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**Enabling Disabled People to Live Good Lives:**  
*Embedding supported decision-making into disability law in  
Aotearoa, New Zealand*

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# Enabling Disabled People to Live Good Lives:

## *Embedding Supported-Decision Making into Aotearoa New Zealand's Law*

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### **Abstract**

The Universal Declaration of Human Rights confirms that all people are born free and equal in dignity and rights. The freedom, dignity and rights of disabled people is affirmed and protected by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Under the UNCRPD, disabled people are guaranteed equality before the law and entitled to equal protection and benefit of the law. Up to the 20<sup>th</sup> century, the prevailing view, internationally and domestically, was that disabled people were, by virtue of their disability, incapable of living autonomously and independently. This led to disabled people being excluded from mainstream society and relegated to second-class citizens. Disabled people have been denied legal personality, leading to institutionalisation and disenfranchisement. Consequently, disabled people continue to face significant barriers to realising full and equal enjoyment of dignity and rights due to social stigma, ignorance, legal and institutional ignorance of disability issues. Article 12 of the UNCRPD requires States to abolish substitute decision-making regimes and replace them with supported decision-making. This paper explores how we can reimagine our domestic legal frameworks using the principles of supported decision-making to empower disabled people in Aotearoa New Zealand to attain freedom and equality in dignity and rights. Using a supported decision-making model empowers disabled people to make their own decisions in a way that is appropriate to their circumstances. It is suggested that this is the key to increasing autonomy and self-determination amongst disabled people enabling them to participate in society and live freely and equally in dignity and rights. This dissertation focuses on the concept of supported decision-making and argues for the implementation of a Supported Decision-Making Bill in New Zealand. The draft Bill included in this dissertation is designed to give effect to the rights of disabled people to live their lives according to

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<sup>1\*</sup> Frankie Emmett Karetai Wood-Bodley is a disabled person who identifies as trans and gay and was a Master of Laws (Dissertation) student at Victoria University of Wellington supervised by Professor Bill Atkin. This dissertation was submitted in fulfilment of the requirements for LAWS592: Dissertation and the degree requirements for Master of Laws (Dissertation).

The author expresses their gratitude to Professor Bill Atkin, their husband Rāwā, whānau, and friends for their encouragement, love and support during the writing of this dissertation. This dissertation is dedicated to the author's father Peter Wood-Bodley who has lived a life being a fierce co-conspirator with marginalised communities and adapted to life with Parkinson's disease with courage and humour.

their will and preference and ensure that New Zealand complies with its obligations under international human rights law, particularly art 12 of the UNCRPD.

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## Chapter 1: Introduction

The Universal Declaration of Human Rights begins with the statement, “All human beings are born free and equal in dignity and rights”.<sup>2</sup> Disabled people deserve to live freely and equally in dignity and rights. They deserve to be at the forefront of discourse and discussion about issues affecting them. However, we have a long way to go before this dream becomes a reality. Supported decision-making is but one tool that will facilitate a societal change in understanding what it means to be a disabled person and what it means to have lived experience of disability.

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), to which New Zealand is a signatory, requires States to take action to ensure that the rights of disabled people are affirmed and realised.<sup>3</sup> The purpose of the UNCRPD is to “promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity”.<sup>4</sup> Additionally, all people are recognised as being equal before the law and entitled to equal protection and benefit of the law. States are required to prohibit all forms of discrimination on the basis of disability to guarantee equal and effective legal protection against discrimination.<sup>5</sup>

In New Zealand, the dignity and rights of disabled people are recognised and protected through a variety of domestic legal frameworks. Our disability law is primarily found in the New Zealand Bill of Rights Act 1990 (NZBORA), Human Rights Act 1993 (HRA), Pae Ora (Healthy Futures) Act 2022 and the Protection of Personal and Property Rights Act 1988 (PPPR Act).

Disability law in New Zealand has three key strands. Firstly, it defines which organisations have operational responsibility for delivering core public services to the disabled community. Secondly, it defines which

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<sup>2</sup> Article 1.

<sup>3</sup> United Nations Convention on the Rights of Persons with Disabilities 2515 UNTS 3 (opened for signature 30 March 2007, entered into force 3 May 2008).

<sup>4</sup> Above n 2, art 1.

<sup>5</sup> Above n 2, art 5.

organisations are responsible for realising and advocating for the protection and promotion of the rights of disabled people. Thirdly, it defines when individuals have mental capacity and what happens when they lack the mental capacity to manage their affairs.

Primary operational responsibility for delivering services to disabled people is shared by the Whaikaha – Ministry of Disabled People, Te Whatu Ora – Health New Zealand, Te Aka Whai Ora – Māori Health Authority and Ministry of Social Development. Whaikaha – Ministry of Disabled People, Te Whatu Ora – Health New Zealand, Te Aka Whai Ora – Māori Health Authority are responsible for providing disability support services, and the Ministry of Social Development is responsible for social welfare support. Additionally, the Ministry of Education and Kāinga Ora provide other social support through providing support in the education system and social housing. Collectively, these agencies are responsible for delivering services to disabled people, in conjunction with community service providers, to enable them to live good lives.

Further, the Office for Disability Issues, Human Rights Commission, and the Health and Disability Commissioner share responsibility for protecting and promoting the rights of disabled people in New Zealand. The Office for Disability Issues is responsible for supporting the New Zealand government in implementing the UNCRPD through the New Zealand Disability Strategy and Disability Action Plan.<sup>6</sup> In accordance with the HRA, the Human Rights Commission is responsible for investigating and preventing discrimination on the basis of disability. The Health and Disability Commissioner is responsible for promoting and protecting the rights of consumers under the Health and Disability Commissioner (Code of Health and Disability Service Consumer's Rights) Regulations 1996 (the Code).<sup>7</sup>

“Supported decision-making” (SDM) has emerged as an accepted framework for empowering disabled people to assert their dignity and

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<sup>6</sup> Office for Disability Issues *Disability Action Plan 2019-2023* (online ed, Office for Disability Issues, 2019).

<sup>7</sup> Health and Disability Commissioner Act 1994.



rights. SDM permeates the policy underlying the UNCRPD. In particular, art 12 requires States to take appropriate measures to ensure that disabled people have access to the support they need to exercise their legal capacity with appropriate and effective safeguards in accordance with international human rights law.

SDM is a key tool, enabling disabled people to live good lives where they realise self-determination and have their inherent dignity and rights protected, respected, and affirmed. It is effectively another way of describing the concept of providing informed consent using disability language.

The key themes of SDM are not unique to the realm of intellectual disability. Indeed, they reflect the decision-making support, whether formal or informal, that most people utilise when making choices affecting their everyday lives. Using an SDM model empowers disabled people to make their own decisions in a way that is appropriate for their circumstances. This is the key to increasing autonomy and self-determination amongst disabled people enabling them to participate in society and live freely and equally in dignity and rights. Put simply, these reasonable accommodations, when provided, enable disabled people to realise their right to self-determination in recognition of their legal capacity and dignity as human rights holders, as affirmed by the UNCRPD, the HRA and the NZBORA.

The concept of SDM exists domestically at an operational level within Whaikaha – Ministry of Disabled People, the Ministry of Health, Te Whatu Ora, and the Ministry of Social Development as well as within Disabled Persons Organisations, primary health organisations and community service providers. However, it does not feature in our primary legislation governing the delivery of disability services or the protection of disabled people. To a limited extent, the concept of SDM is reflected in the informed consent right in the Code.<sup>8</sup>

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<sup>8</sup> See sch 1 cl 2 right 7(3).

This dissertation explores how we can reimagine our domestic legal frameworks and use SDM to empower disabled people in New Zealand to attain freedom and equality in dignity and rights. This dissertation contributes to New Zealand's legal scholarship on SDM by arguing for and providing a draft Supported Decision-Making Bill to embed SDM into our domestic legal frameworks.

Chapter 2 sets the scene by defining disability for the purposes of this dissertation and adopts the definition of disability included in s 21(1)(h) of the HRA.

Chapter 3 provides an overview of the role the Government has in supporting and enabling disabled people to live good lives. In particular, it describes and discusses the roles that Whaikaha – Ministry of Disabled People, the Accident Compensation Corporation, Ministry of Social Development, Ministry of Education, Kāinga Ora, Human Rights Commission, and the Independent Monitoring Mechanism play in the lives of disabled people. It also highlights where SDM is currently used and opportunities for SDM to be adopted, demonstrating that an ad hoc approach has been taken at an operational level to give effect to our international law obligations under art 12 of the UNCRPD.

Chapter 4 defines SDM for the purposes of this dissertation and discusses the key elements of a supported decision-making arrangement (SDM arrangement). This discussion focuses on the nature of an SDM arrangement, disabled people, supporters, supports and reasonable accommodations.

Chapter 5 discusses the international legal context and provides a brief history of international human rights law on the rights of disabled people, the UNCRPD, a discussion of art 12 and the UNCRPD Committee's General Comment on art 12, and New Zealand's compliance with art 12.

Chapter 6 discusses New Zealand's domestic law relating to disability and decision-making from 1868 to the present. The discussion explores the eugenics and institutionalisation era with reference to the Lunatics Act

1868 (repealed), Mental Defectives Act 1911 (repealed), and the Aged and Infirm Persons Protection Act 1912 (repealed). The discussion then focuses on our current law with reference to the PPPR Act, the HRA, the Code, the common law doctrine of necessity, and the inherent jurisdiction of the High Court of New Zealand.

Chapter 7 focuses on New Zealand's domestic legal scholarship on SDM and the key themes arising from this scholarship.

Chapter 8 provides a clause-by-clause analysis of the proposed Supported Decision-Making Bill (SDM Bill). It describes the background to the SDM Bill's overall design and the intentions and factors considered during the drafting process.

Chapter 9 applies the proposed SDM Bill to the circumstances of five characters who have been developed to demonstrate how the SDM Bill would work in practice alongside our existing suite of decision-making laws and highlights complex issues that could arise because of the intersection between the SDM Bill with the PPPR Act.

Decision-makers at all levels and in all disciplines exercise power over the ability of disabled people to realise their human rights and participate equitably in civil society. It is essential that the lived experience of disabled people is valued and that disabled people are included as partners, empowered to lead conversations about matters that affect their human rights and ability to participate equitably in society. Disabled people should be the guiding light in these spaces if society and indeed the law is ever to facilitate the equitable recognition and protection of dignity and rights under the law – “Nothing about us, without us”.<sup>9</sup>

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<sup>9</sup> United Nations “International Day of Disabled Persons 2004” (3 December 2004) United Nations Department of Economic and Social Affairs Disability <[www.un.org](http://www.un.org)>.

## **Chapter 2: Defining Disability**

This chapter defines disability for the purposes of this dissertation. The New Zealand definition of disability, the nature of the disability and international law definition of disability are discussed.

### *I New Zealand's Definition of Disability*

The definition of disability for the purposes of New Zealand law comes from the HRA. Section 21(1)(h) of the HRA defines disability for the purposes of New Zealand law as meaning:

- (i) physical disability or impairment:
- (ii) physical illness:
- (iii) psychiatric illness:
- (iv) intellectual or psychological disability or impairment:
- (v) any other loss or abnormality of psychological, physiological, or anatomical structure or function:
- (vi) reliance on a disability assist dog, wheelchair, or other remedial means:
- (vii) the presence in the body of organisms capable of causing illness:

As demonstrated above, New Zealand law takes a broad approach to the definition of disability, recognising the five main types of impairments: intellectual, psychiatric, physical, and neurological. or sensory. Additionally, it includes physical illnesses and having organisms in the body that can cause illness, such as having the breast cancer gene as a disability.

The definition also includes reliance on a guide dog, use of wheelchairs or other aids such as hearing aids as being within the broad ambit of disability. This recognises that disabled people who rely on guide dogs, wheelchair users and those reliant on other aids often face discrimination because of these factors. Additionally, the definition applies to impairments regardless of whether short, long-term, or intermittent.

The dignity and rights of disabled people are recognised and protected through a variety of domestic legal frameworks that will be discussed in Chapter 6.

## *II Definition from the United Nations Convention on the Rights of Persons with Disabilities*

From an international human rights law perspective, disability is defined by the UNCRPD. Article 2 of the UNCRPD defines “persons with disabilities” as including:

[T]hose who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others.

The primary difference between the definition in the HRA and the UNCRPD is that the HRA includes short-term disabilities and impairments. The UNCRPD requires long-term physical, mental, intellectual, or sensory impairment. Additionally, the UNCRPD does not expressly include illnesses or having organisms in the body capable of causing illness.

## *III The Nature of Disability*

New Zealand uses the “social model” of disability, recognising that individuals do not have disability, rather they are disabled due to barriers in society that prevent inclusion.<sup>10</sup> Under the social model of disability, disability occurs when a person with an impairment is excluded or unable to participate equitably in society because their impairments are not adequately accommodated.<sup>11</sup> The social model of disability can be compared to the “medical model” of disability which is a deficit focused approach that pathologises and seeks to “cure” disability through medical intervention to the extent possible.<sup>12</sup>

New Zealand takes a rights-based approach to disability, recognising that disabled people have the same legal rights as non-disabled people. The rights-based approach also recognises that disabled people have the right to live on an equitable basis as non-disabled people.<sup>13</sup>

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<sup>10</sup> Office for Disability Issues “Guidance for policy makers” (14 April 2019) <<https://www.odt.govt.nz/guidance-and-resources/>>.

<sup>11</sup> IBID.

<sup>12</sup> IBID.

<sup>13</sup> IBID.

A person can be born with an impairment or acquire it via an accident or illness. Impairments can be intellectual, psychiatric, physical, neurological, or sensory. Additionally, impairments can be short-term or long-term and may intermittently impact a person.<sup>14</sup>

Individual experience of disability depends on the nature of a disabled person's impairment. When disability intersects with other factors such as gender identity, sexuality, ethnicity, culture, and age this can compound a person's experience of disability.<sup>15</sup> As people age, they are more likely to experience multiple impairments.

#### *IV Adopted Definition of Disability*

For the purposes of this dissertation, the social model of disability and the rights-based model of disability will be adopted as well as the definition of disability included in the HRA. References are made to the UNCRPD definition of persons with disabilities in this dissertation for comparative purposes.

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<sup>14</sup> IBID.

<sup>15</sup> IBID.

## **Chapter 3: Disability and the Machinery of Government**

The New Zealand government has a fragmented approach to coordinating the delivery of state support to disabled people. As part of operational practice, many Ministries, Departments, departmental agencies, independent Crown entities and service providers incorporate SDM into delivering disability support services.

Responsibility for policy and delivery of public services for disabled people is primarily split between the newly established Whaikaha - Ministry of Disabled People, Accident Compensation Corporation (ACC), Ministry of Social Development (MSD), Ministry of Education (MoE), and Kāinga Ora.

Responsibility for overseeing the government's performance at the Executive branch level is primarily split between the Office for Disability Issues (ODI), the Human Rights Commission (HRC) and the Independent Monitoring Mechanism (IMM). Finally, the Courts of New Zealand are responsible for upholding the rights of individuals and reviewing government decision-making.

The purpose of this section is to describe and discuss the role of each public sector entity in delivering state support to disabled people. This will provide important insights into the complex operational context within which an SDM framework would operate in New Zealand.

### *I Whaikaha – Ministry of Disabled People*

The newly established Whaikaha – Ministry of Disabled People (Whaikaha) is responsible for providing leadership across the government on disability rights issues and for delivering core disability support services.<sup>16</sup> This section outlines the journey to establishing Whaikaha – Ministry of Disabled People and its core responsibilities.

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<sup>16</sup> See generally Pae Ora (Healthy Futures) Act 2022.

## A *Announcement and Establishment Phase*

On 29 October 2021, the then Minister for Disability Issues, Hon Carmel Sepuloni, announced that from 1 July 2022, there will be a departmental agency hosted by the Ministry of Social Development known as the Ministry of Disabled People which would, for the first time in New Zealand's history, centralise the provision of disability supports such as education, social and health services within a single entity.<sup>17</sup> This reform is part of the health and disability system reforms announced by the Hon Andrew Little on 21 April 2021.<sup>18</sup>

The Establishment Unit, housed within the Ministry of Social Development, was responsible for the organisational design and operational transition to the Ministry for Disabled People on 1 July 2022. The officials working in this space had a significant influence on whether the Ministry of Disabled People is fit for purpose and serves the needs of disabled people.<sup>19</sup>

The announcement was met with significant optimism and excitement from the disabled community. However, there was a strong caution to the government by disabled community leaders that disabled people must lead the establishment of the Ministry for Disabled People and that the leadership must comprise of disabled people.<sup>20</sup>

Dr Justine Cornwall was appointed as the Executive Director for the Establishment Unit for the Ministry of Disabled People.<sup>21</sup> Dr Cornwall's appointment was controversial because they did not openly identify as a disabled person, nor were they known to the disabled community.<sup>22</sup>

Prominent leaders within the disabled community, such as the then Human Rights Commissioner for Disability Paula Tesoriero and

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<sup>17</sup> Russell Palmer "Government announces new Ministry for Disabled People and accessibility law" *Radio New Zealand* (online ed, Auckland, 29 October 2021).

