD

Article 25 asks States to "require health professionals to provide care of the same quality to persons with disabilities as to others".[195] If a disability results in distortions of thought and perception, thus impairing the individual's decision-making capacity, merely providing support or adopting an individual's choice without reservation could seriously undermine that individual's right to health care.[196] In turn, if an individual in a deep psychotic state is refusing healthcare that may relieve their impairment and restore their capacity for agency, for example, it would be contentious to say healthcare providers are promoting the "highest attainable standard of health" by allowing an individual to remain in that state.[197]

2. Right to life - Article 10, CRPD

Article 10, the right to life, requires States Parties to "reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others."[198] Despite this, the General Comment's paradigm diminishes actions designed to prevent adverse decisions by individuals with disabilities, if these actions include treatment without consent or substitute decision-making.[199] This poses the question – to what extent can the support paradigm be used in cases

[194] CRPD, Article 12(4); Martin and others, above n 57, at 41.
[195] CRPD, Article 25.
[196] Freeman and others, above n 133, at 846.
[197] At 846-847.
[198] CRPD, Article 10.
[199] Douglass and Snelling, above n 52, at 173 and 177; Freeman and others, above n 133, at 847.

that involve serious adverse risks to an individual or others when an individual is unable to contemplate the risks? As Genevra Richardson asks, does the CRPD "really require us to abandon the person to the consequences of her choice?"[200] In hard cases this may close viable options for saving lives; a devastating situation when an individual's capacity could have been restored through such treatment.[201]

This argument is not intended to frame the right to life or an individual's objectively perceived welfare as a trump card. Rather, it indicates where support networks fail and substitute decision-making regimes are needed, to prevent unconceived risk to life, the Committee's assertion that involuntary treatment or substituted decisions must never occur cannot be accepted.

3. The parens patriae doctrine

States may be obliged under the *parens patriae* doctrine to use substitute decision-making and capacity tests in hard cases. The *parens patriae* doctrine requires States to act as de facto parents to vulnerable individuals, undertaking a sovereign duty to safeguard and promote their independent welfare and developmental interests.[202] Whilst paternalistic, this doctrine seeks to centralise the interests of the individual within the State's actions, requiring a balance between protecting and empowering individuals. This balance can be reoriented in different cases based on the impairment experienced by the individual and the decision being made and will operate alongside the proportional requirements of Article 12(4).[203] In this regard, *parens patriae* can be used in cases where an individual's decision is not conducive to their rights, will and preferences or overall interests.

4. The "panoply of rights and choices"

Denying an individual's capacity to make legally-effective decisions is accepted as restricting their liberty. However, this restriction must recognise that when rights conflict, some rights

[200] Genevra Richardson "Mental Disabilities and the Law: From Substitute to Supported Decision-Making?" (2012) 65 Current Legal Problem 333 at 349.
[201] Freeman and others, above n 133, at 847.
[202] Senior Courts Act 2016, s 12(a) (formerly, prior to repeal on 1 March 2017, s 17 Judicature Act 1908); Alisson Douglass "Rethinking necessity and best interests in New Zealand mental capacity law" (2018) 18 Medical L Intl 3 at 13. Douglass notes that despite the jurisdiction of the court, the parens patriae doctrine is rarely used.
[203] Douglass "Supported Decision-Making", above n 80, at 1.19.

will take precedence over others. In practice, the potential alternatives, such as criminal sanctions where an individual's choice harms others or property, pose a greater restriction on an individual's liberty, integrity and participatory rights.[204] On balance, therefore, substitute decision-making in certain cases may provide the fairest and most equitable option, at times being the least restrictive means of intervention.

A broader contention is recognised to show that informed consent, as an exercise of legal capacity, is intended to serve a therapeutic function. The law's role extends beyond enabling people to be free from outside influence and subject only to the obligations they, themselves, have chosen to undertake.[205] Whilst encouraging individuals to exercise their own legal capacity remains part of the law's role, the protection of vulnerable individuals is also required. To operate otherwise, championing the right to self-determination as triumphant over all other rights, means health-care providers will have little practical input in extreme cases. In consequence, the benefits of rights may stagnate for individuals who do not experience success under the application of support.

5. Article 4(4), CRPD – an exclusionary provision?

Article 4(4) of the CRPD states that:[206]

> "Nothing in the present Convention shall affect any provisions which are more conducive to the realization of the rights of persons with disabilities and which may be contained in the law of a State Party or international law in force for that State. There shall be no restriction upon or derogation from any of the human rights and fundamental freedoms recognized or existing in any State Party to the present Convention pursuant to law, conventions, regulation or custom on the pretext that the present Convention does not recognize such rights or freedoms or that it recognizes them to a lesser extent."

Article 4(4) may indicate where interpretations of the CRPD derogate human rights, as has been suggested above, State parties will not be obliged to change their laws and practices.[207] However, the conclusion of the General Comment is clear and appears to provide little scope

[204] CRPD, arts. 14, 17, 29 and 30.
[205] Kjersti Skarstad "Human rights through the lens of disability" (2018) 36 *Netherlands Quarterly of Human Rights* 24 at 37 and 39-40.
[206] CRPD, Article 4(4).
[207] Freeman and others, n 133, at 849.

for an exclusionary principle to Article 12. The General Comment, therefore, must be read to state, albeit controversially, that the rights enshrined in Article 12 are universally held and absolute in the face of all other rights. This cannot be accepted if we prioritise legal reform in line with the arguments proposed in this dissertation.

I. Summation

Where there is a conflict between rights, one right must take priority.[208] As shown above, there are times where an individual's right to self-determination should give way to other rights. Without wider debate of how to provide workable and patient-centric laws, giving reference to an individual's panoply of rights, the General Comment's shift towards "will and preferences" will not provide beneficial guidance for legal reform. The patient-centric and empowering notion of the support paradigm, as a rights-based approach, is encouraged but must be considered within the array of obligations and rights that exist under the law, giving due consideration to how human rights should function.