<sup>18</sup> Hon Andrew Little, Hon Peeni Henare and Hon Dr Ayesha Verrall "Major reforms will make healthcare accessible for all NZers" (press release, 21 April 2021).

<sup>19</sup> Ministry of Social Development "New Ministry for Disabled People" (29 October 2021) <[www.msd.govt.nz/about-msd-and-our-work/](http://www.msd.govt.nz/about-msd-and-our-work/)>.

<sup>20</sup> Arielle Kauaeroa "Disabled leaders disappointed non-disabled persons will lead set-up of new ministry" *Stuff* (online ed, Wellington, 24 December 2021).

<sup>21</sup> *IBID.*

<sup>22</sup> Above n 19.



disability law expert Dr Huhana Hickey, spoke publicly of their concerns about the appointment.<sup>23</sup> The Green Party of Aotearoa, New Zealand, spoke out against the Government in support of the disabled community's concerns about Dr Cornwall's appointment and the damage it had done to the already tenuous and strained relationship between the Crown and disabled people.<sup>24</sup>

### *B The Beginning of a New Chapter for Disabled New Zealanders*

On 1 July 2022, Whaikaha – Ministry of Disabled People was launched, bringing together the Ministry of Health's Disability Support Services branch and ODI within a single departmental agency hosted by the Ministry for Social Development.<sup>25</sup>

At the time, the permanent Chief Executive's appointment had not been finalised, but the disabled community was reassured that it would, for the first time in New Zealand's history, be led by a disabled person.

On 30 August 2022, it was announced that the then Disability Rights Commissioner Paula Tesoriero was the incoming Chief Executive of Whaikaha – Ministry of Disabled People.<sup>26</sup> Ms Tesoriero has made it clear that Whaikaha – Ministry of Disabled People is committed to ensuring that it realises the disabled community's mantra of "Nothing about us, without us".<sup>27</sup>

### *C Responsibility for Providing Disability Support Services*

Disability Support Services (DSS), which was formerly part of the Ministry of Health, covers people with physical, intellectual, or sensory disabilities that are likely to continue for at least six months which limits their ability to function independently, requiring ongoing support.<sup>28</sup> These services are also provided to people with certain neurological

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<sup>23</sup> IBID.

<sup>24</sup> IBID.

<sup>25</sup> Public Service (Ministry for Disabled People) Order 2022, sch 2 pt 2.

<sup>26</sup> Public Service Commission "Chief Executive, Whaikaha – Ministry of Disabled People appointed" (press release, 30 August 2022).

<sup>27</sup> Whaikaha – Ministry of Disabled People "Who we are" (1 July 2022) <[www.whaikaha.govt.nz/about-us](http://www.whaikaha.govt.nz/about-us)>.

<sup>28</sup> Whaikaha – Ministry of Disabled People "Who can get support" (1 July 2022) <[www.whaikaha.govt.nz/assessments-and-funding/who-can-get-support/](http://www.whaikaha.govt.nz/assessments-and-funding/who-can-get-support/)>.

conditions that result in permanent disabilities such as Parkinson's Disease, developmental disabilities such as autism and disabilities that co-exist with a health condition or injury.<sup>29</sup>

DSS does not cover diabetes, asthma, mental health and addiction conditions or conditions commonly associated with aging, such as Alzheimer's disease. Impairments caused by accident or injury are not covered because they are covered by ACC.<sup>30</sup>

Since 1998 there have been significant policy shifts towards enabling disabled people to live autonomous lives which are self-determined and enable them to realise their dreams and aspirations.<sup>31</sup> In the last decade, particularly, there has been a conscious shift towards embedding SDM as a key tool for disabled people to live good lives in accordance with their dreams and aspirations. These significant policy shifts are discussed below.

### *1 The Individualised Funding Model*

This was first attempted through the "Individualised Funding Model" (IF), which aims to give disabled people more choice and control by enabling them to directly manage the support services provided to them.<sup>32</sup> IF is available to eligible disabled people across the country.<sup>33</sup>

IF has a narrow scope focusing primarily on purchasing household management and personal care services and respite for full-time carers so they can have a break. It can be used to pay family members for household management or personal care. However, IF does not cover the costs of medical supplies, equipment, or modifications to property to improve accessibility, leisure, or recreational activities.<sup>34</sup>

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<sup>29</sup> IBID.

<sup>30</sup> IBID.

<sup>31</sup> Ministry of Health *Individualised Funding: Guidance and Good Practice* (Ministry of Health, Wellington, September 2003) at 4.

<sup>32</sup> Whaikaha – Ministry of Disabled People "What is Individualised Funding (IF)" (1 July 2022) <[www.whaikaha.govt.nz/types-of-support/](http://www.whaikaha.govt.nz/types-of-support/)>.

<sup>33</sup> IBID.

<sup>34</sup> IBID.

The IF model supports disabled people to live more self-determined lives by giving them choices and control over procuring disability support services. However, the IF model does not encourage SDM outside of procuring disability support services.<sup>35</sup>

## *2 The Enhanced Individualised Funding Model*

The “Enhanced Individualised Funding Model” (EIF) expanded the scope of IF beyond traditional supports such as household management, personal care, and respite services.<sup>36</sup> It is only available in the Eastern and Western Bay of Plenty.<sup>37</sup>

EIF puts disabled people in charge of their disability support budget and enables it to be used to purchase any disability support, which is part of the disabled person’s plan and helps them progress towards achieving their goals.<sup>38</sup>

However, EIF only enables disabled people to purchase support provided by Whaikaha – Ministry of Disabled People. It cannot be used to purchase support provided by other government agencies. This is a key limitation of the EIF model because it treats disabled people as a customer of a government agency rather than recognising that supporting disabled people often engages more than one government agency.<sup>39</sup>

As with IF, the EIF model provides limited scope for encouraging disabled people to use SDM outside of procuring disability support services and respite care.

## *3 The Enabling Good Lives Approach*

Whaikaha – Ministry of Disabled People is piloting a scheme called “Enabling Good Lives” (EGL), the inspiration for the title of this dissertation. The pilot is currently running in Hamilton, Palmerston

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<sup>35</sup> IBID.

<sup>36</sup> Ministry of Health “Enhanced Individualised Funding” (09 November 2021) <[www.health.govt.nz/your-health/services-and-support/disability-services](http://www.health.govt.nz/your-health/services-and-support/disability-services)>.

<sup>37</sup> Ministry of Health *Your guide to Enhanced Individualised Funding* (Ministry of Health, Wellington, December 2013) at 1.

<sup>38</sup> IBID, at 4-7.

<sup>39</sup> Above n 36.

North, and Christchurch.<sup>40</sup> The pilot phase of the EGL programme started in 2012, and there is uncertainty about when it will be rolled out nationally.

EGL envisions a future where disabled people and their families have choice and control over the support they receive and how they live their lives.<sup>41</sup> The principles are self-determination, beginning early, person-centred, ordinary life outcomes, mainstream first, mana enhancing, easy to use and relationship building.<sup>42</sup>

The EGL approach has five interrelated characteristics: self-directed planning and facilitation, cross-government individualised and portable funding, considering the person's wider context, strengthening families or whānau and community building.<sup>43</sup>

Self-directed planning and facilitation mean that the disabled person's personal plan detailing their goals and aspirations is used to design and measure supports and services necessary to maintain a good life.

Cross-government individualised and portable funding means that disabled people have control over their funding for services and supports and can use them flexibly as their preferences and needs change.

Considering the person in their wider context recognises that friends, family, and community are respected as a fundamental part of a disabled person's identity and belonging.

Strengthening families or whānau recognises the value of investing in support networks by educating and building understanding to increase opportunities to maximise choice and control.

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<sup>40</sup> Enabling Good Lives "About Enabling Good Lives" (2018) <[www.enablinggoodlives.co.nz/about-egl/](http://www.enablinggoodlives.co.nz/about-egl/)>.

<sup>41</sup> Enabling Good Lives "Vision" (2018) <[www.enablinggoodlives.co.nz/about-egl/egl-approach](http://www.enablinggoodlives.co.nz/about-egl/egl-approach)>.

<sup>42</sup> Enabling Good Lives "Principles" (2018) <[www.enablinggoodlives.co.nz/about-egl/egl-approach](http://www.enablinggoodlives.co.nz/about-egl/egl-approach)>.

<sup>43</sup> Enabling Good Lives "Key Characteristics" (2018) <[www.enablinggoodlives.co.nz/about-egl/egl-approach](http://www.enablinggoodlives.co.nz/about-egl/egl-approach)>.

Community building recognises that disabled people are valued members of the community and supports disabled people to achieve desired outcomes from a social, economic, and cultural perspective.<sup>44</sup>

The EGL approach identifies five interrelated elements of system change: building knowledge and skills of disabled people, investment in families, changes in the community, service provision, as well as government systems and processes.<sup>45</sup>

Building knowledge and skills of disabled people recognises the role of the government in ensuring disabled people can utilise opportunities to have more choice and control over support services.

Investment in families recognises that families need support to enable their disabled family member to develop a vision and aspirations and live a good life.

The EGL model encourages the use of SDM to enable disabled people to live good lives according to their dreams and aspirations. This happens by focusing on the disabled person and enabling them to build natural support and receive support from various sources (not just in personal care).<sup>46</sup>

#### *D Office for Disability Issues*

The Office for Disability Issues (ODI) was formerly an independent Crown entity housed within MSD that is now part of Whaikaha – Ministry of Disabled People. It monitors and reports on the New Zealand government's compliance with the UNCRPD.<sup>47</sup>

ODI is responsible for the “New Zealand Disability Strategy” and the “Disability Action Plan”. The New Zealand Disability Strategy guides work on disability issues across the government for a 10-year period. The Disability Action Plan provides the specific actions that government agencies intend to undertake over a 5-year period.

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<sup>44</sup> IBID.

<sup>45</sup> IBID.

<sup>46</sup> IBID.

<sup>47</sup> Office for Disability Issues “Our role and responsibilities” (9 August 2022) <[www.odi.govt.nz/about-us/home/](http://www.odi.govt.nz/about-us/home/)>.

The New Zealand Disability Strategy 2016-2026 and Disability Action Plan 2019-2023 include the following specific areas of focus: education, employment and economic security, health and wellbeing, rights protection and justice, accessibility, attitudes, choice and control and leadership.<sup>48</sup> The Disability Action Plan retrospectively measures the progress the New Zealand government has made on disability issues when reporting to the UNCRPD Committee.

Outcome 7 includes an action to reduce barriers to disabled people making decisions to determine their own lives. This includes further action to ensure that disabled people can exercise their legal capacity, including through recognition of SDM.<sup>49</sup>

## *II Accident Compensation Corporation (ACC)*

ACC is the New Zealand government's publicly funded accidental injury insurance agency, established in 1974 to nationalise access to financial and rehabilitative assistance following an accident.<sup>50</sup> Prior to the establishment of ACC, people had to take legal action under the common law tort of personal injury to recover compensation in the event of an accident. This was inequitable for parties who needed the means to take legal action to establish their claim.<sup>51</sup>

In the disability context, ACC is responsible for providing access to financial and rehabilitative support for people who have become disabled because of a personal injury.<sup>52</sup> There are two main forms of compensation available for disabled people in addition to medical, social, and vocational rehabilitation services.<sup>53</sup>

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<sup>48</sup> Above n 5.

<sup>49</sup> Office for Disability Issues "Outcome 7 – Choice and control" (21 November 2016) <[www.odi.govt.nz/nz-disability-strategy/outcome-7-choice-and-control/](http://www.odi.govt.nz/nz-disability-strategy/outcome-7-choice-and-control/)>.

<sup>50</sup> See generally, Accident Compensation Act 1972.

<sup>51</sup> Lewis N. Klar "New Zealand's Accident Compensation Scheme: A Tort Lawyer's Perspective" (1983) 33(1) University of Toronto Law Journal 80 at 80.

<sup>52</sup> Accident Compensation Act 2001, ss 20, 67, 69 and sch 1, cls 54 to 62; Injury Prevention, Rehabilitation, and Compensation (Lump Sum and Independence Allowance) Regulations 2002, reg 4.

<sup>53</sup> See generally, Accident Compensation Act 2001, Part 4.

Firstly, disabled people are entitled to a lump sum permanent impairment payment from ACC, which is determined based on the degree of “whole person impairment” arising from the accident. To be eligible, they must have a whole-person impairment of 10 per cent or more.<sup>54</sup> Entitlement continues until the whole person impairment is assessed as falling below the minimum threshold of 10 per cent.<sup>55</sup>

Secondly, ACC provides financial support through weekly compensation when a person is unable to work because of an injury. Weekly compensation is set at 80% of their salary.<sup>56</sup> Entitlement to weekly compensation continues until a person is assessed as well enough to return to their regular pre-injury work or another suitable role.<sup>57</sup>

Where an injury has occurred, ACC focuses on medical, social, and vocational rehabilitation. The costs of medical rehabilitative services such as physiotherapists, specialists, and surgeons are covered under the scheme.<sup>58</sup> ACC provides social rehabilitation such as temporary or permanently modifying a person’s home, public and private transport, and support workers to help with personal care from showering and bathing to household cleaning and laundry.<sup>59</sup> Vocational rehabilitation is available to enable a person to remain in work, return to work, find new work or become work ready following an injury.<sup>60</sup>

ACC’s service delivery model provides little opportunity for disabled people to make their own decisions using SDM. This is because of the legislative constraints and the complexity of their operating context. For SDM to be effective, the supporter(s) would need to have significant experience working within the ACC framework.

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<sup>54</sup> Above n 52, ss 20, 67, 69 and sch 1, cls 54 to 62.

<sup>55</sup> Accident Compensation Corporation “Financial support if you have a permanent injury” (20 October 2021) <[www.acc.co.nz/im-injured/financial-support/](http://www.acc.co.nz/im-injured/financial-support/)>.

<sup>56</sup> Accident Compensation Corporation “Getting paid if you can’t work – weekly compensation” (13 December 2022) <[www.acc.co.nz/im-injured/financial-support/weekly-compensation/](http://www.acc.co.nz/im-injured/financial-support/weekly-compensation/)>.

<sup>57</sup> IBID.

<sup>58</sup> Above n 52, s 69.

<sup>59</sup> Above n 52, s 81.

<sup>60</sup> Above n 52, s 80.

### *III Ministry of Social Development (MSD)*

The Ministry of Social Development (MSD) is responsible for administering social welfare services on behalf of the New Zealand government.<sup>61</sup>

In the context of disability, MSD is responsible for providing financial support through the Supported Living Payment, the Disability Allowance and, where relevant, the Child Disability Allowance.<sup>62</sup> For many high and complex needs disabled people, social welfare benefits are their main or sole source of income.<sup>63</sup> Disabled people who can work receive little to no support from MSD unless they meet the requirements for benefits that are not income-tested.<sup>64</sup>

The Supported Living Payment is the main benefit claimed by disabled people over the age of 16 years. To be eligible for the Supported Living Payment, a person must be permanently or severely restricted in their ability to work due to an illness, injury, or disability. They must be regularly unable to work more than 15 hours per week, with this incapacity expected to last at least two years. Disabled people who are totally blind automatically qualify.<sup>65</sup>

The Disability Allowance and the Child Disability Allowance assist with the ongoing costs of goods and services incurred because of a disability, such as doctors' visits, prescriptions, and treatments.<sup>66</sup>

To be eligible for the Disability Allowance, the impairment must likely continue for at least six months and have reduced independent function to the point that ongoing support is necessary for the normal functions of life or ongoing supervision or treatment by a health professional is

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<sup>61</sup> See generally, Social Security Act 2018.

<sup>62</sup> Social Security Act 2018, ss 34-37, 79-83, 84-49.

<sup>63</sup> Ministry of Social Development "Supported Living Payment" <[www.workandincome.govt.nz/products/a-z-benefits/](http://www.workandincome.govt.nz/products/a-z-benefits/)>; Ministry of Social Development "Disability Allowance" <[www.workandincome.govt.nz/products/a-z-benefits/](http://www.workandincome.govt.nz/products/a-z-benefits/)>; Ministry of Social Development "Child Disability Allowance" <[www.workandincome.govt.nz/products/a-z-benefits/](http://www.workandincome.govt.nz/products/a-z-benefits/)>.

<sup>64</sup> IBID.

<sup>65</sup> Above n 61, ss 34-37.