[208] See Louis Henkin, *The Age of Rights*, (Columbia University Press, New York, 1990) at 4. The general view of human rights is that, while fundamental, they are not absolute and may be "sacrificed if countervailing societal interests are important enough, in particular circumstances, for limited times and purposes, to the extent strictly necessary".

V. Theorising the General Comment

The General Comment states that to deny an individual legal capacity is to deny them "a core human right".[209] This is a highly contentious jurisprudential claim that is grounded in rights theory. By locating the relevance of capacity within rights theory, this section will shed light on the function of rights for individuals with disabilities. It will focus on how an individual's interests and how the practice of informed consent, as an exercise of legal agency, operate as elements of an individual's autonomy.

A. Human rights

Human rights are of fundamental value and prescribe certain moral guarantees that exist for all individuals. In turn, human rights outline the necessary positive (duty conferring) and negative (preventing interference in an individual's life) rights and elements that are the necessary pre-requisites for all individuals to live a minimally good life.[210]

1. The Hohfeldian conception of rights

Human rights are the conditions and freedoms that all humans enjoy because of their humanity.[211] Assertions of rights can be understood through the Hohfeldian incidents, the relationship between these can be seen below:[212]

Opposites	*Correlatives*	
Claim / No Claim	Claim – Duty	*1st Order*
Liberty / Duty	Liberty – No Claim	
Power / Disability	Power – Liability	*2nd Order*
Immunity / Liability	Immunity - Disability	

This framework recognises that for individuals with impaired decisional capacity, the incident of a "power" is contentious. Power is a second-order right that allows individuals to change rules based on their rights, provided they have the capability to enforce the rights correlative

[209] UN Committee, n 3, at [15].
[210] Lief Wenar, "Rights" (2015) Stanford Encyclopedia of Philosophy <https://www.lawfoundation.org.nz/style- guide2019/chapter-7.html#7.1>.
[211] Mhairi Cowden "Capacity, claims and children's rights" (2011) 11 Contemporary Political Theory 362 at 365.
[212] At 366.

duty onto others.[213] In the medical sphere, power is the legal agency of an individual to enforce respect for their right to self-determination.[214] An individual will engage a power when they exercise their right to informed consent, waiving the corresponding liability of a healthcare clinician for the medical treatment.

Two key rights theories explain the effect of this power; the interest theory and the will theory. It is argued the General Comment implicitly adopts the will theory of rights; however, its application is contentious in hard cases. The challenge, therefore, is to find a way of framing the exercise of legal agency in cases involving an irremediable absence of decisional capacity.

2. The Will Theory of Human Rights

The will theory of rights asserts the function of a right is to give its holder express control over another's duty, promoting positive rights that allow an individual to remain sovereign over their own life.[215] The necessary condition of a will theory claim, therefore, is that the right-holder has the functional ability to demand the fulfilment of an obligation of another person regarding their right.[216] In this respect, the "power" must be intrinsic to the individual, denying the possibility of a proxy decision-maker.[217] In consequence, an individual who is unable to enforce their power is, due to the conclusive linking of legal agency and legal standing, deemed unable to hold rights and therefore denied legal personhood before the law.

3. The Interest Theory of Human Rights

The interest theory of rights frames the justification for the structure of an individual's normative standing on the general fact of what advances their interests.[218] As Joseph Raz states "x has a right if y an aspect of x's well-being (his interest) is a sufficient reason for holding some other person(s) to be under a duty".[219] In consequence, human rights duties that advance an individual's interests are owed to the individual, even if the individual has no intrinsic

[213] At 369.
[214] At 368.
[215] Wenar, above n 192.
[216] Zuzana Palovičová "Human Rights: Autonomy? Interest Or Specific Needs? (2017) 110 Institute of Philosophy Slovak Academy of Sciences 159 at 160.
[217] Piers Gooding "Navigating the "Flashing Amber Lights" of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns" (2015) 15 *Human Rights Law Review* 45 at 57.
[218] Lief Wenar, above n 192.
[219] Cowden, above n 193, at 370; Joseph Raz "The nature of rights" (1984) 93 Mind 194 at 195.

measure of control over them.[220] A right-holder is the entitled person, who places obligations on others where their interests justify those obligations. Crucially, this recognises individuals who require others to give effect to their rights.[221]

Adopting this into practice, the interest theory represents capacity in the medical sphere by defining claims in regard to a duty bearer's actions.[222] The application of mental capacity, through informed consent, refers to the actions of the duty-bearer by requiring health practitioners to obtain authorisation for their prima facie illegal acts.[223] In this way, the interest theory of rights provides a better framework for a rights-based system of decision-making, allowing the fundamental premise, that all individuals have rights, to continue despite the relational nature of some decision-making.

4. The General Comment's position

The General Comment is clear, developing on the preparatory notes of the CRPD,[224] States will not respect an individual's legal capacity if they respect their legal standing, but not their legal agency.[225] The focus on legal agency stresses that individuals with disabilities should be allowed to make decisions for themselves, equal to other persons.[226] In consequence, a distinction between the capacity to have rights and the capacity to exercise those rights is denied.[227] By framing capacity as "the power to engage in transactions and create, modify or end legal relationships,"[228] the support paradigm foresees an individual possessing power with the aid of others. For individuals with profound disabilities, however, support alone is unlikely to be sufficient to allow an individual to make their own decision and therefore give effect to their right. Equally, the contingent framing of legal personhood on decisional capacity means

[220] Gopal Sreenivasan "A Hybrid Theory of Claim Rights" (2005) 25 Oxford Journal of Legal Studies 257 at 262.
[221] Zuzana, above n 199, at 161.
[222] Cowden, above n 193, at 371.
[223] HDC Code, Right 7(1).
[224] Ad Hoc Committee "Report of Seventh Session", above n 114. In the preparatory notes of the CRPD, it was debated whether a footnote should be included to emphasise legal standing over legal agency, this footnote was not included in the final text. This indicates legal standing and legal agency are joined terms.
[225] UN Committee, above n 3, at [13].
[226] Antonio Martinez-Pujalte "Legal Capacity and Supported Decision-Making: Lessons from Some Recent Legal Reforms" (2019) 8 Laws 4 at 6.
[227] Browning, Bigby and Douglas, above n 113, at 40.
[228] UN Committee, above n 3, at [12].

when another right takes precedence over the right to self-determination, the individual's recognition before the law is challenged.

5. Will theory versus interest theory – in support of the interest theory

The will theory is unlikely to be able to explain all the rights contained in the CRPD. The will theory focuses on rights that require an external individual to undertake a duty concerning the rights-holder (positive rights) and therefore cannot apply to unwaivable rights (a negative right of non-interference that does not place a duty on third parties).[229] However, the CRPD contains an amalgamation of both negative and positive rights. Therefore the will theory of rights challenges a State's ability to deliver, for example, the support mechanisms required under Article 12(3) (a positive right), while at the same time adhering to safeguard obligations under Article 12(4) (a negative right).[230]

Additionally, the will theory's mandate that a right-holder must have the power to enforce their right cannot apply to individuals who lack decisional capacity. A rights-based approach that relies on an individual intrinsically making a choice is grounded in a past dominated by individualistic liberal theories of rights, framing an individual as a rational, independent agent.[231] The General Comment's interpretation reprioritises the dominance of choice in the rights framework, claiming that all individuals are capable of exercising their legal capacity. This exempts individuals with impaired capacity from being rights-holders. Human rights theory has moved beyond this to consider the relational nature of decision-making.[232]

The CRPD's claim that legal capacity is universally held is hard to understand under the General Comments claim for the primacy of choice. Capacity, when exercised as informed consent, cannot be explained solely by the right to self-determination. Instead, the concept is threefold, including alongside self-determination, considerations of bodily integrity and well-being.[233] This reflects the broader interests that individuals without decisional capacity have even when self-determination is not possible.[234] Consequently, human rights should be

[229] At [12].
[230] Douglass "Supported Decision-making", above n 80, at 2.23.
[231] Kjersti Skarstad "Human rights through the lens of disability" (2018) 36 *Netherlands Quarterly of Human Rights* 24 at 28-29.
[232] Samantha Brennan "Paternalism and Rights" (1994) 24 Canadian Journal of Philosophy 419 at 420-421.
[233] Cantor, above n 150, at 37-38.
[234] At 38.

understood as the ideals which give effect to an individual's interests, based on their personal situation, within an interdependent society.[235] In this way, the interest theory of rights recognises that different human beings have different abilities and challenges and in parallel, the fulfilment of equal rights will require different approaches, at times including the engagement of third parties. This indicates that a mere focus on choice cannot form the "conceptual and practical bridge" to better realising all individual's rights and autonomy.[236]

B. Reframing capacity and autonomy

The presumption of legal capacity in New Zealand represents a consideration of autonomy, however, this is lower than the level expressed in the CRPD. The General Comment makes autonomy explicit, equating all limits on the exercises of capacity as limits on the autonomy of an individual.[237] This is premised on a strong social model that proclaims respect for autonomy as absolute, stating autonomy is never lost so an individual will always be capable of authentically expressing their values, no matter their mental state.[238] There are fundamental flaws in this due to the social model's failure to account for impairments that are organically formed and internal to the individual.

There are various conceptions of autonomy within the academic literature outside of the General Comment.[239] In the context of decisional capacity, a holistic and relational interpretation of autonomy is advanced, identifying that decisional capacity relates to context-specific decisions that leave an individual free to make decisions in all other aspects of their life.[240] Autonomy, therefore, exists in degrees so an individual will occupy various places on a continuum depending on the time, subject matter, and circumstances of their decision.[241] At points, an individual may require the assistance of others to act on their autonomy because they

[235] Skarstad, above n 213, at 34.
[236] Gooding "Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law", above n 10, at 432.
[237] UN Committee, above n 3, at [18] and [33].
[238] Hyslop, above n 36, at 32.
[239] For full coverage of the concepts of autonomy see Natalie Stoljar "Theories of Autonomy" in Richard Ashcroft and others *Principles of Health Care Ethics* (2nd ed, Wiley, West Sussex, 2007) at 11. See also, at 12 and 16, for discussion on the shift to consider autonomy as relational, a quality dependent on a person's relationships rather than on their functional abilities.
[240] Dawson, above n 116, at 73.
[241] Sophie Nunnelly *Coercive Care in Civil Mental Health Law: An Autonomy Lens* (CPHS, Working Paper, 2015) at 4.

cannot do so, especially in cases where an individual suffers from internal constraints, such as delusions, paranoia or false beliefs, restraints that cannot be remedied under the social model.

Where individuals lack autonomous capacities, adherence to a support model will not result in universal autonomy. This is a consequence of the social model's limited recognition of intrinsic impairments that break down an individual's intentional agency.[242] Respect for autonomy (and by parallel legal personhood), therefore, is not respect for all decisions of an individual, at all times. Instead, substitute decision-making forms an important part of an individual's autonomy as a means to give effect to their values when they cannot.

C. Summation

Human rights cannot be premised on choice and autonomy cannot be contingent on each decision an individual makes. In consequence, the interest theory of rights is promoted to focus the rationale for rights on an individual's interests, not their individualised choice. In consequence, all individuals can be rights-holders, albeit a need for external mechanisms to give effect to their rights.[243] This frames human rights within a broader system of values,[244] however, in doing so the relationship between legal reform and the safeguarding of an individual's interests becomes increasingly important.