<sup>66</sup> Above n 61, ss 79-83, 84-49.



required. The allowance is income-tested. An additional benefit called Temporary Additional Support is available if support costs exceed the Disability Allowance entitlement.<sup>67</sup>

The Child Disability Allowance is paid to caregivers of children with a physical or mental impairment likely to last more than one year, requiring constant care and intention. This entitlement is not income-tested and can be paid in addition to the Disability Allowance.<sup>68</sup>

The Supported Living Payment, Disability Allowance and Child Disability Allowance require a doctor to certify that the claimant meets the requirements every two years. This requirement is particularly fraught where the person has a lifelong, congenital disability, for which they are not expected to “recover” such as Down's Syndrome.<sup>69</sup>

The Social Security Act 2018 requirements determine entitlement to social welfare support. In this context, there is little opportunity to use SDM when engaging with MSD. SDM could primarily be used to support a disabled person in applying for social welfare and navigating the application process.

#### *IV Ministry of Education (MoE)*

The Ministry for Education (MoE) is responsible for providing education services to New Zealanders, from early childhood education to tertiary education and vocational education and training.<sup>70</sup> It is compulsory for domestic students to be enrolled and attend school from the age of six to 16 years old.<sup>71</sup> Students requiring special education are permitted to attend school up to 21 years of age.<sup>72</sup>

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<sup>67</sup> Above n 61, ss 84-89.

<sup>68</sup> Ministry of Social Development “Child Disability Allowance” <[www.workandincome.govt.nz/products/a-z-benefits/](http://www.workandincome.govt.nz/products/a-z-benefits/)>.

<sup>69</sup> Above n 62.

<sup>70</sup> See generally Education and Training Act 2020.

<sup>71</sup> Above n 69, s 35.

<sup>72</sup> Above n 69, s 37.

## *A Special Education Generally*

Section 34 of the Education and Training Act 2020 confirms that disabled people have the same rights as non-disabled people to enrol and be educated in state schools. Special education is delivered through a variety of mechanisms such as learning support, specialist services, teacher aide funding, specialist teachers and schools.<sup>73</sup>

Access to additional learning support largely depends on the parent's awareness of their child's disability or having a teacher with the skills necessary to identify additional learning needs. Increased awareness of disability issues such as congenital intellectual disabilities grows (often referred to as "invisible disabilities"), and it is becoming increasingly common for parents and teachers to identify additional learning needs during primary schooling. However, it is still reasonably common for congenital intellectual disabilities such as autism spectrum, ADD and ADHD to be identified and diagnosed in early adulthood.

Early identification of intellectual disabilities and provision of additional learning supports is critically important to ensuring that disabled learners are educated on an equitable basis to their non-disabled peers. This is the difference between learners being perceived as "difficult" and having "behavioural issues" and being able to meaningfully participate in the education system and progress on to tertiary level study.

## *B Learning Support*

Learning support is available for children and young people with autism or that are blind or low vision, deaf or hard of hearing, as well as those with speech, language, and communication needs.<sup>74</sup> The learning support available varies depending on the nature of the student's disability.

Examples of learning support can include providing students with extra help with their National Certificate Educational Achievement

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<sup>73</sup> Ministry of Education "Students requiring learning support" (13 October 2022) <[www.education.govt.nz/school/student-support/special-education/](http://www.education.govt.nz/school/student-support/special-education/)>.

<sup>74</sup> IBID.

assessments, specialist schools, and the provision of specialist equipment and technology to increase and improve learning and participation.<sup>75</sup>

### *C Specialist Services*

Specialist services are available to support students with a physical disability, to help with managing difficult behaviour and providing holistic wraparound services for children and young people with significant challenges in their lives.<sup>76</sup> For example, the Physical Disability Service helps schools and teachers to ensure that the learning environment meets students' needs.<sup>77</sup>

The Te Kahu Tōi, Intensive Wraparound Service (IWS) provides support to students aged five to 14 years with highly complex and challenging behaviour, social and/or learning needs requiring support at school, home and in the community. It ensures that a multi-disciplinary team is built around the student and their whānau, often including friends and service providers.<sup>78</sup>

### *D Specialist Schools*

Specialist schools are available for students that have high needs.<sup>79</sup> This includes day specialist schools, residential specialist schools and regional health schools. Day specialist schools are available for students with high needs that require specialist teaching. Residential specialist schools are available for students with specific education needs, such as vision and hearing. Finally, regional health schools are available in Auckland, Wellington, and Christchurch, to support children that are unwell to participate in education where they are too unwell to attend school.<sup>80</sup>

The Decile System is used to rate the affluence of the school community on a scale of one to 10, with one being the poorest school community and

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<sup>75</sup> IBID.

<sup>76</sup> IBID.

<sup>77</sup> IBID.

<sup>78</sup> Ministry of Education “Te Kahu Tōi, Intensive Wraparound Service (IWS)” (13 June 2022) <[www.education.govt.nz/school/student-support/special-education/](http://www.education.govt.nz/school/student-support/special-education/)>.

<sup>79</sup> Above n 72.

<sup>80</sup> Ministry of Education “Specialist schools” (12 May 2022) <[www.education.govt.nz/school/student-support/special-education/](http://www.education.govt.nz/school/student-support/special-education/)>.

10 being the wealthiest. MoE uses it to provide targeted funding to schools to assist with overcoming learning barriers for students that are from a low socio-economic background. Accordingly, the lowest decile schools receive more funding from MoE.<sup>81</sup> From January 2023, this system is being phased out. It will be replaced by the Equity Index, a new way of identifying and responding to socio-economic barriers in education.<sup>82</sup>

The Zoning System determines who can attend which schools. Entitlement to attend a school is a “postcode lottery” determined based on the learners’ primary place of residence.<sup>83</sup> Students are guaranteed a place in a school if they live within the zone for the school.<sup>84</sup> If a student lives outside a school zone, they may be offered a place at their school of choice through a ballot system.<sup>85</sup>

## V *Kāinga Ora*

Kāinga Ora is responsible for the provision of good quality, affordable social housing services.<sup>86</sup> They own or manage a housing portfolio of almost 70,000 properties.<sup>87</sup>

Kāinga Ora notes that part of their work is to ensure that they have the right homes in the right places to meet demand. Currently, they do not have enough homes in urban areas where there is high demand for social housing, and they do not have the right kinds of homes and units to meet demand.<sup>88</sup>

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<sup>81</sup> Ministry of Education “School deciles” (9 November 2022) <[www.education.govt.nz/school/funding-and-financials/resourcing/operational-funding/](http://www.education.govt.nz/school/funding-and-financials/resourcing/operational-funding/)>.

<sup>82</sup> Ministry of Education “The Equity Index” (16 December 2022) <[www.education.govt.nz/our-work/changes-in-education/equity-index/](http://www.education.govt.nz/our-work/changes-in-education/equity-index/)>.

<sup>83</sup> Ministry of Education “Enrolment Schemes (school zones)” (1 December 2022) <[parents.education.govt.nz/primary-school/schooling-in-nz/enrolment-schemes-zoning/](http://parents.education.govt.nz/primary-school/schooling-in-nz/enrolment-schemes-zoning/)>.

<sup>84</sup> Above n 69, s 74(1).

<sup>85</sup> Above n 69, s 74(2).

<sup>86</sup> Kāinga Ora - Homes and Communities Act 2019.

<sup>87</sup> As of 30 September 2022, Kāinga Ora manages or owns 69790 properties. Kāinga Ora *Managed Kāinga Ora Properties* (online ed, Kāinga Ora, 2022).

<sup>88</sup> Kāinga Ora “Housing statistics” (25 November 2022) <[kaingaora.govt.nz/publications/housing-statistics/](http://kaingaora.govt.nz/publications/housing-statistics/)>.

Access to high-quality accessible housing in New Zealand is a problem. This is particularly acute for disabled people. As of June 2020, Kāinga Ora reported that they did not know exactly how many houses met universal design or accessibility standards but estimated that 3,900 properties had been modified to include handrails, ramps, or wet area showers.<sup>89</sup> At that time, MSD reported that there were 900 people waiting for accessible state housing.<sup>90</sup> Kāinga Ora has an Accessibility Policy that commits them to ensuring that at least 15 per cent of new and existing homes across the country meet universal design standards.<sup>91</sup>

Anecdotal evidence suggests that disabled people, particularly wheelchair users, are being placed in inaccessible Kāinga Ora houses.<sup>92</sup> That means that the house may not be equipped with wheelchair ramps and may have stairs which means that the disabled tenants cannot easily use all or part of the house or lack appropriately modified bathroom facilities.<sup>93</sup>

This arguably puts New Zealand in breach of its obligations under the UNCRPD to recognise the right of disabled people to have an adequate standard of living, including adequate housing.<sup>94</sup> While a right to housing is not specifically protected under New Zealand's unwritten constitutional arrangements, particularly the NZBORA, as aforementioned, disability is a prohibited ground of discrimination with limited exceptions.<sup>95</sup>

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<sup>89</sup> Sarah Robson “Kāinga Ora unaware of how many state houses meet accessibility standards” *Radio New Zealand* (online ed, Auckland, 16 June 2020).

<sup>90</sup> *IBID.*

<sup>91</sup> Kāinga Ora “Accessibility at Kāinga Ora” (29 July 2022) <[kaingaora.govt.nz/about-us/accessibility-at-kainga-ora/](https://kaingaora.govt.nz/about-us/accessibility-at-kainga-ora/)>.

<sup>92</sup> Above n 88.

<sup>93</sup> *IBID.*

<sup>94</sup> Above n 2, art 28.

<sup>95</sup> New Zealand Bill of Rights Act 1990, s 19.

## VI *Human Rights Commission (HRC)*

The Human Rights Commission (HRC) is another independent Crown Entity established under the HRA responsible for broadly advancing, defending, and advocating for human rights.

The HRA requires the appointment of a Disability Rights Commissioner.<sup>96</sup> The Disability Rights Commissioner has a broad mandate for ensuring the promotion and protection of the rights of disabled New Zealanders.<sup>97</sup> They partner with government, business, community partners, education providers, and media to assist them to understand their rights and legal obligations. The HRC also undertakes projects to remove barriers for disabled people.<sup>98</sup>

## VII *Independent Monitoring Mechanism*

The Independent Monitoring Mechanism (IMM) is responsible for monitoring the implementation of the UNCRPD, including analysing legislation and policy, monitoring progress, identifying areas of focus, and reporting to the government.<sup>99</sup> The membership includes the Disabled Persons Organisation Coalition, the Human Rights Commission, and the Ombudsman.<sup>100</sup> It was established in October 2011 through a notice in the New Zealand Gazette in accordance with art 33(2) of the UNCRPD.<sup>101</sup> The IMM reports annually on the progress of implementing the UNCRPD.<sup>102</sup>

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<sup>96</sup> Human Rights Act 1993, s 8.

<sup>97</sup> Human Rights Commission “Disability Rights Commissioner” (2020) < [www.hrc.co.nz/about/commissioners-and-senior-leadership/](http://www.hrc.co.nz/about/commissioners-and-senior-leadership/)>.

<sup>98</sup> Human Rights Commission “Disabled people” (2022) < [www.hrc.co.nz/our-work/people-disabilities/](http://www.hrc.co.nz/our-work/people-disabilities/)>.

<sup>99</sup> Human Rights Commission “Independent Monitoring Mechanism on the Disability Convention” (2022) < [www.hrc.co.nz/our-work/people-disabilities/](http://www.hrc.co.nz/our-work/people-disabilities/)>.

<sup>100</sup> Office of the Ombudsman *Independent Monitoring Mechanism – Designated under the Convention on the Rights of Persons with Disabilities* (online ed, Office of the Ombudsman, May 2020) at 2.

<sup>101</sup> “Notice of Independent Monitoring” (13 October 2011) 155 *New Zealand Gazette* 4345 at 4448.

<sup>102</sup> Above n 101.

## *VIII Concluding Observations*

As is evident from the previous discussion, the system delivering public services to support disabled people is fragmented, clunky and complex. This makes it challenging for disabled people and their whānau to identify and easily access services and support.

Further radical reform is required to ensure that public services meet the needs of disabled people and enables them to live good lives free and equal in dignity and rights. The establishment of Whaikaha – Ministry of Disabled People is just the beginning.

## **Chapter 4: Defining and Contextualising Supported Decision-Making**

This chapter defines and contextualises the concept of SDM, which is the core focus of this dissertation. SDM will be defined, and then the key elements of a supported decision-making arrangement (SDM arrangement) will be described and discussed.

### *I Supported Decision-Making Defined*

The essence of SDM can be easily understood from the term; however, what it means and how it looks within the context of the disabled community is worthy of exploration and definition.

For the purposes of this dissertation, “supported decision-making” is defined as:<sup>103</sup>

A process of enabling disabled people to make decisions that affect their lives based on their will and preferences with the support of one or more persons.

This definition is drawn from the Ministry of Social Development and Ministry of Health guidance on SDM. It has been adopted because it succinctly encapsulates the essence of SDM and clearly identifies the key elements.

Disabled People’s Organisations and disability support service providers use similar definitions. For example, People First, in a resource written

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<sup>103</sup> Ministry of Social Development “Supported decision-making” (3 December 2021) Ministry of Social Development <[www.msd.govt.nz/about-msd-and-our-work/work-programmes/accessibility/supported-decision-making.html](http://www.msd.govt.nz/about-msd-and-our-work/work-programmes/accessibility/supported-decision-making.html)>; COVID-19 Vaccination Programme “Making a decision about having the COVID-19 vaccine: A supported decision-making tool” (May 2021) Ministry of Health <[www.health.govt.nz/system/files/documents/pages/covid-19-vaccine-decision-making-tool-easy-read-24may2021.pdf](http://www.health.govt.nz/system/files/documents/pages/covid-19-vaccine-decision-making-tool-easy-read-24may2021.pdf)>.



for disabled people in the Easy Read format<sup>104</sup>, describes SDM in the following terms:<sup>105</sup>

Everyone has the right to make their own decisions. Sometimes you might need support to make your decisions. Supported decision-making means that people assist you to make your own decisions. This way, you have control and choice over your life.

The disability support services provider IHC has adopted the following definition:<sup>106</sup>

Supported decision-making is a framework in which people with disabilities are able to exercise their legal capacity by being supported to make decisions that promote self-determination, will and preference.

In New Zealand, there is no universally used definition of SDM. Definitions are articulated differently depending on the audience and the purpose of the publication. However, the essence of SDM is the same, drawing on universally accepted concepts and elements.

SDM focuses on consensually supporting disabled people to make decisions according to their will and preferences by assisting them to make and communicate decisions, providing support by providing or explaining relevant information or identifying their will and preferences.<sup>107</sup>

Key elements of SDM include positive relationships between the disabled person and their supporter(s), a commitment by their supporter(s) to engage with the disabled person to understand their will and preferences, commitment to a long-term and stable relationship, ensuring that they

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<sup>104</sup> “Easy Read” is an accessible and alternative format which presents text and simple illustrations in a clear and easy to understand format. It is typically used by people with learning disabilities or other conditions which affect processing information. Office for Disability Issues “A guide to making Easy Read information” (20 April 2017) <[www.odi.govt.nz/guidance-and-resources/a-guide-to-making-easy-read-information/](http://www.odi.govt.nz/guidance-and-resources/a-guide-to-making-easy-read-information/)>.

<sup>105</sup> Auckland Disability Law “Supported Decision-Making Leaflet” (3 September 2016) People First NZ <[www.peoplefirst.org.nz/supported-decision-making-tools-you-can-use/](http://www.peoplefirst.org.nz/supported-decision-making-tools-you-can-use/)>.

<sup>106</sup> IHC *Research Report: What does helpful supported decision-making look like to people with intellectual disabilities?* (online ed, IHC, Wellington) at 6.

<sup>107</sup> Jeanne Snelling and Alison Douglass “Legal Capacity and Supported Decision-Making” I Reuvcamp and J Dawson (eds) *Mental Capacity Law in New Zealand* (Thomas Reuters, New Zealand, 2019) 163 at 166 – 167.

assist the disabled person free from bias, listen to the disabled person and effectively communicate information to the disabled person and ensuring the support arrangement is consensual.<sup>108</sup>

The key difference between SDM and “substitute decision-making” is that disabled people are supported to make *their own decisions*, based on their will and preference, rather than relying on someone else (usually appointed by the Family Court under a PPPR Act order) to make decisions for them based on their welfare and best interests.<sup>109</sup> Thus, SDM enables disabled people to live self-determined lives.

## *II Key Elements of a Supported Decision-Making Arrangement*

The purpose of this section is to describe the key elements of an SDM arrangement to provide context for future discussion, analysis, and critique in later chapters.

### *A Nature of Supported Decision-Making Arrangements*

As described in the definitions above, SDM enables disabled people who might not otherwise have the mental capacity to make their own decisions to do so with the support of other people, referred to as supporters.

From the outset, it is important to note that disabled people may be described as having fluctuated mental capacity depending on the nature of the decision before them. As such, SDM can be seen as one of many tools that can be used to enable disabled people to make decisions.

In the context of an SDM arrangement, the focus is on the nature of the decision that needs to be made and what support the disabled person requires to be able to give informed consent on the matter.