[242] Robert F Schopp, "Therapeutic Jurisprudence and Conflicts Among Values in Mental Health Law" (1993) 11 Behavioural Sciences and the Law 31 at 37.
[243] Bridgit Mirfin-Veitch *Exploring Article 12 of the United Nations Convention on the Rights of Persons with Disabilities: An Integrative Literature Review* (Donald Beasley Institute: Dunedin, 2016) at 41.
[244] John Coggon "Mental Capacity Law, Autonomy, and Best Interests: an Argument for conceptual and practical clarity in the court of protection" (2016) 24 Medical Law Review 396 at 408.

Part II

I. The legal framework

Recognising the need for legal reform in New Zealand, Part I identified the tensions in the General Comment to establish a need for the limited retention of substitute decision-making under an alternative rights-based approach. In this part, it will be proposed that New Zealand's current regimes can be improved to make provisions of support a primary expectation, after which, mental capacity tests can be engaged. In this way, the broader cultural shift underlying the General Comment can be realised within a cohesive legal framework, to recognises the need for both supported and substituted decision-making regimes.

New Zealand's Labour coalition government is not currently undertaking, nor planning to undertake, a revision of New Zealand's law to recognise supported decision-making.[245] However, changes are occurring in various sectors domestically and internationally. At a clinical level, the Victorian Branch of the Royal Australian and New Zealand College of Psychiatrists has released a position paper to educate members, consumers and their families on the principles and application of supported decision-making frameworks.[246] New Zealand's Disability Rights group "People First" has also released a similar document on the principles of supported decision-making.[247] The work of these groups represents an attempt to reinvigorate discussion about how a collective approach to improved health, with a shift away from past attitudes on mental health towards support principles, can be facilitated.[248]

A. The pathway to reform

New Zealand's pathway to reform with regards to decisional capacity will be long and complex. This is in contradiction with the General Comment, which explicitly notes the rights contained in Article 12 are civil and political rights and therefore not subject to progressive realisation.[249] However, any immediate action to overhaul the legal system in this manner

[245] New Zealand Government "The New Zealand Government's response to 'the list of issues prior to submission of the combined second and third periodic review of New Zealand" (March 2018) CRPD/C/NZL/2-3 at [104].
[246] RANZCP, above n 187, at 4-5.
[247] Auckland Disability Law *Supported Decision-making* (People First New Zealand, 3 September 2016).
[248] RANZCP, above n 187, at 2.
[249] UN Committee, above n 3, at [1] and [30].

would take place in the absence of robust evidence.[250] This lack of evidence is crucial given the potential anti-therapeutic risks of the support paradigm when it is applied in an absolutist sense. This section will outline the measurable steps New Zealand could take towards the realisation of Article 12, moving to adopt a mixed-mechanism approach of support and substitute decision-making. This mixed-mechanism approach aims to adopt the capability-enhancing elements of the support paradigm, whilst recognising the need, in exceptional cases, for substitute decision-making.

B. The place of supported decision-making

When support and decision-making operate contemporaneously, to allow an individual (or their expressed interests) to direct a "supporter",[251] there is "potential to empower and enrich" the lives of individuals with disabilities.[252] Provisions that can facilitate this focus already exist within New Zealand law, for example, s 105 of the Evidence Act 2006 allows evidence to be given through alternative means due to physical, intellectual, psychological, or psychiatric impairments to the witness.[253] Further, s 80(3) of the Act provides that a witness in a civil or criminal proceeding is entitled to communication assistance that will "enable or facilitate communication with a person" who "has a communication disability".[254]

In adopting an explicit recognition of support, such as alternative forms of communication and decision-making, the potential disenfranchisement suffered by individuals with disabilities can be remedied. *R v Willeman,*[255] a sexual assault case, involved a complainant who was tetraplegic, severely physically disabled and found to lack decisional capacity presumably as a result of his perceived inability to communicate.[256] However, the complainant with the support of his wife (who read aloud the alphabet) was able to communicate by moving his big toe to spell out words. Recognising the complainant had a right under the Evidence Act to support, arguably akin to an individual's right to effective communication under Right 5 of the Code,

[250] Mirfin-Veitch, above n 243, at 32; see New Zealand Government, above n 245, at [109]-[111] where the New Zealand Government recognised there is currently no record of how many individuals are currently under the provisions of guardianship laws.
[251] Browning, Bigby and Douglas, above n 113, at 36.
[252] At 34.
[253] Evidence Act 2005, ss 103 and 105.
[254] Section 4(1).
[255] *R v Willeman* [2008] NZAR 644.
[256] At [2] and [9], citing the testimony of Samir Sadaq Anwar, a consultant in rehabilitation medicine employed by the Auckland District Health Board.

the court ordered communication assistance to allow the complainant to give evidence. The order also required the interpreter to give evidence about the method of communication assistance he undertook to safeguard the complainant and the reliability of the evidence.[257] In this way, the law shows an ability to accommodate deficits in decision-making capacities, such as communication impairments, by developing and recognising diverse and unconventional means of communication.[258] *R v Willeman* reveals the extent to which support can be applied and should be recognised when considering future thresholds of capacity.

1. The support framework

The facilitation of the support model under the proposed mixed-mechanism prioritises the role of supporters. While the General Comment recognises the need for formal and informal support mechanisms, the academic literature disagrees on whether purely legal measures should be considered or if informal arrangements without legal enforceability are required.[259] Examples of formal and informal models of supported decision-making include support agreements, independent advocates, personal assistance and peer support, as well as the continued use of advance directives and Enduring Power of Attorney's (EPOA's).[260] Under all approaches, an emphasis on personal and biographical - rather than clinical - knowledge is promulgated.[261] Equally, the need for trust[262], the development of positive relationships and procedural and personal commitment[263] are emphasised.[264]

Formal mechanisms minimise the risk of conflicting interests and undue influence, however, they in turn risk decisions being made through underdeveloped personal relationships. This is because they assume the individual and the supporter will have the time and capacity to gain knowledge about each other. In *R v Willeman* the judge recognised that even if supporters could be trained quickly, their acceptance by an individual requires the development of a