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<sup>108</sup> Alison Douglass, Greg Young, and John McMillan *Assessment of Mental Capacity: A New Zealand Guide for Doctors and Lawyers* (Victoria University Press, Wellington, 2020) at 129-130.

<sup>109</sup> See generally, *General comment on Article 12, Equal recognition before the law* UN/Doc/CRPD/C/11/1 (25 November 2013).

It is implicitly/explicitly recognised that by virtue of a supported decision-making arrangement being utilised a disabled person needs support to be able to exercise their legal capacity to make the decision or needs advice from trusted sources to be able to give informed consent.

SDM enables disabled people to give informed consent by ensuring that they have access to information in formats that they can understand and are supported by others to make decisions based on their “will and preferences”.<sup>110</sup> It is a flexible, disabled person first, mana enhancing, way of ensuring that disabled people are included in society on an equitable basis to non-disabled people. For example, they may be able to make decisions about what they would like to eat for breakfast in the morning or what they would like to wear. However, the disabled person may not have the mental capacity to make decisions about entering into a complex financial transaction like a loan agreement, give informed consent to enter an intimate relationship or get married.

SDM arrangements involve: a disabled person, one or more supporters and the provision of supports or reasonable accommodations to assist the disabled person with making a decision. There is no requirement for a SDM arrangement to be recorded in writing. They tend to exist by convention and the terms of the supported decision-making arrangement are communicated regularly between the disabled person and their supporter(s) as opportunities to make decisions arise. These key elements of supported decision-making will be discussed and described in more detail below.

### *B Disabled People*

SDM is not relevant to all disabled people, therefore not all disabled people will use SDM. SDM is particularly relevant to disabled people with intellectual and learning disabilities which impact on their cognitive function. Disabled people with intellectual and learning disabilities often have difficulty receiving and understanding information, identifying, and

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<sup>110</sup> Above n 105.

appreciating the consequences of potential courses of action and/or communicating decisions to others.<sup>111</sup>

Some disabled people may, in legal terms, lack capacity to make their own decisions. It is important to note that a lack of capacity does not always coincide with having an intellectual or learning disability. Generally, disabled people with intellectual or learning disabilities have capacity to make their own decisions providing they have access to information in a format they understand.<sup>112</sup>

All people, including disabled people with intellectual and learning disabilities, have the right to make decisions affecting their lives.<sup>113</sup> This includes the right to make decisions that would be considered foolish or unwise so long as there has been a reasonable opportunity to give informed consent to the decision. This is known as having the “dignity of risk”.<sup>114</sup> What is critical is that the decision-maker can know and understand the consequences of potential courses of action, balancing the risks and benefits and appreciating the likely outcomes.

For disabled people, the key to a successful SDM arrangement is having supporter(s) that know and understand them.<sup>115</sup> This includes knowing their will and preferences, understanding their disability or disabilities and the nature of the supports required.<sup>116</sup>

It is also important that their supporter(s) recognise their role in assisting to facilitate the decision-making process and respect the disabled person’s right to make decisions affecting their life.<sup>117</sup> For this reason, supported decision-making arrangements often arise from carer, friend or whānau relationships.<sup>118</sup>

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<sup>111</sup> Above n 110.

<sup>112</sup> Above n 105.

<sup>113</sup> IBID.

<sup>114</sup> IBID.

<sup>115</sup> IBID.

<sup>116</sup> IBID.

<sup>117</sup> IBID.

<sup>118</sup> IBID.

## *C      Supporters*

The role of the supporter(s) is to ensure that the disabled person has access to the information they need to make a fully informed decision in accordance with their “will and preferences”. They ensure that the disabled person they are supporting has access to the tools necessary to make an informed decision.<sup>119</sup>

Generally, supporters are family members, friends, or care support workers. They should always be a person who knows the disabled person well and understands their support needs as well as their will and preferences. Support arrangements tend to exist by convention, meaning that they emerge based on the relationship, trust, and confidence the disabled person has in the person supporting them.

It is paramount to the success of the SDM arrangement that the supporters themselves have full legal capacity to make their own decisions. Logically it follows that a supporter cannot support a disabled person to make decisions if they are unable to make decisions either.

An SDM arrangement can involve the disabled person and their supporter(s) identifying possible options, undertaking a cost-benefit analysis, discussing the consequences of any proposed course of action, or implementing a decision. Supporter(s) are responsible for ensuring that the disabled person gets quality information, at the right time, in the format that suits their needs and has sufficient time to consider the information before making their decision.<sup>120</sup>

SDM is contextual and tailored to meet the support needs of each disabled person depending on the nature of their disability. Supporters play a pivotal role in enabling disabled people to exercise their legal capacity on an equitable basis with non-disabled people.<sup>121</sup>

The way in which supports are provided to disabled people materially defines the quality of outcomes under the supported decision-making model. This comes down to spending quality time with the disabled

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<sup>119</sup> IBID.

<sup>120</sup> IBID.

<sup>121</sup> IBID.

person, understanding their disability or disabilities and the reasonable accommodations they need to participate actively and meaningfully in the decision-making process.<sup>122</sup>

#### *D Supports or Reasonable Accommodations*

Supports or reasonable accommodations enable disabled people who would traditionally have been considered to lack “mental capacity” to make decisions affecting their lives.<sup>123</sup> As described above, supporter(s) ensure that the disabled person has access to the support they need to make an informed decision.

Reasonable accommodations can include providing access to information necessary to decide in accessible and alternative formats such as large print, braille, easy read, audio, sign language interpretation and where relevant audio description, closed captioning and picture-in-picture sign language interpretation.<sup>124</sup> Alternatively, it can involve ensuring ample time to consider the information provided or assistance with weighing the risks, benefits, and potential outcomes of the decision.<sup>125</sup>

The focus is on adjusting access to information, communication of options, risks and benefits and other environmental factors to ensure they are appropriate considering the disabled person’s support needs. Reasonable accommodations help ensure that disabled people have an equitable opportunity to make their own decisions and live good lives like non-disabled people.<sup>126</sup> While people with similar disabilities are likely to need similar reasonable accommodations, it cannot and should not be assumed that one size fits all approach is appropriate for every disabled person.<sup>127</sup>

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<sup>122</sup> IBID.

<sup>123</sup> IBID.

<sup>124</sup> Above n 2, art 19.

<sup>125</sup> Above n 105.

<sup>126</sup> IBID.

<sup>127</sup> IBID.

## *E Supported Decision-Making Arrangements*

SDM arrangements tend to arise organically between disabled people and their supporter(s). At present there is no legal requirement for a SDM arrangement to be recorded in writing. This requirement may exist by virtue of operational policy in residential care facilities for risk management and health and safety reasons.

SDM arrangements tend to exist by convention, meaning that they emerge based on the relationship, trust, and confidence the disabled person has in their supporter(s). Supporters tend to be family members, care support workers or friends of the disabled person. People who spend significant time with the disabled person and know them well.

The terms of the SDM arrangement are generally communicated regularly between the disabled person and their supporter(s) as opportunities to make decisions arise and as the disabled person's will and preferences emerge or change over time. This provides flexibility to enable the SDM arrangement to adapt to new contexts. However, this also means that supported decision-making arrangements could be susceptible to being used to take advantage of disabled people.

## *III Concluding Observations*

Supported decision-making enables disabled people to make decisions that affect their lives based on their will and preferences with the support of one or more people. It relies on strong and trusted relationships between the disabled person and their supporter(s) and understanding support needs. At its heart, supported decision-making is about enabling disabled people to realise their dreams and aspirations to live freely and equally in dignity and rights.<sup>128</sup>

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<sup>128</sup> IBID.

## Chapter 5: International legal context

This chapter provides an overview of the international legal context relating to the human rights of disabled people. It provides a brief history of international human rights law for disabled people, an overview of the UNCRPD, a detailed discussion of art 12 of the UNCRPD and the UNCRPD Committee's Comment on art 12 and the Committee's comments on New Zealand's compliance with art 12.

### *I Brief History of International Human Rights Law for Disabled People*

Disabled people were relatively invisible in international human rights law until the 21<sup>st</sup> century. Disabled people were not specifically mentioned in the "International Bill of Rights" comprising the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights and the International Covenant on Economic, Social and Cultural Rights.<sup>129</sup>

During the 1970s there were slow movements towards recognising the rights of disabled people under international law. The United Nations (UN) adopted two non-binding declarations: the Declaration on the Rights of Mentally Retarded and the Declaration on the Rights of Disabled Persons.<sup>130</sup> These declarations were based on the medical model of disability and did not truly recognise disabled people as equal rights holders. Disabled people were only recognised as having equal rights to the "maximum degree of feasibility".<sup>131</sup>

In 1981 the UN appointed Special Rapporteurs to report on the global conditions of disabled people for the first time. Further developments occurred in 1991 when the UN adopted the principles on "the protection

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<sup>129</sup> *Universal Declaration of Human Rights* GA Res 217A (1948); *International Convention on Civil and Political Rights* 99 UNTS 171 (open for signature on 16 December 1966, entered into force 28 December 1978); *International Covenant on Economic, Social and Cultural Rights* 993 UNTS 3 (open for signature on 16 December 1966, entered into force 3 January 1976).

<sup>130</sup> *Declaration on the Rights of Mentally Retarded* GA Res 2856 (XXVI) (1971) and *Declaration on the Rights of Disabled Persons* GA Res 3447 (XXX) (1975).

<sup>131</sup> *IBID.*



of persons with mental illness and the improvement of mental health care”.<sup>132</sup>

In 2000 national and international disability organisations met in Beijing to discuss the strategy for advancing the rights of disabled people in the 21<sup>st</sup> century. The meeting highlighted the failures of international human rights instruments to improve the lives of disabled people. Participants committed to pursuing a legally binding international convention to ensure the protection of the rights of disabled people and enable their full and equal participation in society.<sup>133</sup>

The journey towards developing the UNCRPD began in 2001 when the UN passed a resolution sponsored by Mexico to establish an ad hoc Committee to consider proposals for a Convention. The impressively named “Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities” met eight times from 2001-2006 to negotiate the text of the UNCRPD.<sup>134</sup>

## *II The United Nations Convention on the Rights of Persons with Disabilities*

The UNCRPD is the most important international human rights instrument protecting the rights and freedoms of disabled people. It was adopted at the United Nations Headquarters on 13 December 2006 and opened for signature on 30 March 2007. It entered into force on 3 May 2008 and as of 2022 has been ratified by 185 States and 164 signatories.<sup>135</sup>

The UNCRPD has an explicit social development dimension to facilitate a shift from viewing disabled people as objects worthy of charity, medical

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<sup>132</sup> Lucy Series “Disability and Human Rights” N Watson and S Vehmas (eds) *Routledge Handbook of Disability Studies 2<sup>nd</sup> Edition* (Routledge, New York, 2019) 72 at 75.

<sup>133</sup> Above n 134 at 75-76.

<sup>134</sup> Above n 134, at 76.

<sup>135</sup> United Nations “*Convention on the Rights of Persons with Disabilities (CRPD)*” (2022) <[www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/](http://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/)>.

treatment, and social protection to being subjects who enjoy a full suite of human rights, make their own decisions, and live their lives freely and fully as active and contributing members of society.<sup>136</sup> It affirms the right of all disabled people to enjoy all human rights and fundamental freedoms by setting out core human rights and clarifying how they apply to disabled people to ensure they can effectively exercise their rights and seek redress whether their rights have been violated.<sup>137</sup> The UNCRPD embodies the social model of disability, promoting the independence of disabled people by recognising the need for support to exercise legal capacity and unequivocally rejects paternalism.<sup>138</sup>

The UNCRPD established a Committee on the Rights of Persons with Disabilities (the Committee) made up of 18 independent experts, including New Zealander Sir Robert Martin, a prominent disabled person with a learning disability.<sup>139</sup> The Committee operates on the social model of disability recognising that failure to implement a human rights model of disability perpetuates discrimination and exclusion of disabled people in society.<sup>140</sup>

The Committee has two main functions: to advocate for the human rights of disabled people and to support States to implement the UNCRPD by providing recommendations. The Committee provides commentary to assist States with interpreting and implementing provisions of the UNCRPD. It also consistently advocates for disabled people to be included in all initiatives and decisions that affect them.<sup>141</sup>

Article 35 requires all States to provide regular reports to the Committee reporting on the progress made by the State as it implements the

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<sup>136</sup> IBID.

<sup>137</sup> IBID.

<sup>138</sup> Above n 109, at 165.

<sup>139</sup> United Nations Human Rights Office of the High Commissioner “Introduction to the Committee: Committee on the Rights of Persons with Disabilities” (2022) <[www.ohchr.org/en/treaty-bodies/crpd/introduction-committee](http://www.ohchr.org/en/treaty-bodies/crpd/introduction-committee)>; United Nations Human Rights Office of the High Commissioner “Membership: Committee on the Rights of Persons with Disabilities” (2022) <[www.ohchr.org/en/treaty-bodies/crpd/membership](http://www.ohchr.org/en/treaty-bodies/crpd/membership)>.

<sup>140</sup> IBID.

<sup>141</sup> IBID.

UNCRPD. The Committee recommends to each State how to strengthen implementation and compliance with the UNCRPD via concluding observations.<sup>142</sup> It is then up to each State's legislature to respond to the concluding observations and determine how they will respond and act on the recommendations made.<sup>143</sup>

The Optional Protocol entered into force on the same date as the UNCRPD and provides the Committee with the authority to receive and examine complaints made by individuals and investigate grave and systemic violations of the Convention where reliable evidence exists.<sup>144</sup>

### *III Article 12 of the UNCRPD*

At an international level, UNCRPD requires States, like New Zealand, to abolish substitute decision-making regimes like welfare guardianship and property management and replace it with supported decision-making with appropriate safeguards. Article 12 solidifies "supported decision-making" as the default method for enabling disabled people to live self-determining autonomous lives.

Article 12 affirms that disabled people have the right to universal recognition as legal persons before the law on an equal basis to non-disabled people in all areas of life.<sup>145</sup> This is reinforced by art 12(3) which places States under an obligation to ensure that appropriate measures are taken to enable disabled people to exercise their legal capacity ***on an equal basis*** (emphasis added).

Legal capacity is something that entitles a person to act within a legal system.<sup>146</sup> This right can be exercised by the person concerned, assigned to a person acting as an agent, or in cases where a person lacks mental capacity it can be assigned to another person to act as a substitute decision-maker.<sup>147</sup> Equal recognition of legal capacity before the law is

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<sup>142</sup> IBID.

<sup>143</sup> IBID.

<sup>144</sup> IBID.

<sup>145</sup> Above n 2, art 12(1).

<sup>146</sup> Above n 109 at 165.

<sup>147</sup> IBID.

important for disabled people to exercise civil, political, economic, social, and cultural rights. Legal capacity enables disabled people to make decisions relating to their health, education, and work. Denial of legal capacity has deprived disabled people of fundamental rights.<sup>148</sup>

Article 12(4) requires States to implement appropriate and effective safeguards to prevent abuses in accordance with international human rights law. Safeguards must ensure that supported decision-making arrangements are free from conflicts of interest and undue influence. They must be fair, reasonable, and proportionate in the individual's circumstances regarding their effect on the person's rights and interests.

Article 12(5) provides examples of where supported decision-making arrangements apply including the right to own and inherit property, control financial affairs, and have access to loans and other financial credit. Additionally, States must ensure that disabled people are not deprived of their property arbitrarily.

#### *IV UNCRPD Committee's General Comment on Article 12*

In 2015 the UNCRPD Committee released a General Comment on Art 12 of the UNCRPD. The General Comment noted that there had been a general failure by States to understand the human rights-based model of supported decision-making and the move away from substitute decision-making regimes such as welfare guardianship and property management.<sup>149</sup>

The General Comment on UNCRPD confirms that States must abolish all substitute decision-making regimes to comply with its obligations under art 12. The prevailing view is that substitute decision-making regimes treat disabled people in a discriminatory manner because it removes the ability for a disabled person to personally exercise their legal capacity by vesting it in another person.<sup>150</sup> SDM highlights the importance of ensuring that disabled people exercise their legal capacity to the greatest

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<sup>148</sup> Above n 109 at 165.

<sup>149</sup> Above n 111, at 3.

<sup>150</sup> Above n 109 at 166.

extent possible, regardless of their mental capacity. States that have implemented SDM regimes have retained pre-existing substitute decision-making regimes recognising that there are circumstances where despite significant and active support, it is not possible for a disabled person to make their own decisions.<sup>151</sup>

The Committee reiterated that under international human rights law, there are no permissible circumstances where disabled people can be denied their right to equal recognition as a person before the law.<sup>152</sup> This has been reinforced in the UDHR and the International Convention on Civil and Political Rights as well as the Convention on the Elimination of All Forms of Discrimination Against Women.<sup>153</sup>

The central theme is that full recognition of legal rights on an equal basis with non-disabled people ensures that disabled people are also afforded the same protections by the legal system.<sup>154</sup>

#### *V Committee Comments on New Zealand's Compliance with Article 12*

New Zealand's first report (First Report) on the implementation of the UNCRPD was submitted to the Committee in March 2011. On art 12 New Zealand noted that disabled people enjoyed equal recognition before the law, including protection of civil and political rights as well as the capacity to manage their own affairs.<sup>155</sup> The First Report noted that the HRA was the primary vehicle for protecting disabled people from discrimination.<sup>156</sup>

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<sup>151</sup> Above n 109 at 164.

<sup>152</sup> Above n 111, at 5.

<sup>153</sup> Above n 2; International Convention on Civil and Political Rights 99 UNTS 171 (open for signature on 16 December 1966, entered into force 28 December 1978); Convention on the Elimination of All Forms of Discrimination Against Women 1249 UNTS 1 (opened for signature on 18 December 1979, entered into force 3 September 1981).

<sup>154</sup> Above n 111, at 12.

<sup>155</sup> Office for Disability Issues "First New Zealand report on implementing the UN Convention on the Rights of Persons with Disabilities" (March 2011) < [www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/un-reviews-of-nzs-implementation-of-the-convention/](http://www.odi.govt.nz/united-nations-convention-on-the-rights-of-persons-with-disabilities/un-reviews-of-nzs-implementation-of-the-convention/) > at [65].

<sup>156</sup> Above n 157, at [66].

The First Report discussed the PPPR Act in detail, identifying it as the primary mechanism for safeguarding the interests of disabled people who are unable to manage their own affairs. New Zealand stated that the PPPR Act operates on the principle of least possible interference with individual decision-making because of the presumption of competence, the ability to make decisions and manage their own affairs.<sup>157</sup>

In 2014 the Committee undertook its first review of New Zealand's implementation of the Convention and issued its concluding observations in October 2014.<sup>158</sup> On art 12 the Committee recommended that New Zealand take immediate steps to replace its substitute decision-making regime with SDM. Recommending that New Zealand ensures that a wide range of measures is implemented to respect a disabled person's capacity to make decisions according to their will and preference, dignity, and autonomy.<sup>159</sup>

New Zealand's second and third report on the implementation of the UNCRPD was submitted to the Committee in March 2019. New Zealand advised that no programme of work was underway to recognise SDM. The Code was noted for being an avenue for disabled people to give informed consent. Additionally, New Zealand advised that the disability support system transformation work was going to be a vehicle for SDM to be available in addition to Funded Family Care.<sup>160</sup>

The Committee issues its concluding observations for both reviews in September 2022.<sup>161</sup> On art 12, the Committee was concerned about New Zealand's lack of progress on abolishing substitute decision-making regimes and the lack of timeframe for implementing a replacement SDM regime. The Committee noted that the Law Commission was due to

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<sup>157</sup> Above n 157, at [67]-[69].

<sup>158</sup> *Concluding observations on the initial report of New Zealand* CRPD/C/NZL/CO/1 (31 October 2014) at 1.

<sup>159</sup> Above n 160, at 3.

<sup>160</sup> *Concluding observations on the combined second and third periodic reports of New Zealand* CRPD/C/NZL/2-3 (26 September 2022) at 15.

<sup>161</sup> Above n 162, at 1.

undertake a review into adult decision-making capacity.<sup>162</sup> As a result, the Committee recommended that New Zealand:<sup>163</sup>

[R]epeal any laws and policies and end practices or customs that have the purpose or effect of denying or diminishing the recognition of any person with disabilities as a person before the law, and implement a nationally consistent supported decision-making framework that respects the autonomy, will and preferences of persons with disabilities.

Since the Committee issued its concluding observations, the Law Commission has released its preliminary issues paper for public consultation outlining the proposed scope of the review.<sup>164</sup> The New Zealand government is expected to formally respond to the Committee in 2023.

## *VI Concluding Observations*

To date, New Zealand has yet to make any meaningful steps towards implementing SDM or abolishing substitute decision-making in accordance with the UNCRPD.

Implementing supported decision-making regimes has been challenging for all signatories to the UNCRPD.<sup>165</sup> Few jurisdictions have succeeded in implementing supported decision-making regimes and have yet to successfully abolish existing substitute decision-making regimes.<sup>166</sup> The most transformational and aspirational legislation implementing a supported decision-making regime in the Republic of Ireland was passed in 2015; however, has not come into force.<sup>167</sup>

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<sup>162</sup> Above n 162, at 5.

<sup>163</sup> IBID.

<sup>164</sup> Law Commission *Review of Adult Decision-Making Capacity Law: Preliminary Issues Paper* (NZLC IP49, 2022).

<sup>165</sup> Above n 111.

<sup>166</sup> IBID.

<sup>167</sup> IBID.

## **Chapter 6: New Zealand's Law Relating to Disability and Decision-Making**

This part aims to provide an overview of New Zealand's legislative history and outline New Zealand's existing law related to disabled people and decision-making.

The part includes a discussion of the then Lunatics Acts (repealed), Aged and Infirm Persons Protection Acts (repealed), the Mental Defectives Act 1911 (repealed), Mental Health Act 1969 (repealed), the PPPR Act, HRA, the Code. Additionally, the common law approach and the inherent jurisdiction of the High Court relating to disabled people and decision-making will be discussed.

The discussion will focus on the major policy shifts in the treatment of disabled people over the last 150 years from eugenics to institutionalisation and corrective treatment, to care in the community and the self-determined rights-based approach.

### *I Lunatics Act 1868 (Repealed) and Lunatics Act 1882 (Repealed)*

New Zealand's first statutes dealing with disabled people and decision-making were the Lunatics Act 1868 (repealed), Lunatics Act 1882 (repealed) (together referred to as the Lunatics Acts).

The Lunatics Acts provided a regulatory framework for dealing with persons described as a "lunatic". "Lunatic" was defined in the 1882 Act as: "any insane person, idiot, lunatic, or a person of unsound mind and incapable of managing himself or his affairs, whether found lunatic by inquisition or not, and includes any person detained in any public or private establishment or house in New Zealand, authorised or used for the reception of lunatics under the provisions of this Act".<sup>168</sup> It is clear from the definition above that the Lunatics Acts were intended to apply

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<sup>168</sup> Compare: Lunatics Act 1882, s 2; Lunatics Act 1868, s 3.



to disabled people who had intellectual disabilities or those with mental health conditions.

The Lunatics Acts provided three primary modes of institutionalisation whereby people were placed in an asylum, in a hospital or in a licensed house.<sup>169</sup> Asylum was defined to mean “any public asylum house, building or place...provided for the reception of lunatics and patients and proclaimed a public asylum...”.<sup>170</sup> Hospital was defined as meaning “...such part only of any hospital as shall be devoted to the reception of lunatics”.<sup>171</sup> Licensed house was defined as meaning “any house a licence to keep which for the reception of lunatics shall be granted under this Act”.<sup>172</sup>

The Lunatics Acts empowered the Courts to commit people deemed “dangerous lunatics” displaying a “derangement of mind” that was likely to commit a serious offence or suicide to be detained in an asylum or a hospital.<sup>173</sup> If, upon further enquiry, it was established that the person was not an “insane person” or a “dangerous lunatic” then they were able to be certified by a medical practitioner and liberated from the asylum or hospital they were detained in.<sup>174</sup>

The Lunatics Acts also deemed persons wandering at large dangerous lunatics and empowered the Police to detain them immediately and bring them before the Courts.<sup>175</sup> The Courts would then enquire into the circumstances of the person and determine whether they were being properly cared for and controlled or subjected to cruel or neglectful treatment by relatives or those charged with the person’s care.<sup>176</sup> If the person was not properly cared for or controlled or subjected to cruel or

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<sup>169</sup> Lunatics Act 1868, s 3.

<sup>170</sup> Lunatics Act 1882, s 2.

<sup>171</sup> IBID.

<sup>172</sup> Above n 172, s 2.

<sup>173</sup> Above n 171, s 5.

<sup>174</sup> Above n 171, s 6.

<sup>175</sup> Above n 171, s 10.

<sup>176</sup> IBID.

neglectful treatment, the Courts could commit the person to an asylum or hospital.<sup>177</sup>

The Lunatics Acts also provided for procedures whereby two medical professionals were able to certify that a person was insane so that they could be committed to an asylum or hospital.<sup>178</sup> Additionally, individuals who were deemed to be alcoholics were able to be detained in an asylum or hospital and subjected to “curative treatment”.<sup>179</sup>

## *II Mental Defectives Act 1911 (Repealed) and the Mental Health Act 1969 (Repealed)*

The Mental Defectives Act 1911 (repealed) repealed and replaced the Lunatics Act 1908 and provided for the institutionalisation of “mentally defective persons”.<sup>180</sup>

“Mentally defective persons” included persons with a mental health condition that requires oversight, care, or control for their own good or due to the public interest.<sup>181</sup> Mentally defective persons were classified in six categories: persons of unsound mind, being mentally infirm, idiots, imbeciles, feeble-minded and epileptics.<sup>182</sup> In modern terms the Act provided a regime to protect disabled people by providing third party oversight, care and control over their welfare.

The Act provided authority for disabled people to be detained in institutions. This required a Magistrate to examine the disabled person in their home and be assisted by two medical practitioners to provide medical certificates regarding the mental condition of the disabled person to determine whether they are mentally defective.<sup>183</sup> If the disabled person was deemed to be mentally defective then an order could

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<sup>177</sup> IBID

<sup>178</sup> Above n 171, ss 15-18.

<sup>179</sup> Above n 171, s 21.

<sup>180</sup> Mental Defectives Act 1911, s 139.

<sup>181</sup> Above n 182, s 2.

<sup>182</sup> IBID.

<sup>183</sup> Above n 182, s 5.

be made for them to be detained and received at an institution.<sup>184</sup> Disabled people would then be “cared” for in these institutions by medical practitioners; a practice which is now subject of public examination via a Royal Commission of Inquiry into Abuse in State Care.<sup>185</sup>

The Mental Defectives Act 1911 was subject to several amendments before being repealed and replaced by the Mental Health Act 1969 (repealed).<sup>186</sup> The new Act modernised and consolidated the existing regime of institutionalising “mentally disordered” in “psychiatric institutions”. The Act applied to people with mental health conditions, those who were considered mentally infirm, and those considered mentally subnormal.<sup>187</sup> In modern terms these people would also be considered disabled people.

### *III Aged and Infirm Persons Protection Act 1912 (Repealed) and Aged and Infirm Persons Protection Amendment Acts 1957, 1969 and 1975*

The Aged and Infirm Persons Protection Act 1912 and amendments were the first piece of legislation in New Zealand designed to protect the property of “aged” and “infirm” people.<sup>188</sup> It was amended several times in 1957, 1969 and 1975 as changes were made to related pieces of legislation.

The terms “aged” and “infirm” were not directly defined. Section 4 confirms that the Act would cover a person if they were unable to manage their affairs, likely to be subjected to undue influence or otherwise in need of protection due to age, disease, illness or physical or mental infirmity.<sup>189</sup> The Act also applied to people who had alcohol or drug

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<sup>184</sup> Above n 182, ss 5-6.

<sup>185</sup> Abuse in Care Royal Commission of Inquiry “Disability and mental health” (2022) <[www.abuseincare.org.nz/our-inquiries/](http://www.abuseincare.org.nz/our-inquiries/)>.

<sup>186</sup> Mental Health Act 1969, s 129.

<sup>187</sup> Above n 188, Long Title.

<sup>188</sup> Aged and Infirm Persons Protection Act 1912, Long Title.

<sup>189</sup> Above n 190, s 4.

addictions.<sup>190</sup> In modern terms, the Act protected the property of elderly and/or disabled people.

The Act provided a regime that enabled an application to be made to the then Supreme Court for a protection order which appointed the spouse of a “protected person”, a company or partnership, or the Public Trustee to take possession of the estate of the protected person according to the terms of the order.<sup>191</sup> The Act was only concerned with the property of the protected person. It did not provide a regime for managing their welfare if they could no longer make their own decisions.<sup>192</sup> The role of the inherent jurisdiction of the High Court will be discussed later in this chapter.

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

The Protection of Personal and Property Rights Act 1988 (PPPR Act) was enacted in 1988 to provide modern mechanisms for dealing with the property and welfare of people who were no longer deemed able to manage their own affairs. It repealed and replaced the Aged and Infirm Persons Protection Act 1912 and pt 7, sch 3 of the Mental Health Act 1969.<sup>193</sup>

##### *A Enduring Powers of Attorney*

Part 9 of the PPPR Act established the ability for a person (the donor) to appoint another person (the donee) as an enduring power of attorney (EPOA).<sup>194</sup> The concept of “enduring” powers of attorney did not exist under the common law of agency. While a person could appoint another

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<sup>190</sup> Above n 190, s 5.

<sup>191</sup> Above n 190, ss 6-7.

<sup>192</sup> Note that a disabled person would be covered by the Mental Defectives Act 1911 where they are required to be considered a “mentally defective person”. Where this Act applied the welfare and property of the disabled person were not administered under the Aged and Infirm Persons Protection Act 1912.

<sup>193</sup> Protection of Personal and Property Rights Act 1988, sch 4. Note that the Mental Health Act 1969 was substantially repealed by the Mental Health (Compulsory Assessment and Treatment) Act 1992.

<sup>194</sup> Iris Reuvecamp “Enduring Powers of Attorney, Welfare Guardians and Property Managers” I Reuvecamp and J Dawson (eds) *Mental Capacity Law in New Zealand* (Thomas Reuters, New Zealand, 2019) 141 at 142.

person to act as their attorney under the common law, this agency relationship ceased when the donor ceased to have mental capacity.<sup>195</sup> The PPPR Act resolved this issue by enabling a person to appoint an EPOA to act for them when they lose mental capacity. EPOAs can enable a substitute decision-maker to act with regard to the donor's care, welfare or property.<sup>196</sup> The Family Court has supervisory jurisdiction over the EPOA's conduct.<sup>197</sup> There are also statutory limitations on the EPOAs powers; for example, an enduring attorney cannot make decisions about marriage or divorce and cannot refuse consent to standard medical treatment or procedures which could prevent serious damage to the donor's health or save their life.<sup>198</sup>

### *B Welfare Guardians, Property Managers and Other Orders*

The Family Court also has the authority to appoint welfare guardians and property managers. Welfare guardians and property managers can make decisions on behalf of a person who lacks mental capacity relating to their care, welfare, and property.<sup>199</sup> Welfare guardians and property managers are also expected to support people who lack the capacity to make their own decisions.<sup>200</sup>

Welfare guardians are appointed by the Family Court rather than by a person under an EPOA. The PPPR Act states a welfare guardian's paramount consideration must be to promote and protect the welfare and best interest of the person concerned and encourage them to develop and exercise the decision-making capacity they have.<sup>201</sup> This includes encouraging the person to act on their own behalf and consulting the

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<sup>195</sup> Above n 196 at 141.

<sup>196</sup> Protection of Personal and Property Rights Act 1988, s 99.

<sup>197</sup> Above n 198, s 94A; see *Courtney v Estate of Courtney* [2016] NZDC 20578, [2017] DCR 390 at [14].

<sup>198</sup> Above n 196 at 145.

<sup>199</sup> Above n 198, ss 12 and 31.

<sup>200</sup> *IBID.*

<sup>201</sup> Above n 198, s 18(3).

person as far as possible on matters regarding their welfare.<sup>202</sup> The appointment must be the least restrictive option available.

The Family Court must be satisfied that a person lacks the capacity to make or communicate decisions relating to their personal care that the court order will cover. Appointing a welfare guardian must be the only satisfactory way to ensure appropriate decisions are made.<sup>203</sup> A potential welfare guardian must be able to exercise judgement and common sense, act in the person's best interests, and objectively without undue influence. They must also have a sympathetic relationship with the person concerned.<sup>204</sup>

The Family Court also has jurisdiction to make a wide variety of orders under s 10 of the PPPR Act. Orders can be made to make arrangements for the care of a person after the death of a parent.<sup>205</sup> A person can be ordered to attend an institution, ordering a person to be provided with certain living arrangements, medical advice or treatment, educational, rehabilitative therapeutic or other services.<sup>206</sup> Finally, orders can be made to restrict or prevent the person from leaving New Zealand or appointing a person as a litigation guardian for the person subject to the order in District Court or Family Court proceedings.<sup>207</sup>

### *C Effect of Decisions Made Under the PPPR Act*

The PPPR Act deems decisions made by welfare guardians, property managers and EPOAs to have the same legal effect as though the decision was made by the person who lacks capacity.<sup>208</sup> The authority for the substitute decision-maker to act is limited to the terms of the EPOA or the court order appointing them as a welfare guardian or property manager. However, EPOAs and court orders generally contain the broad

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<sup>202</sup> Above n 198, s 18(4).

<sup>203</sup> Above n 196 at 153; Above n 199, ss 12(2) and 76.