[257] At [46].
[258] Browning, Bigby and Douglas, above n 113, at 37.
[259] Gooding "Navigating the "Flashing Amber Lights"", above n 217, at 50 and 64.
[260] *Report of the Special Rapporteur on the rights of persons with disabilities*, above n 14, at [54].
[261] Series, above n 158 at 83.
[262] See *Wandsworth Clinical Commissioning Group v IA* [2014] EWHC 990 (COP); *Re JB* [2014] EWHC 342 (COP). UK jurisprudence indicates that individuals have been found to lack capacity when assessments are undertaken by individual's they do not trust, individuals have subsequently passed the threshold when they feel supported and in a trustworthy state.
[263] Jo Goodhew *Report of the Minister for Senior Citizens on the Review of the Amendments to the PPPR Act 1988 made by the PPPR Amendment Act 2007* (Wellington, June 2014).
[264] Mirfin-Veitch, above n 243, at 41.

relationship and bond.[265] Equally, formal mechanisms assume individuals will be able and willing to go to a court and that supporters will be available for all cases. New Zealand currently has a recognised shortage of independent welfare guardians and no public agency to facilitate these roles.[266] Reliance on these formal roles, therefore, is unlikely to promote the rights and interests of individuals in all cases.

Informal regimes, by comparison, are likely to allow for support mechanisms in everyday practice to acknowledge that medical decisions are not limited to situations of significant risk or consequence.[267] Recognising this, a Government co-designed prototype, "Mana Whaikaha" has been implemented in the MidCentral District Health Board Area from October 2018.[268] This support prototype provides individuals with disabilities and their families various options in decision-making, reducing the need to acclimate to the formal services offered. Prototypes such as this are important to recognise the involvement of family, friends and civil systems of support within decision-making.[269]

Informal systems, however, will require monitoring[270] due to an increased risk of undue influence or supporters views becoming ensnared with the individuals, both of which risk distorting the patient-centric focus of the support framework.[271] Furthermore, due to the unofficial role of the supporter, formalised and external mechanisms may be required to approach the potential tension in cases when families cannot agree on a course of treatment, or decision, or are unwilling to collectively provide appropriate support, recognising that the supporter role is voluntary.[272]

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[265] *R v Willeman,* above n 255, at [43].
[266] Douglass "Supported Decision-making", above n 80 at 62.
[267] At 61.
[268] New Zealand Government, above n 245, at [7].
[269] Jonathan Herring "Forging a relational approach: Best interests or human rights?" (2013) 13 Med L Intl 32 at 35 and 41-42.
[270] Terry Carney and Fleur Beaupert "Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making" (2013) 36 *University of New South Wales Law Journal* 175 at 200. Carney and Beaupert warn that informal support in decision-making, although compatible with the equality principle, is especially vulnerable to misuse if protective mechanisms are not established.
[271] For example, Herring "Forging a relational approach: Best interests or human rights?", above n 260, at 50-51. Herring frames a hypothetical to suggests that a person with incontinence problems could be subjected to surgery to correct this despite his refusal if his partner found dealing with his incontinence "unpleasant".
[272] Douglass "Supported Decision-making", above n 80, at 62.

New Zealand must consider the breadth of regulations that attach to various support mechanisms to address the responsibility paradigm. Private law mechanisms will likely engage contractual and fiduciary duties, whilst statute based decisions may be exposed to administrative law liability.[273] As such, the boundary line between public and private for support provisions is unclear and will need to be considered by regulators.

C. Decision-making outside of the support paradigm

In linking the previous and current sections, it bears reemphasising that autonomy is about respecting an individual's interests by reference to their values, rather than a reverence for choice.[274] In undertaking this emphasis, the reform suggested in this section will fail to comply with the General Comment's interpretation of the CRPD. The focus remains rights-based, acknowledging that beneficial legal reform must be conscious of situations where the support model is no longer successful in advancing an individual's capacity. In these hard cases, decision-makers must be provided with a guided process that is cognisant of all of the rights an individual has. In consequence, finding that an individual lacks decisional capacity cannot open the floodgates for another individual to impress their preferences. New Zealand must harmonise their law to facilitate support, to the maximum extent, after which decision-makers should be provided with a guided process for undertaking decisions.[275]

1. Mental Capacity Tests

As can be seen from Part I, it is implausible and at times undesirable, to completely sever legal capacity from mental capacity.[276] Consequently, a realistic appraisal is argued for to recognise that mental capacity assessments provide an important evaluative threshold to validate healthcare providers otherwise illegal acts.[277] Where support no longer provides effective assistance to an individual, a substitutive mechanism must be used.[278] This provision must become reinforced and developed in practice to recognise both internal and external impairments on the individual's decisional capacity.

[273] Carney and Beaupert, above n 245, at 188.
[274] John Coggon, above n 244, at 403.
[275] See Department of Constitutional Affairs *Mental Capacity Act 2005 Code of Practice* (The Stationery Office, 2007).
[276] Snelling and Douglass, above n 64, at 177.
[277] Wall and Herring, above n 104 at 703.
[278] Martin and others, above n 57, at 19.

A recent survey on New Zealand clinicians in Wellington and Hutt Valley Hospitals about how assessments of mental capacity are completed has revealed a variety of assessment processes are undertaken.[279] Reasons for suspecting incapacity included a patient presenting with "cognitive impairments", a "mental illness", "clinical intuition" or the fact that a "patient could not communicate".[280] This broad spectrum of approaches is likely in parallel with the recognised theme that capacity assessments are cloaked in a *"*confusing and often contradictory web of legislation".[281]

This necessitates a clarification in New Zealand's legal and practical approach to mental capacity. The PPPRA currently provides various tests for capacity, whilst the Code fails to define capacity in relation to informed consent. Legal reform, therefore, should codify the common law functional test[282] and include an explicit requirement of support for individuals. Section 6(1) of the PPPRA outlines the fundamental basis for the provision of this reform and can be developed to include a section stating, for example, "no person shall be found to lack capacity under subsection (1) until they have been provided with all reasonable and practicable levels of support for their capacity, and this support has not succeeded". A similar provision should also be included in the Code to make capacity tests subject to explicit support provisions.

Furthermore, legal reform should recognise capacity as an interdependent process that involves, to various degrees, external parties.[283] In consequence, mental capacity tests will assess how people make decisions with the support of family and friends.[284] Section 8(b) of the PPPRA, regarding a courts objective to "enable or encourage that person [subject to an application] to exercise and develop such capacity as he or she has to the greatest extent possible", indicates an implicit provision in this regard. However, this section is only engaged after an individual is found to lack decisional capacity.[285] To make support explicit the above sections must be reframed to allow pre-assessment support.[286] In consequence, mental

[279] Greg Young, Alison Douglass and Lorraine Davison "What do doctors know about assessing decision-making capacity?" (2018) 131 NZMJ 58 at 60.
[280] At 60.
[281] At 62.
[282] See Mental Health Act 2005 (UK), s 4.
[283] Browning, Bigby and Douglas, above n 113, at 34.
[284] Series, above n 158 at 83; Jonathan Herring "Caring and the Law" (Ashgate, Hart Publishing, Portland, 2013) at 157.
[285] Douglass "Supported Decision-making", above n 80, at 2.38.
[286] Browning, Bigby and Douglas, above n 113, at 42.

capacity tests should routinely take place in conjunction with supporters and health practitioners to assess, whether, *after* the application of support, an individual can understand and appreciate the decision and its consequences.

2. Alternative Decision-Making Options

Accepting that a support regime cannot be the only decision-making mechanism in New Zealand's medico-legal framework, this section considers a continuum of regimes that honestly respond to the hard cases. It is accepted that the proposed mixed-mechanism approach will breach the Committee's statement that States will fail to comply with Article 12 if regimes of substitute decision-making continue to exist in parallel with systems of supported decision-making.[287]

(a) Facilitated Decision-Making

Disagreements about the extent to which individuals with disabilities can exercise their right to self-determination under voluntary support have led to some Disability Rights Advocates promoting facilitated decision-making as a response to hard cases.[288] Under facilitated decision-making, a third party uses information known about an individual, beginning with their will and preferences but also extending to broader considerations such as their religion and values, to form a decision *of* the individual.[289] The use of information about the individual maintains, at least so it is argued, that the decision is the subjective preferences of the individual, not the objective interpretation of the third party. On face value, therefore, this is outside of the General Comment's definition of "substitute decision-making regimes."[290]

An intuitive reading of facilitated decision-making, however, indicates that in practice it will likely operate under the same premise as substitute decision-making. This is especially so in cases where the information known about an individual is limited due to profound or long-term disabilities.[291] To suggest in these cases that the facilitating party is making a decision of the individual incorrectly implies the facilitators have the capacity to become the individual themselves, rendering the individual invisible as they become embodied by the facilitator.[292]

[287] UN Committee, above n 3, at [26].
[288] Mirfin-Veitch, above n 243, at VI; see also Silver and Francis, above n 191, at 476.
[289] Kerzner and Bach, above n 18, at 91-93.
[290] UN Committee, above n 3, at [23].
[291] Series, above n 158, at 87.
[292] Douglass and Snelling, above n 76, at 171.

Facilitated decision-making, therefore, is unlikely to be a workable alternative framework for the hard cases of medical decision-making.

(b) The limited retention of substitute decision-making

It is accepted that support for decision-making should be provided, as much as is reasonable, on a continuum personalised to an individual with disabilities.[293] At a point along this continuum, because we do not know anything about an individual, because the individual never formulated the relevant values, or because they espouse inconsistent values, third party decision-makers will need to decide on behalf of an individual.[294] The legal challenge in this regard is to regulate substitute decision-making so it respects the individual, whilst providing clear guidance for decision-makers to balance the various interests and rights of individuals.

(c) Adherence to Will and Preferences

Chapter IV outlined the potential problems that may arise when an individual's will and preferences are accepted without reservation. In light of these problems, respect for the "rights, will and preferences" cannot be interpreted as requiring absolute adherence to an individual's will and preferences. Instead, a proportional approach is promoted to allow an individual's autonomy to be promulgated through various means based on the decisional capacity that they hold.

(d) The Best Interests Test

New Zealand should not dispose of the best interests tests in favour of complete adherence to an individual's will and preferences. However, the "best interests" test requires reform. A recent Select Committee report from the United Kingdom has found "the best interests principle is widely praised but its implementation is problematic".[295] New Zealand's "best interests" remains largely undefined, rendering its guidance as a decision-making *process* largely invisible.[296] In practice, if "best interests" is the legal foundation for intervention against an individual's will and preferences, the need for clarity is paramount.[297]

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[293] Kerzner and Bach, above n 18; Mirfin-Veitch, above n 243 at 42.
[294] See Gooding "Supported Decision-Making: A Rights-Based Disability Concept and its Implications for Mental Health Law", above n 10 at 441; Silver and Francis, above n 191, at 476-477.
[295] Mental Capacity Act 2005 (UK) (Select Committee Report) at [90].
[296] Douglass "Supported Decision-making", above n 80, at 5.47.
[297] Douglass "Rethinking necessity and best interests in New Zealand Mental Capacity Law", above n 202, at 32.

New Zealand should consider s 4 of the Mental Capacity Act 2005 (United Kingdom)[298] and ss 7-9 of the Mental Health Act 2014 (Western Australia)[299] as processes and outlines of considerations for a best interests analysis.[300] Central to these considerations are the values and wishes of the individual for whom the decision is being made, as well as any communication (formal or informal) they have made regarding the decision at hand.[301] These factors are mandatory considerations but are not instructive of the final decision. In this way, a symbolic and instructive message can be sent to decision-makers and courts that draws attention to and recognises an individual's values. In consequence, respect can be afforded to the right of an individual to self-determination as well as their other rights, including the right to the highest standard of healthcare, right to life and right to liberty.