<sup>204</sup> Above n 198, s 12(5).

<sup>205</sup> Above n 198, s 10(1)(b)-(c).

<sup>206</sup> Above n 198, s 10(1)(e)-(g).

<sup>207</sup> Above n 198, s 10(1)(h)-(i).

<sup>208</sup> Above n 196 at 142.

authority to enable the substitute decision-maker to act on behalf of the person lacking mental capacity in most circumstances.<sup>209</sup>

The primary objectives of exercising jurisdiction under the PPPR Act are to make the least restrictive intervention possible and to encourage or enable the person subject to an order to exercise and develop the capacity they have to the extent possible.<sup>210</sup> Enabling disabled people to make their own decisions to the extent they have the capacity to do so is largely an afterthought. This requirement only applies after an order has been made under the PPPR Act.<sup>211</sup>

The PPPR Act is largely viewed as draconian by disabled people. The appointment of a welfare guardian or property manager removes the ability for the disabled person to manage their affairs personally. Instead, this power is vested in another individual appointed by the Family Court.<sup>212</sup>

The PPPR Act was intended to be rights centric and to enhance the mana of disabled people. However, disabled people argue that the emphasis is not on enabling disabled people to live autonomous and self-determined lives. It is a paternalistic regime protecting disabled people from being a risk to themselves which is neither mana enhancing, nor rights focused.<sup>213</sup>

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<sup>209</sup> IBID.

<sup>210</sup> Above n 198, at s 8.

<sup>211</sup> Above n 198, ss 12 and 31.

<sup>212</sup> See generally, above n 198, at ss 14 and 36.

<sup>213</sup> Compare, above n 198, ss 12(5)(b), 31(5)(b), 97A and s 97A(2).

## V *Human Rights Act 1993*

The HRA is an important piece of legislation because it defines disability for the purposes of New Zealand law.

The HRA defines “disability” for the purposes of New Zealand law as meaning:<sup>214</sup>

A physical disability or impairment, physical illness, psychiatric illness, intellectual or psychological disability or impairment, any other loss or abnormality of psychological, physiological, or anatomical structure or function, reliance on a guide dog, wheelchair or other remedial means, or the presence in the body of organisms capable of causing illness.

The definition provides a mechanism for identifying disabled people as a population group and prohibits discriminating against disabled people based on their disability.<sup>215</sup> It also applies to the three branches of Government via s 19 of the NZBORA which incorporates and affirms the right to be free from discrimination on the prohibited grounds outlined in the HRA.

As aforementioned, the definition of disability included in the art 1 of the UNCRPD only includes long term disabilities such as physical, mental, intellectual, or sensory impairments.<sup>216</sup> It therefore does not include temporary impairments.

The definition of disability included in the HRA is relevant in the SDM context because it enables us to identify the population of people who would be most likely to use SDM from a legal perspective. However, not all disabled people will require SDM to live good lives according to their dreams and aspirations. It is difficult to predict how many disabled New

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<sup>214</sup> Above n 95, s 21(1)(h).

<sup>215</sup> Above n 95, s 21.

<sup>216</sup> See above n 2, art 2. For the purposes of the UNCRPD persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.



Zealanders would benefit from SDM based on population data because lived experience of disability is unique.

## *VI Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996*

The Code sets out the fundamental rights of consumers of health and disability services (services). The Code covers the minimum legal and ethical standards for health practitioners and consumers to abide by when accessing services.

Right 7 recognises that consumers have the right to make an informed choice and give informed consent to services.<sup>217</sup> It provides that services can only be provided where an informed choice is made and informed consent is given, for the procedure.<sup>218</sup> There is a presumption that patients are competent to choose and consent unless there are reasonable grounds for displacing the presumption.<sup>219</sup>

Right 7(3) provides that consumers with diminished competence can give informed consent to the extent appropriate given their level of competence. While this right 7(3) does not provide for supported decision-making per se it recognises that people with impaired mental capacity are able to make some decisions regarding their healthcare providing it is appropriate in the circumstances. In practice this does invite the opportunity to use SDM with disabled patients by providing information in accessible and alternative formats or with the support of trusted people.

Right 7(4) provides for how decisions can be made about medical treatment situations where the patient is “not competent to make an informed choice and give informed consent”.<sup>220</sup> In those circumstances, health care providers can provide treatment, without the patient's

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<sup>217</sup> Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996, sch 1 cl 2 right 7.

<sup>218</sup> Above n 219, at sch 1 cl 2 right 7(1).

<sup>219</sup> Above n 219, at sch 1 cl 2 right 7(2).

<sup>220</sup> Above n 219, at sch 1 cl 2 right 7(4).

informed consent, if it would be in their best interests, and reasonable steps have been taken to obtain the patient's views.<sup>221</sup>

Where the patient has expressed a view, the health care provider must regard it and provide services in a way that would reasonably be consistent with the patient's choice if they were competent.<sup>222</sup> Alternatively, if the patient's views have not been obtained then the health care provider must consider the views of persons who are interested in the patient's welfare if they are available.<sup>223</sup>

While right 7 of the Code could be viewed as more progressive than the PPPR Act, it could be argued that it embodies a form of medical paternalism by authorising medical practitioners to act as substitute decision-makers where a patient cannot provide informed consent. Both the Code and the PPPR Act are designed to encourage people who lack mental capacity to participate in decision-making that affects their care, welfare, or property.

## *VII Common Law Doctrine of Necessity*

The doctrine of necessity was inherited from English common law. It broadly recognises that there is a lawful reason for interfering with the rights of another person on necessity grounds.<sup>224</sup> The House of Lords in *Re F (Mental Patient Sterilisation)* summarised the key principles of the doctrine of necessity as:

- (a) it must be necessary to act when it is not practical to communicate with the person receiving treatment;
- (b) the proposed action must be reasonable in the circumstances (objectively assessed against the reasonable person); and
- (c) it must be in the person's best interest.<sup>225</sup>

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<sup>221</sup> Above n 219, at sch 1 cl 2 right 7(4)(a)-(b).

<sup>222</sup> Above n 219, at sch 1 cl 2 right 7(4)(c)(i).

<sup>223</sup> Above n 219, at sch 1 cl 2 right 7(4)(c)(ii).

<sup>224</sup> Iris Reuecamp and John Dawson "Healthcare in the Absence of Consent" I Reuecamp and J Dawson (eds) *Mental Capacity Law in New Zealand* (Thomas Reuters, New Zealand, 2019) 125 at 127.

<sup>225</sup> *Re F (Mental Patient Sterilisation)* [1990] 2 AC 1 (HL) at [75]-[76].

It is commonly applied in health and disability contexts to provide services without a person's consent. For example, the doctrine of necessity enables a person who does not have capacity to provide consent to be given treatment to preserve their life, health, or well-being.<sup>226</sup> However, it does not only apply in circumstances where action must be taken immediately or because of an emergency. The intervention must be necessary.<sup>227</sup>

In New Zealand, the doctrine of necessity applies when providing medical treatment to a person who cannot provide consent and the treatment is potentially lifesaving.<sup>228</sup> In *R v Harris* Miller J summarised the test as follows:<sup>229</sup>

The common law allows a doctor to administer medical treatment without consent where the patient is incapable of consent, the treatment is thought reasonably necessary in the circumstances, and (in the case where incompetence is not due to some permanent disability) the treatment cannot safely be delayed until the patient is able to consent.

The doctrine of necessity can, therefore, only be used in the most acute circumstances where treatment is necessary, potentially lifesaving and consent cannot otherwise be obtained. The common law test for the doctrine of necessity underpins right 7(4) of the Code, which as aforementioned, permits medical practitioners to make decisions where a person lacks the capacity to give informed consent to treatment.

### *VIII Jurisdiction of the High Court of New Zealand*

The jurisdiction of the High Court of New Zealand is summarised by s 12 of the Senior Courts Act 2016 (Senior Courts Act) as including the existing jurisdiction of the Court prior to the commencement of the Act, judicial jurisdiction necessary to administer the laws of New Zealand and

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<sup>226</sup> Above n 226, at 128.

<sup>227</sup> Above n 227 at [76].

<sup>228</sup> *R v Harris* (2006) NZHC Palmerston North CRI-2006-043-1008, 21 November 2006.

<sup>229</sup> Above n 230 at [41].

jurisdiction conferred by any other Act. It is the only New Zealand Court with originating and inherent jurisdiction.

The *parens patriae* jurisdiction was inherited from English law and forms part of the inherent jurisdiction of the High Court of New Zealand. The *parens patriae* jurisdiction enables the Court to have a paternal and protective role of persons subject to its jurisdiction.<sup>230</sup>

Section 14 of the Senior Courts Act the Court has jurisdiction and control in relation to disabled people who are wholly or partly unable to manage their own affairs.<sup>231</sup> Section 14 is a legislative recognition of the inherent jurisdiction in relation to vulnerable adults.

The *parens patriae* jurisdiction also enables a remedy to be provided outside the scope of a statutory regime.<sup>232</sup> The application of the *parens patriae* jurisdiction is expressly recognised by s 114 of the PPPR Act which clarifies that the PPPR Act does not limit the scope of s 14 of the Senior Courts Act. However, *Carrington v Carrington* also suggests that the inherent jurisdiction cannot be used if the PPPR Act applies in the circumstances.

## *IX Concluding Observations*

This chapter has demonstrated that New Zealand's law relating to disability and decision-making is fragmented across multiple statutes and supplemented by the common law and inherent jurisdiction of the High Court. Our existing law focuses on decision-making where a disabled person partially or wholly lacks the capacity to make decisions or consent cannot be obtained. As a result, New Zealand law favours substitute decision-making regimes in breach of our obligations under art 12 of the UNCRPD.

Currently, New Zealand law does not provide an overarching legal framework for enabling disabled people to make their own decisions with

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<sup>230</sup> Senior Courts Act 2016, s 14.

<sup>231</sup> See generally Senior Courts Act 2016, s 12.

<sup>232</sup> *Carrington v. Carrington* (2014) NZHC 869 (2014) 29 FRNZ 738 Katz J, at [103]. See also *Dawson v. Keesing* (2004) 23 FRNZ 493.

the support of others via SDM. SDM has most commonly been implemented at an operational level as part of delivering disability support services.

The lack of an overarching legal framework for SDM casts doubt on the legal status and effect of decisions made using SDM and does not resolve questions about liability for decisions or provide appropriate safeguards for disabled people. The gap in our existing disability and decision-making law could be remedied by implementing an SDM framework via primary legislation, which is the focal point of this dissertation.

## Chapter 7: Domestic Legal Scholarship on Supported Decision-Making

Alison Douglass is one of New Zealand's leading legal experts in decision-making law and has written extensively on SDM. This chapter outlines her perspectives on SDM in a New Zealand context.

### *I SDM Rejects the Deficit-Based Approach of Capacity*

Douglass characterises the primary objective of SDM in art 12 of the UNCRPD as enabling all disabled people, regardless of their cognitive status, to exercise full legal capacity.<sup>233</sup> A person's right to make legally effective decisions, and exercise their inherent legal capacity, has traditionally been determined with reference to "mental capacity".<sup>234</sup> Mental capacity is determined using functional tests to determine whether the person can retain and understand information, use and weigh that information, and communicate their decisions.<sup>235</sup> Rather than looking at mental capacity, according to SDM, it is preferable to consider what level of support or support mechanisms are necessary to enable disabled people to express their will and preferences.<sup>236</sup>

Douglass submits that art 12 of the UNCRPD requires a rejection of the deficit-based view that mental capacity is a prerequisite for exercising legal capacity.<sup>237</sup> It must also be recognised that disabled people can exercise their legal capacity with support, although they would traditionally have been described as lacking mental capacity.<sup>238</sup>

The emphasis on consensual support reinforces the rejection of paternalist regimes where substitute decision-makers are mandatory and imposed on disabled people.<sup>239</sup> This also reinforces the idea of "dignity of risk" which is the right of disabled people to make their own decisions

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<sup>233</sup> Above n 109 at 166.

<sup>234</sup> Above n 109 at 163.

<sup>235</sup> Above n 109 at 165.

<sup>236</sup> Above n 110 at 123.

<sup>237</sup> Above n 109 at 166.

<sup>238</sup> IBID.

<sup>239</sup> Above n 109 at 168.

even if they are unwise or potentially harmful.<sup>240</sup> Exercising choice includes the right to take risks when exercising legal capacity.<sup>241</sup>

## *II SDM Focuses on the Disabled Person's Will and Preference*

Douglass notes that there needs to be more consensus internationally about how to implement supported decision-making in law and policy.<sup>242</sup> Unhelpfully, the UNCRPD needs to define SDM or prescribe a model for how States can implement it.<sup>243</sup>

Douglass notes that it may be difficult to ascertain the will and preference of disabled people in hard cases. This is particularly the case where a disabled person has a profound intellectual disability or is completely unable to communicate.<sup>244</sup> Under art 12, SDM applies to all disabled people regardless of the nature and extent of their disability or the outcome of the decisions being made.<sup>245</sup>

## *III Supports Need to Be Flexible and May Change Over Time*

Support is intensely contextual; it can be informal or formal, and the support provided will vary in intensity depending on the disabled person's needs.<sup>246</sup> Where a disabled person has communication difficulties, States have an obligation to support disabled people in developing their communication skills (conventional and assisted) to enable them to retain their legal capacity.<sup>247</sup> There is also an obligation

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<sup>240</sup> IBID.

<sup>241</sup> 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 436.

<sup>242</sup> Above n 109 at 164.

<sup>243</sup> Above n 109 at 167.

<sup>244</sup> Above n 109 at 170.

<sup>245</sup> Above n 109 at 171.

<sup>246</sup> Above n 109 at 167.

<sup>247</sup> Above n 111, at 17.

to provide disabled people with information in accessible and alternate formats such as Easy Read.<sup>248</sup>

For some disabled people, they may have the ability to make fully autonomous decisions initially, but the need to make decisions via SDM may fluctuate and ultimately increase over time.<sup>249</sup> There will be a point where a disabled person is unable to exercise their legal capacity even with support. This will depend on the context, in particular, the complexity of the decision and the extent to which the disabled person is able to express a preference. Support should still be provided even when a person no longer has the capacity to make their own decisions; this is because the likely will and preference of the disabled person should remain central to the decision-making process.<sup>250</sup>

#### *IV Implementing Effective Safeguards*

Douglass identifies that there is a tension between the obligation of States to support disabled people to make decisions according to their will and preference and the obligation to ensure there are effective mechanisms to mitigate the risk of abuse, exploitation, and self-inflicted harm.<sup>251</sup> It is up to the State to determine the appropriate safeguards to give effect to art 12(4).

SDM involves an inherent power imbalance between the disabled person requiring support and the third party or parties providing support. Generally, the third party has a significant ability to influence the disabled person's decisions giving rise to risks around manipulation and exploitation.<sup>252</sup>

Douglass argued that there might be substantial issues around determining when a support person is exercising undue influence over the disabled person and what constitutes exploitation or abuse.<sup>253</sup>

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<sup>248</sup> Above n 110 at 124.

<sup>249</sup> Above n 109 at 168.

<sup>250</sup> Above n 110 at 123.

<sup>251</sup> Above n 109 at 169.

<sup>252</sup> Above n 109 at 169.

<sup>253</sup> IBID.



Traditionally, protection from harm, abuse and exploitation is the rationale for appointing substitute decision-makers under the PPPR Act and for the existence of the inherent protective jurisdiction of the High Court of New Zealand.<sup>254</sup>

In particular, Douglass notes concerns about the use of SDM where the disabled person's decision could be harmful or life-threatening.<sup>255</sup> These circumstances are often used to justify the retention of substitute decision-making, recognising that denying a disabled person's legal capacity may be required to avoid serious adverse consequences.<sup>256</sup> This is seen as a proportionate response to safeguarding and protecting the rights and freedoms affirmed under the UNCRPD.<sup>257</sup>

## *V Concluding Observations*

Douglass sees the UNCRPD as requiring member States to facilitate SDM and encourage a cultural shift that recognises disabled people with cognitive impairments as having legal capacity.<sup>258</sup> Achieving substantive equality between disabled and non-disabled people and ensuring equal recognition before the law are seen as reasonable. However, the competing obligations of States in implementing art 12 of the UNCRPD give rise to significant practical difficulties, particularly distinguishing between paternalistic interventions and the need to safeguard the realisation of the will and preferences of disabled people.<sup>259</sup>

Douglass submits that SDM poses significant challenges where respecting the will and preference of the disabled person would result in serious adverse consequences. Additionally, disabled people should be supported to express their will and preferences, and these should be paramount unless it would result in significant harm.<sup>260</sup>

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<sup>254</sup> Above n 110 at 124.

<sup>255</sup> Above n 109 at 172.

<sup>256</sup> IBID.

<sup>257</sup> IBID.

<sup>258</sup> Above n 109 at 177.

<sup>259</sup> IBID.

<sup>260</sup> IBID.