D. Safeguards

By adopting a mixed-mechanism approach to decisional capacity, safeguards must balance the freedom and protection of individuals with disabilities, whilst also affording the individual respect for the capacities they do hold.[302] Potential safeguards are considered below which should form the minimum of New Zealand's legal reform.

1. Review Panel

Where an individual is subject to the consequences of a decision made or communicated by a "supporter", the potential for abuse and exploitation is paramount. A proactive response is encouraged, therefore, to provide both a prospective and retrospective mechanism of review of decisions made and the processes undertaken. This mechanism could, in turn, provide resolutions in cases where an individual's values cannot be ascertained, where a support person cannot be contacted or where there is a dispute within a support group. Under the jurisdiction of the panel an individual's rights, as well as the safeguard requirements of proportionality, protection from undue influence and the duration of decision's impact can be reviewed.[303] This

[298] Mental Capacity Act 2005 (UK), s 4.
[299] Mental Health Act 2014 (Western Australia), ss 7-9.
[300] See Appendix 1.
[301] Mental Health Act 2014 (Western Australia), s 8.
[302] Mirfin-Veitch, above n 243, at 54.
[303] Victorian Law Reform Commission *Guardianship Final Report* (Final Report 24, 2012) at 25, 58 and 237–272. In Victoria, Australia an Independent Mental Health Tribunals has been set up to execute oversight into more restrictive interventions. The jurisdiction has also restricted the powers professionals and support persons have available to them under the law in an effort to reduce the duration of restraint and seclusion interventions.

jurisdiction will become increasingly important when long-term, highly invasive or life-threatening decisions are being considered.

British Columbia, Canada, has established a monitoring role similar to above to serve as a safeguard for decision-making.[304] Under the Canadian regime, a monitor can be appointed to oversee the powers and duties of a representative, review information and records about an individual's representation, and review the continuation of any agreement itself.[305] Furthermore, jurisprudence from the United Kingdom has indicated a willingness by some judges to meet with individuals subject to the Mental Capacity Act 2005 (UK) to gain an expression of their interests when significant decisions are being made, such as the refusal of life-saving treatment.[306] In these situations, the individual concerned should have an explicit right to be engaged in the proceedings as far as practicable. Section 74(1) of the PPPRA provides a basis for this mechanism,[307] however, the right is implicit and in consequence, only 24 out of 79 cases under the provisions have recorded an active engagement by the individual concerned.[308]

2. Transparency of supporters

New Zealand does not currently have a public register to record the appointment of a third party or the activation of EPOA's concerning an individual who is deemed to lack capacity.[309] This is likely to lead to difficulties when an individual is under hospital care outside of their domestic domain or where they are unconscious or unable to contact their support person(s), resulting in significant accountability measures being left underdeveloped. A registry of supporters, both formal and informal, would enable third parties to verify the identity of support persons and the scope of their role and authority. In implementing this process, however, care must be had for the privacy rights of individuals given the inevitable sharing of personal information.

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[304] Nidus Personal Planning Resource Centre and Registry "Types of Planning" (2012) <nidus.ca>.

[305] Representation Agreement Act 1996 (Canada), ss 7, 12 and 20.

[306] *Wye Valley,* above n 1, at [18]. Peter Jackson J noted that in the circumstances there was "no substitute for a face-to-face meeting where the patient would like it to happen".

[307] PPPRA, s 74(1). It states the person in respect of whom an application for the exercise of the court's jurisdiction under this Act is made shall be present throughout the hearing unless excused or excluded by the court under subsection (2) or subsection (3).

[308] Douglass "Supported Decision-making", above n 80, at 186.

[309] Snelling and Douglass, above n 64, at 176.

3. Intra-clinical Options

Capacity, as expressed through informed consent, is not a clinical decision, but a normative category that functions to permit or veto the exercise of rights.[310] Yet in practice, the task of assessing capacity generally occurs within clinical settings.[311] This necessitates, in conjunction with any legal reform, a framework for education for those involved in the decision-making processes. This education should include provisions for assessing capacity, understanding potential signs of undue influence and duress and a prescribed contact for individuals where concerns about the decisions being made or processes undertaken arise. Alison Douglass, G Young and J McMillan's "Toolkit for Assessing Capacity" and proposal for a Code of Practice is a welcomed start in this regard.[312]

4. Resources

In revealing the benefits of support in decision-making, *R v Willeman* brings into focus the level of resource commitment that may be required to facilitate support networks. Resource distribution is a policy matter outside the scope of this dissertation, however, recognition should be had for the impacts of policy decisions in the socio-political environment. An appreciation of the social model is constructive in this regard, highlighting how law and society operate together. As Piers Gooding states, it is "perhaps as easy to give the law too much credit for solving personal and social maladies, as it is to give it too much blame for causing them."[313] Taking learnings from the current legal regime, merely reforming the legal framework without engaging social and structural mechanisms will not ensure the laws explicit application in practice. In consequence, substitute decision-making may not be limited to the hard cases, risking the application of the CRPD and rights to all individuals.[314]

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[310] Wexler and Winick, above n 4, at 81.

[311] Young, Douglass and Davison, above n 260, at 58.

[312] Alison Douglass "Code of Practice" in A Douglass *Mental Capacity: Updating New Zealand's Law and Practice* (New Zealand Law Foundation, Dunedin, 2016) 155; Allison Douglass, Greg Young and John McMillan "A Toolkit for Assessing Capacity" in A Douglass *Mental Capacity: updating New Zealand's Law and Practice* (New Zealand Law Foundation, Dunedin, 2016) 235.