## **Chapter 8: Analysis of the Supported Decision-Making Bill 2022**

This dissertation proposes a model law or draft Bill to embed supported decision-making into New Zealand law. A complete copy of the proposed Supported Decision-Making Bill 2022 is included at Appendix A.

This part aims to explain and analyse the proposed SDM Bill which would be administered by the Minister for Disability Issues and Whaikaha – Ministry for Disabled People.

This part undertakes a part-by-part analysis of the draft provisions of the SDM Bill. For ease of reading, where relevant, specific clauses of the SDM Bill are embedded in the analysis and critique.

This part does not include analysis and critique of technical sections such as the title, commencement date, interpretation section, guide to the act, transitional, savings and related provisions or the schedules to the SDM Bill. This is because these elements of the SDM Bill feature in all pieces of legislation in accordance with the 2021 Edition of the Legislation Design and Advisory Committee Guidelines (LDAC Guidelines) used by the Parliamentary Counsel Office.

### *I Background*

The SDM Bill provides a comprehensive framework to embed supported decision-making into New Zealand law. The SDM Bill fills an existing gap in the law where disabled people can make their own decisions; however, they need support and reasonable accommodations to do so on an equitable basis. In these circumstances, it would be unnecessary, and indeed overbearing, for a welfare guardian and/or a property manager to be appointed under the PPPR Act to manage the disabled person's affairs.

The SDM Bill recognises that disabled people can exercise their legal capacity with support. However, they would be considered from a legal perspective as lacking the mental capacity to make decisions on their own.

The New Zealand Law Commission (Law Commission) is currently undertaking a project on adult decision-making law in New Zealand,

which will include consideration of supported decision-making within the broad context of adult decision-making generally.<sup>261</sup> Members of the Law Commission attended the seminar presentation preceding this dissertation which took place in December 2021, and has been kept updated with progress. The Law Commission expects to have issues papers out for consultation in late 2022. A final report is expected to be delivered to the Minister of Justice by 30 June 2024.<sup>262</sup>

#### *A Design Overview*

At its heart, the SDM Bill affirms that disabled people in New Zealand are viewed as legal persons on an equitable basis with non-disabled people. It signals a paradigm shift in our law and recognises that disabled people deserve to be free and equal in dignity and rights and can lead meaningful, self-determined lives. The SDM Bill is intended to supplement the existing legal frameworks for decision-making and informed consent rather than replacing them.

The SDM Bill is flexible to apply to a broad range of disabilities, whether short-term, long-term, progressive or transient. It formalises the operational application of supported decision-making used by the Government and health care providers for the last decade by introducing a concept of “supported decision-making arrangements”.

Additionally, the SDM Bill grapples with the complex issue of safeguards which has proved to be a stumbling block for other jurisdictions implementing supported decision-making regimes. It provides for judicial oversight and appeals against supported decision-making arrangements where, for example, there are concerns about fraud or abuse of a special relationship. Civil and criminal offences are also included to signal the moral repugnance of using supported decision-making arrangements to take advantage of disabled people for their own gain.

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<sup>261</sup> Above n 166 at 37-38.

<sup>262</sup> Law Commission “Term of Reference” (2022) <<https://huarahi-whakatau.lawcom.govt.nz/terms-of-reference/>>.

## *B Key Assumptions Underpinning the SDM Bill*

Two key assumptions underlie the SDM Bill. First, disabled people may have the mental capacity and desire support to make their own decisions due to their impairment(s). For example, they may be on the autism spectrum and require social support to appreciate the nature of the decision required.

Secondly, the disabled person may have fluctuating levels of mental capacity due to the degenerative nature of their disability. For example, a person with dementia or Alzheimer's disease who overtime will from a legal perspective, lose their mental capacity but throughout the early phases of their condition largely have mental capacity providing they are well rested and receiving medical treatment for their condition.

## *C Interaction with Existing Legislation and Common Law on Decision-Making*

The SDM Bill does not modify existing legislation or common law relating to mental capacity or professional and clinical guidance for assessing mental capacity. Instead, it supplements these areas of law and policy to provide a complete tool kit to support decision-making, autonomy, dignity, and realisation of human rights. It is intended that the SDM Bill would limit the extent to which PPPR Act orders can be relied on to ensure that they are a tool of last resort rather than the primary intervention.

## *D Drafting Style*

As aforementioned, the SDM Bill has been drafted in accordance with the LDAC Guidelines. It has been modelled on the Pae Ora (Healthy Futures) Act 2022. The rationale for this approach is that at the time of writing the Act was the most comprehensive new piece of legislation broadly relevant to the subject matter of the SDM Bill.

Finally, the SDM Bill draws on inspiration from the Republic of Ireland to create a model which is appropriate for disabled New Zealanders and fits within our legal context. Given the diversity of the needs of disabled

people, it is important that any SDM Bill is flexible to encompass a broad range of disabilities and circumstances.

The Republic of Ireland is the only country in the world that has passed a comprehensive statute implementing supported decision-making. However, it is worth noting that at the time of writing the Act has not come into force despite being passed into law in 2015.<sup>263</sup>

## *II Part 1: Preliminary Provisions*

Part 1 sets out the preliminary aspects of the SDM Bill. This includes the:

- purpose section setting out the purpose of the SDM Bill;
- interpretation section setting out the key definitions for the SDM Bill where they are not otherwise defined;
- guide to the Act providing a part-by-part guide to the layout of the SDM Bill;
- Te Tiriti O Waitangi (the Treaty of Waitangi) section setting out how the Crown intends to give effect to the principles of Te Tiriti O Waitangi with respect to the SDM Bill; and
- supported decision-making principles.

Further, it confirms that the SDM Bill binds the Crown and identifies where the transitional, savings and related provisions are located. These sections are technical in nature and are not discussed in the foregoing analysis.

### *A Purpose Provision*

The purpose section (cl 3 of the SDM Bill), included below at Figure 1, sets out the overall intention of Parliament when enacting the piece of

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<sup>263</sup> Assisted Decision-Making (Capacity) Act 2015.

legislation. It is a useful interpretive guide for all branches of Government, legal professionals, and the public.

**Purpose of this Act**

The purpose of this Act is to enable disabled persons to enter into supported decision-making arrangements in order to—

- (a) enable disabled people to live freely in dignity and rights:
- (b) provide a mechanism for disabled people to exercise legal capacity on an equitable basis to non-disabled people:
- (c) provide safeguards against abuses of power or special relationship status.

***Figure 1: Purpose of this Act (cl 3)***

The purpose section makes it clear that the Parliamentary intention behind the SDM Bill is to provide a legislative framework for disabled people to enter into supported decision-making arrangements (SDM arrangements).

It recognises that such arrangements are required to:

- advance the realisation of the rights of disabled people
- enable disabled people to equitably exercise their inherent legal capacity
- provide safeguards to ensure that disabled people are protected against abuses of power or privilege.

These principles were drawn from the preamble of the UDHR and UNCRPD as well as art 12 of the UNCRPD, which requires States to abolish substitute decision-making regimes and ensure that supported decision-making is implemented with appropriate safeguards.<sup>264</sup>

***B Te Tiriti O Waitangi (the Treaty of Waitangi)***

The Te Tiriti O Waitangi section (cl 6 of the SDM Bill), included at Figure 2 below, sets out the obligations of the Crown to give effect to the principles of Te Tiriti O Waitangi (Te Tiriti) with respect to the SDM Bill.

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<sup>264</sup> Above n 131; Above n 2.

### **Te Tiriti o Waitangi (the Treaty of Waitangi)**

In order to provide for the Crown's intention to give effect to the principles of Te Tiriti o Waitangi (the Treaty of Waitangi), this Act –

- (a) requires parties to a supported decision-making arrangement to act in a way that is consistent with Te Tiriti o Waitangi;
- (b) requires those acting on decisions made under a supported decision-making arrangement to act in a way that is consistent with Te Tiriti o Waitangi;
- (c) requires those reviewing supported decision-making arrangements in accordance with this Act to specifically consider Te Tiriti o Waitangi and te ao Māori when adjudicating on issues arising within the context of a supported decision-making arrangement.

**Figure 2: Te Tiriti O Waitangi (the Treaty of Waitangi) (cl 6)**

This section makes it clear that the Crown is bound to apply the principles of Te Tiriti to SDM arrangements. Additionally, parties to an SDM arrangement are required to act and make decisions in a manner that is consistent with Te Tiriti. Finally, the judiciary and quasi-judicial bodies are required to ensure that reviews of SDM arrangements and decisions made under them occur in accordance with Te Tiriti and te ao Māori.

These sections are a recent legislative drafting convention intended to remove any doubt or ambiguity about the application of Te Tiriti and tikanga Māori to statutes.<sup>265</sup>

Additionally, in *Ellis v R*, the Supreme Court of New Zealand has confirmed that tikanga Māori was the first law of New Zealand and is, therefore, a foundation of the common law of Aotearoa New Zealand subsequently imported under colonialist rule by the British.<sup>266</sup> This judgement also aligns with the extra-judicial writing of Supreme Court Judge the Hon Joe Williams J and Dr Carwyn Jones who has been a long-

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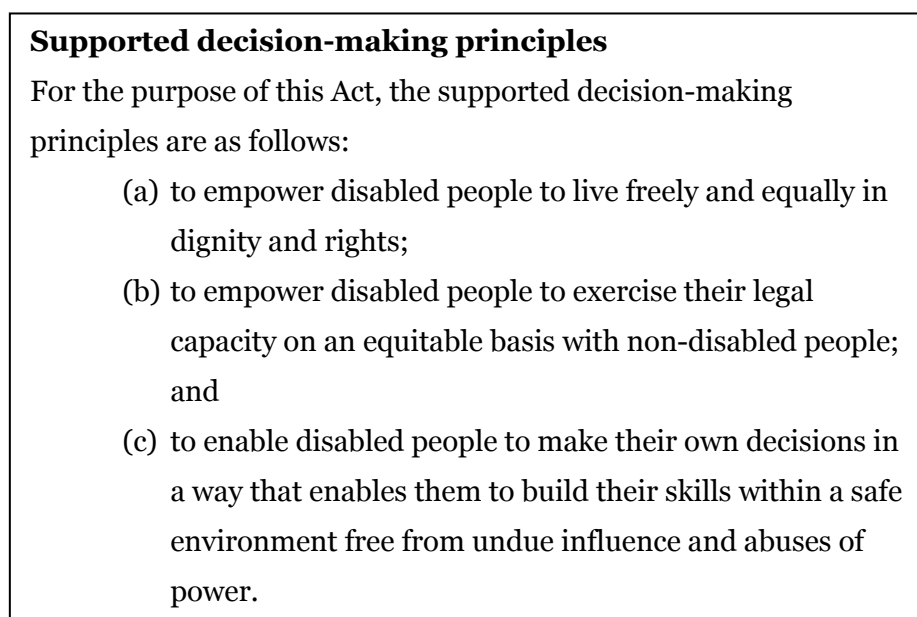
<sup>265</sup> See generally Parliamentary Counsel Office *Legislation Design and Advisory Committee Guidelines* (online ed, Wellington, 2021).

<sup>266</sup> [2022] NZSC 114 at [80] per Glazebrook J.

time advocate for the view that tikanga Māori is the first body of common law governing Aotearoa New Zealand.

### *C Supported Decision-Making Principles*

The SDM principles section (cl 7 of the SDM Bill), included at Figure 3 below, sets out the underlying principles of the SDM framework being implemented via the SDM Bill.



***Figure 3: Supported decision-making principles (cl 7)***

These principles were drawn from the preamble of the UDHR and UNCRPD as well as art 12 of the UNCRPD which requires States to abolish substitute decision-making regimes and ensure that supported decision-making is implemented with appropriate safeguards.<sup>267</sup> They are similar to the principles outlined in the purpose section at cl 3 of the SDM Bill.

### *III Part 2: Key definitions and roles*

Part 2 is critical to the context of the overarching legislative framework because it defines the key terms and roles for the SDM framework being proposed.

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<sup>267</sup> Above n 266.



It defines the following concepts:

- supported decision-making;
- disabled person;
- supporter;
- capacity; and
- supported decision-making arrangement.

*A Supported Decision-Making (cl 10)*

The SDM definition section (cl 10 of the SDM Bill), included at Figure 4 below, defines SDM for the purposes of the SDM Bill.

**Definition of supported decision-making**

For the purposes of this Act, **supported decision-making** is defined as:

- (1) A process that promotes and enables disabled people to exercise their legal capacity to make decisions on an equitable basis with non-disabled people through:
  - (a) Providing information in accessible and alternative formats appropriate for disabled persons having regard to their disabilities;
  - (b) allowing disabled persons extra time to consider all relevant information to ensure they have an equitable opportunity to give informed consent;
  - (c) providing any other reasonable accommodations reasonably necessary to enable disabled persons to make their own decisions equitably with non-disabled people.
- (2) To avoid doubt, supported decision-making does not include substitute decision-making arrangements under the **Protection of Personal and Property Rights Act 1988** and other relevant rules of law.

***Figure 4: Definition of supported decision-making (cl 10)***

This section reinforces the intentions set out in the purpose and principles section discussed in Part 1 above. This is done by defining SDM to reinforce the inherent legal capacity of disabled people and

demonstrate that the purpose of SDM is to enable disabled people to participate equitably in making decisions affecting their lives.

Additionally, it lists three reasonable accommodations that are commonly used to facilitate supported decision making:

- providing access to information in accessible and alternative formats such as New Zealand Sign Language, Braille and Easy Read;
- giving extra time to consider relevant information; and
- a general requirement to provide any other reasonable accommodations that are necessary and relevant in the context.

These requirements were drawn from existing operational definitions of supported decision-making currently in use in Aotearoa New Zealand and abroad.

Finally, the section confirms that SDM is distinct from substitute decision-making arrangements under the PPPR Act. It also clarifies that the SDM Bill exists in addition to substitute decision-making arrangements under the PPPR Act and other relevant rules of law. This is included to remove any doubt about how the SDM Bill fits into our suite of legal arrangements relating to adult decision-making.

The author acknowledges that this means that New Zealand would not be in complete compliance with the requirements outlined in art 12 of the CRPD to abolish substitute decision-making regimes. However, this is entirely consistent with the approaches taken by other jurisdictions that have implemented SDM legislation.<sup>268</sup>

As a result, the author submits that it would be irresponsible for substitute decision-making regimes to be removed entirely from the laws of New Zealand. This is because there are relatively complex and rare circumstances where supported decision-making will simply not be possible or appropriate given the risk and nature of the decisions

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<sup>268</sup> See generally above n 111.

required.<sup>269</sup> The interaction between the SDM Bill and the PPPR Act are explored in more detail in Chapter 9.

### *B Definition of Disabled Person*

The definition of disabled person section (cl 11 of the SDM Bill), included at Figure 5 below, defines disabled person for the purposes of the SDM Bill.

<p><b>Definition of disabled persons</b></p> <p>For the purposes of this Act, a person (Person A) is a <b>disabled person</b> if one or more apply:</p> <ul style="list-style-type: none"><li>(a) physical disability or impairment:</li><li>(b) physical illness:</li><li>(c) psychiatric illness:</li><li>(d) intellectual or psychological disability or impairment:</li><li>(e) any other loss or abnormality of psychological, physiological, or anatomical structure or function:</li><li>(f) rely on a disability assist dog, wheelchair, or other remedial means: or</li><li>(g) the presence in the body of organisms capable of causing illness.</li></ul>
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**Figure 5: Definition of disabled person (cl 11)**

This section includes the definition of disabled person from the HRA to ensure that there is interpretative consistency between the SDM Bill, the HRA and the NZ BORA.<sup>270</sup>

The author notes that the definition of disabled person included in the HRA differs from the UNCRPD because it is broader including temporary as well as permanent impairments.<sup>271</sup> However, given that the HRA definition of disabled person has been used in New Zealand for almost 30 years there is no reason to deviate from the existing definition.

### *C Definition of Supporter*

The definition of supporter section (cl 12 of the SDM Bill), included at Figure 6 below, defines supporter for the purposes of the SDM Bill.

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<sup>269</sup> Above n 109 at 172.

<sup>270</sup> Above n 95, s 21(1)(h).

<sup>271</sup> Above n 2, art 1.

### **Definition of supporter**

- (1) For the purposes of this Act, a person or persons (Person B etc) is a **supporter** where they support a disabled persons to make decisions in accordance with sections 10 (definition of supported decision-making) and 14 (definition of supported decision-making arrangement) of this Act.
- (2) To be eligible to be a supporter a person must:
  - (a) be at least 18 years old;
  - (b) have capacity to make their own decisions without using supported decision-making under a supported decision-making agreement; and
  - (c) be free from conflicts of interest or undue influence.

***Figure 6: Definition of supporter (cl 12)***

This section defines supporter simply as a person or persons who support a disabled person to make decisions using SDM under a SDM agreement. Additionally, the section provides criteria for who can act as a supporter for a disabled person under an SDM arrangement.