[313] Gooding "Navigating the "Flashing Amber Lights"", above n 217, at 48. Gooding notes the benefits of using the law for social justice may become overwhelmed by other powerful forces in society, such as resource allocation or wealth disparity.

[314] See Browning, Bigby & Douglas, above n 113, at 37.

E. Summation

New Zealand's legal reform must recognise that substitute and supported decision-making can coexist. The law must include a primary and explicit requirement for support within its new framework. Subsequently, if an individual is found to lack decisional capacity, they do not lose their right to be involved in the decision-making or to have their rights respected and given effect to. In this way, New Zealand's use of the "best interests" test should remain but should be developed to provide a range of considerations for decision-makers that are in line with an individual's interests. To this extent, the ethos of the General Comment is adopted. However, New Zealand's legal reform will still breach its international obligations. Direct and honest acceptance of this breach is required by regulators, in light of this dissertations alternative rights-based approach, to allow legal reform to be specific in its aim and application and for the scope of safeguards provided to take place on a transparent basis.

Conclusion

Medical decision-making and guardianship laws have questions of capacity at their core. In a radical and absolutist shift by the Committee, the use of mental capacity tests as a threshold for legal capacity has been rejected. Article 12 of the CRPD has been considered as the embodiment of this paradigm shift, framing disability in relation to an individual's socio-political environment, thereby excluding considerations of an individual's intrinsic impairments.

Part I of this dissertation has unpacked the theoretical and practical implications of the General Comment in light of New Zealand's current legal position. It recognises that New Zealand's law does not currently comply with the CRPD, but does not endorse the General Comment's conclusions as a remedy to this. This is because the premise that an individual can always be supported to exercise their right to self-determination, as a reflection of their autonomy, is not plausible in hard cases. The hard cases include individuals who suffer from severe impairments, or who pose a risk to themselves and others, or who were never able to express their will and preferences. To reform the law without recognition of these cases would fail to protect all individuals rights.

Part II, therefore, asked not whether substitute decision-making should take place, but when and how.[315] This reframing is alive to the limitations of support-based regimes, as well as the dangers of using substitute decision-making in all cases when an individual has diminished capacity. Despite the General Comment's conclusions, substitute decision-making is required to help individuals who, even when all means of support have been provided, cannot clearly express their interests or make decisions for themselves.[316] Endorsing the need for legal reform in New Zealand, Part II further considered the potential safeguards that are needed, at a minimum, to guide and facilitate an effective mixed-mechanism regime of supported and substitute decision-making.

This dissertation responds to the crucial gap in the General Comment, the failure of the Committee to elaborate and consider decision-making in "hard cases". Such an absence is

[315] Martin and others, above n 57, at 12.
[316] At 13.

critical and will likely present a constant barrier in States application of the General Comment. In the preparatory notes of the CPRD, the International Disability Caucus states "substituted decision making is based on the premise of incompetence and must not be legitimised. Supported decision making is based on the presumption of competence. The two cannot exist together and successfully achieve the paradigm shift desired."[317] This dissertation rejects this dichotomy, reframing how decision-making, autonomy and capacity operate in a patient-centric, rights-based approach. This approach prioritises supported decision-making whilst also allowing for the limited retention of substitute decision-making for hard cases. New Zealand must reform their law in this regard, however, in doing so must also accept that they will be in breach of their international obligations.

[317] Ad Hoc Committee "Report of seventh session", above n 114.

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Appendix 1

Mental Capacity Act 2006 (UK)

4 Best interests

(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—
  (a) the person's age or appearance, or
  (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

(3) He must consider—
  (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
  (b) if it appears likely that he will, when that is likely to be.

(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

(6) He must consider, so far as is reasonably ascertainable—
  (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
  (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
  (c) the other factors that he would be likely to consider if he were able to do so.

(7) He must take into account, if it is practicable and appropriate to consult them, the views of—
  (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
  (b) anyone engaged in caring for the person or interested in his welfare,
  (c) any donee of a lasting power of attorney granted by the person, and
  (d) any deputy appointed for the person by the court,

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

(8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—
  (a) are exercisable under a lasting power of attorney, or
  (b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.

(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of

subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.

(10) Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.

(11)"Relevant circumstances" are those—

(a) of which the person making the determination is aware, and

(b) which it would be reasonable to regard as relevant.

Mental Health Act 2014 (Western Australia)

7. Matters relevant to decision about person's best interests

(1) This section applies whenever a person or body is required under this Act to decide what is or is not in the best interests of a person.

(2) The person or body making the decision must have regard to these things —

(a) the person's wishes, to the extent that it is practicable to ascertain those wishes;

(b) the views of each of these people —

(i) if the person has an enduring guardian or guardian — the enduring guardian or guardian;

(ii) if the person is a child — the child's parent or guardian;

(iii) if the person has a nominated person — the nominated person;

(iv) if the person has a carer — the carer;

(v) if the person has a close family member — the close family member;

(c) any other matter that the person or body considers relevant to making the decision.

8. Matters relevant to ascertaining person's wishes

(1) This section applies whenever a person or body is required under this Act to ascertain the wishes of a person in relation to a matter.

(2) For the purposes of ascertaining those wishes, the person or body must have regard to the following —

(a) any treatment decision in an advance health directive made by the person that is relevant to the matter;

(b) any term of an enduring power of guardianship made by the person that is relevant to the matter;

(c) anything that the person says or does that is relevant to the matter if it is said or done at a time that is reasonably contemporaneous with when those wishes are required to be ascertained;

(d) any other things that the person or body considers relevant to ascertaining those wishes.

9. Language, form of communication and terms to be used

(1) For this section, communication with a person includes the provision to a person of any advice, explanation, information, notification or reasons.

(2) Any communication with a person under this Act must be in a language, form of communication and terms that the person is likely to understand using any means of communication that is practicable and using an interpreter if necessary and practicable.