The supporter is required to be at least 18 years old, have capacity to make their own decisions without using SDM under an SDM agreement and they must be free from conflicts of interest or undue influence. These requirements were added to ensure that the disabled person is supported by a person who is competent to help another person make decisions with appropriate safeguards.

## D *Definition of Capacity*

The definition of capacity section (cl 13 of the SDM Bill), included at Figure 7 below, defines capacity for the purposes of the SDM Bill.

<p><b>Definition of capacity</b></p> <p>For the purposes of this Act, a disabled person has <b>capacity</b> to enter into a <b>supported decision-making arrangement</b> if:</p> <ul style="list-style-type: none"><li>(a) they know and understand the consequences of the decisions being made; and</li><li>(b) need support to exercise their legal capacity.</li></ul>
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**Figure 7: Definition of capacity (cl 13)**

This section defines capacity for the purposes of the SDM Bill. The emphasis is on ensuring that the disabled person can, with support, know and understand the consequences of the decision being made. Additionally, the disabled person may need additional support to exercise their legal capacity.

This approach recognises that disabled people inherently have legal personality, as recognised by the UNCRPD, and the corresponding right to make their own decisions.<sup>272</sup> It focuses on what disabled people can do rather, acknowledging that society disables people rather than taking a deficit-based approach to mental capacity.<sup>273</sup> This threshold was set because it focuses on the disabled person being able to appreciate the risks, benefits and consequences of their decisions affording them “dignity of risk”.<sup>274</sup>

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<sup>272</sup> Above n 2, art 12.

<sup>273</sup> Above n 105.

<sup>274</sup> Above n 109 at 168.

## *E Definition of a Supported Decision-Making Arrangement*

The definition of a supported decision-making arrangement section (cl 14 of the SDM Bill), included at Figure 8 below, defines SDM agreement for the purposes of the SDM Bill.

<p><b>Definition of a supported decision-making arrangement</b></p> <p>For the purposes of this Act, a <b>supported decision-making arrangement</b> is defined as:</p> <ul style="list-style-type: none"><li>(a) an agreement, whether oral or in writing, between:<ul style="list-style-type: none"><li>(i) a disabled person; and</li><li>(ii) their supporter(s);</li></ul></li><li>(b) where a disabled person relies on their supporter(s) to supported them to make decisions relating to:<ul style="list-style-type: none"><li>(i) welfare; and</li><li>(ii) property.</li></ul></li></ul>
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**Figure 8: Definition of a supported decision-making arrangement (cl 14)**

The definition of SDM arrangement is designed to be flexible so that the agreements can be captured in a variety of formats as technology changes. It would allow for an agreement to be in writing, whether physically or digitally, but is agnostic about the technology used to deliver the solution, for example, delivery via blockchain technologies, non-fungible tokens, or simply by QR code validations.

An SDM agreement is allowed to be made orally or in writing between the disabled person and their supporters to recognise that low risk or minor decisions are often made in the moment and do not require the same level of rigour as high risk or major decisions. An SDM agreement can relate to welfare and property matters reflecting the broad categories for substitute decision-making under the PPPR Act.

Therefore, it is expected that SDM agreements can be entered into to enable a disabled person to be supported to make any decision affecting their life. An SDM arrangement can be entered into on a per decision basis or for decisions of a particular class or character.

#### *IV Part 3: Effect of Supported Decision-Making Arrangements*

Part 3 is critical to the parties understanding the effect of entering into an SDM arrangement. It elaborates on the effect and validity of a supported decision-making arrangement for the parties and those acting on decisions made under an SDM arrangement.

##### *A Effect of a Supported Decision-Making Arrangement*

This section (cl 15 of the SDM Bill), included at Figure 9 below, clarifies the effect of entering into an SDM agreement.

<p><b>Effect of a supported decision-making arrangement</b></p> <p>Where a disabled person and supporter(s) enter into a supported decision-making arrangement it has the following effect:</p> <ul style="list-style-type: none"><li>(a) the supported decision-making arrangement enables the disabled person to make decisions that they would not otherwise have capacity to make; and</li><li>(b) decisions made by a disabled person in accordance with a valid supported decision-making arrangement are binding on a disabled person in accordance with <b>section 17</b> unless <b>section 18</b> applies; and</li><li>(c) supporter(s) liability for decisions made by a disabled person in accordance with a supported decision-making arrangement is determined in accordance with <b>sections 17 and 18</b> of this Act.</li></ul>
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***Figure 9: Effect of a supported decision-making arrangement (cl 15)***

The SDM Bill clarifies that a valid SDM arrangement enables a disabled person to make decisions that they would not otherwise have the mental capacity to make without support. Further, it confirms that a decision made under a valid SDM agreement is binding on a disabled person with limited exceptions.

## *B      Validity of a supported decision-making arrangement*

This section (cl 16 of the SDM Bill), included at Figure 10 below, clarifies the circumstances in which an SDM is valid.

### **Validity of a supported decision-making arrangement**

- (1) A supported decision-making arrangement is considered valid unless there is information to the contrary which indicates that the supported decision-making arrangement was entered into for an improper purpose.
- (2) For the purposes of this provision, **improper purpose** is defined as including circumstances where the supporter(s) benefit from a decision made under a supported decision-making arrangement without the prior knowledge or consent of the disabled person.

***Figure 10: Validity of a supported decision-making arrangement (cl 16)***

The SDM Bill provides for a general presumption that a supported decision-making arrangement is valid unless there is information to the contrary indicating that it was entered into for an “improper purpose” such as for pecuniary advantage or where the agreement was entered into under undue influence.

## *V      Part 4: Liability for Decisions Made Under a Supported Decision-Making Arrangement*

Part 4 is critical to the parties to an SDM arrangement understanding the consequences and liability for decisions made under an SDM arrangement. It elaborates on liability for decisions made by each of the parties to a SDM arrangement.

### *A      Liability of Disabled People*

This section (cl 17 of the SDM Bill), included at Figure 11 below, clarifies the liability of disabled people for decisions made in accordance with a SDM arrangement.



### **Liability of disabled person**

- (1) A disabled person who makes a decision in accordance with a supported decision-making arrangement is personally liable for the consequences of decisions.
- (2) A disabled person will not be personally liable for a decision made under a supported decision-making arrangement if an exemption in **clause 18** applies.
- (3) Nothing in this provision effects the application of remedies available in common law, equity or any other enactment or rule of law.

***Figure 11: Liability of disabled person (cl 17)***

The SDM Bill confirms that the disabled person is presumed to be liable for the consequences of decisions made under the supported decision-making agreement. However, it provides for this presumption to be displaced where the disabled person was unduly influenced to make the decision, or the decision was procured by fraud by the supporter.

## *B Liability of Supporter(s)*

This section (cl 18 of the SDM Bill), included at Figure 12 below, clarifies the liability of supporter(s) for decisions made in accordance with a SDM arrangement.

### **Liability of supporter(s)**

- (1) Supporter(s) are not personally liable for a decision made by a disabled person under a supported decision-making arrangement if **clause 17** applies.
- (2) A supporter who supports a disabled person to make a decision in accordance with a supported decision-making arrangement is personally liable for the consequence of a decision where:
  - (a) section 16(1) relating to entering into a supported decision-making arrangement for an improper purpose applies;
  - (b) the supported decision-making arrangement was entered into at a time when one or more parties was under undue influence;
  - (c) the supported decision-making arrangement was procured by fraud or misrepresentation;
  - (d) the supported decision-making arrangement was entered into by mistake;
  - (e) the supporter(s) knew or should have reasonably known that the disabled person was unable to enter into a supported decision-making arrangement of that nature.
- (3) Nothing in this provision effects the application of remedies available in common law, equity or any other enactment or rule of law.

**Figure 12: Liability of supporter(s) (cl 18)**

This clause confirms that where the supporter(s) has unduly influenced the disabled person they become personally liable for the consequences of the decision and may also face criminal and civil penalties. For completeness, the SDM Bill preserves the application of other remedies available at common law and equity or any other enactment or rule of law.

## *VI Part 5: Resolution of Disputes Between Parties to a Supported Decision-Making Arrangement*

Part 5 provides for the dispute resolution mechanisms available for disputes between parties to a SDM arrangement.

### *A Disputes Between Parties to a Supported Decision-Making Arrangement*

This section (cl 19 of the SDM Bill), included at Figure 13 below, clarifies the dispute resolution process where a dispute arises between the parties to an SDM arrangement.

#### **Disputes between parties to a supported decision-making arrangement**

- (1) Where there is a dispute between the parties to the supported decision-making arrangement, relating to a decision made under a supported decision-making agreement, disputes can be resolved using the following mechanisms:
  - (a) mediation provided by the responsible agency;
  - (b) mediation provided by an agent of the responsible agency;
  - (c) arbitration;
  - (d) an independent panel appointed by the responsible agency.

***Figure 13: Disputes between parties to a supported decision-making arrangement (cl 19)***

The SDM Bill provides for a range of mechanisms to resolve disputes between the disabled person and their supporters or between the supporters themselves. This includes mediation or where relevant asking an independent expert panel to support the disabled person to decide where supporters are unable to do so. The Family Court is the forum of last resort.

### *B Applications Regarding Disputes*

This section (cl 20 of the SDM Bill), included at Figure 14 below, clarifies who can make an application to undergo a dispute resolution process where a dispute arises between the parties to an SDM arrangement.

**Applications can be made by the parties themselves or select third parties**

- (1) An application to resolve a dispute between the parties to a supported decision-making agreement may be made by:
  - (a) the disabled persons: or
  - (b) their supporter(s).
- (2) Additionally, an application to resolve a dispute between parties to a supported decision-making arrangement may be made by:
  - (a) a person holding Enduring Power of Attorney with respect to any of the parties;
  - (b) a person who has been appointed a welfare guardian in accordance with the **Protection of Personal and Property Rights Act 1988**;**
  - (c) a lawyer defined in accordance with **Lawyers and Conveyancers Act 2006**;**
  - (d) an advocate being a person who has been admitted and enrolled as a barrister and solicitor of the High Court of New Zealand who is entitled to hold a practising certificate but does not hold a valid practising certificate;
  - (e) a health practitioner defined in accordance with **Health Practitioners Competence Assurance Act 2003**;**
  - (f) the Disability Commissioner appointed in accordance with the **Human Rights Act 1993** where the Attorney-General consents to the application on behalf of the Crown; or
  - (g) a person or class of persons in accordance with operational policy made by the responsible agency and approved by the Minister under this Act.
- (3) Nothing in this Act permits a whānau or family member or any other person to make an application on behalf of a disabled person to resolve a dispute between the parties to a supported decision-making arrangement.

***Figure 14: Applications regarding disputes (cl 20)***

Applications for dispute resolution can be made by the parties to the supported decision-making agreement themselves or selected third parties such as lawyers and health practitioners.

Applications cannot be made by whānau of family members of the disabled person unless they are a party to the supported decision-making agreement. This has been included to protect disabled people from interference by overbearing relatives.

## *VII Part 6: Appeals Where Disputes Have Been Resolved by the Family Court*

Part 6 contains the appeal mechanisms available for disputes between parties to a SDM arrangement that have been resolved by the Family Court.

### *A Applications to the Family Court to Resolve Disputes*

This section (cl 21 of the SDM Bill), included at Figure 15 below, clarifies that applications to the Family Court with regards to resolving disputes under an SDM arrangement are to be a tool of last resort.

#### **Applications to the Family Court to resolve disputes a tool of last resort**

- (1) Applications to the Family Court are an option of last resort if an option in **section 19** has not adequately resolved the dispute.
- (2) Applications to the Family Court may be made without notice or on notice in accordance with the **Family Court Rules 2002**.
- (3) Applications lodged in accordance with this provision do not attract filing fees or incur costs liability unless the application is:
  - (a) frivolous:
  - (b) vexatious:
  - (c) made in bad faith: or
  - (d) made for an improper purpose.

***Figure 15: Applications to the Family Court to resolve disputes a tool of last resort (cl 21)***

Where a matter requires Family Court intervention, applications can be made without notice or on notice and filing fees and costs liability are

waived providing the application is not frivolous, vexatious, or made in bad faith.

*B Appeals relating to disputes resolved via the Family Court*

This section (cl 22 of the SDM Bill), included at Figure 16 below, outlines the procedures which apply to appeals of Family Court decisions under the SDM Bill to the High Court, Court of Appeal and Supreme Court of New Zealand.

**Appeals relating to disputes resolved via the Family Court**

- (1) Where a dispute between a disabled person and their supporter(s) is resolved through the Family Court an appeal may be heard in the High Court of New Zealand in accordance with **High Court Rules 2016**.
- (2) Applications made under subsection (1) may be determined *de novo* in accordance with the inherent jurisdiction of the High Court to determine matters.
- (3) Where a dispute is appealed to the High Court in accordance with subsection (1), a further appeal may be made with leave of the Court of Appeal granted in accordance with **Court of Appeal (Civil) Rules 2005**
- (4) Where a dispute is appealed to the Court of Appeal in accordance with subsection (3), a further appeal may be made with leave of the Supreme Court granted in accordance with **Supreme Court Rules 2004**.
- (5) Appeals lodged in accordance with this provision do not attract filing fees or incur costs liability unless:
  - (a) frivolous:
  - (b) vexatious:
  - (c) made in bad faith: or
  - (d) made for an improper purpose.

**Figure 16: Appeals relating to disputes resolved by the Family Court (cl 22)**

Determinations of the Family Court are not final and may be appealed with leave through to the High Court, Court of Appeal and Supreme Court. The discretion of the superior courts with regards to costs is

preserved as a deterrent to applications which are frivolous, vexatious, or made in bad faith.

## **Chapter 9: Critical analysis of the proposed Supported Decision-Making Bill**

The purpose of this chapter is to test and critically analyse the proposed SDM discussed in Chapter 8 and included in Appendix A. The scope of this chapter is limited to testing and analysing the key operational aspects of the SDM Bill. Where relevant, other aspects of the SDM Bill such as the definitions and interactions with other statutes will be incorporated in the analysis.

This chapter introduces five disabled people: Max, Pita, Manaia, Lorna and Tuī. Firstly, each disabled person's unique circumstances will be outlined including their disabilities, support people, support needs and an important decision they are facing.

Secondly, each character's circumstances will be used to test how the SDM Bill would operate to ensure it is sufficiently flexible to cover a broad range of disabilities and circumstances and identify unintended consequences to ensure it is "fit for purpose". Some of the character's circumstances will also demonstrate how the SDM Bill would interact with our existing legal frameworks.

### *I      Max*

Max is 25 years old and lives alone in a private rental property in Wellington. He does not have contact with his biological family, but he has a chosen family in his close friends Connor and Nikki who he has known since high school.

Max is autistic and has autoimmune diseases which means he has high support needs. Max receives financial assistance from the Ministry of Social Development through the Supported Living Payment and Disability Allowance. He also receives 4 hours of care support each day to assist with personal care and home management with funding from Whaikaha – Ministry of Disabled People.

Max is comfortable making decisions about day-to-day matters such as what to eat, wear and how to occupy their time on their own. Max is not



confident about making decisions about important issues such as managing housing, their finances and medical treatment without support. They require support to make decisions on important issues to help them understand the long-term benefits, risks, and consequences of decisions they make.

Max relies on two of his close friends Connor and Nikki to help him make decisions on important issues. Connor and Nikki have known Max for a significant period, they understand Max's will and preferences and their support needs.

Two years ago, Max was living in a private rental property which was expensive and became damp and mouldy. The environment was impacting on his health and making his asthma worse. As a result, he needed to see the doctor more often which increased his medical expenses significantly this meant that Max often did not have enough money for food and other necessities.

Connor and Nikki could see that Max's housing situation was having a significant impact on his mental health as well. Connor and Nikki asked Max if he had spoken to Kāinga Ora about whether he was eligible to live in social housing.

One day Max said to Connor and Nikki that he was struggling to make ends meet and wanted to investigate moving into a new house that was warm and dry. Max asked Connor and Nikki to help him with making decisions about moving house. Max had never had to move house without the support of his parents and was worried he would make bad decisions because he is inexperienced at making his own decisions.

Max, Connor, and Nikki discussed Max's housing needs, created a budget to work out rent affordability and identified suitable locations and properties. Connor and Nikki supported Max by providing access to relevant information, explaining it in a way that he understood, giving him extra time to think about what he wanted and regularly checked with Max to see if his needs or circumstances had changed.

One day Max received a phone call from Kāinga Ora offering him a fully fenced two-bedroom house in a new social housing development that had recently been completed. The house is in Porirua which is close to where Max goes for his weekly swimming lessons. The rent was significantly cheaper than his current home at \$80 per week plus power and internet and Max was allowed to have his dog at the property too.

Max, Connor, and Nikki went to a meeting with Kāinga Ora to view the property together and support Max through reading the tenancy agreement and help Max understand their rights and responsibilities as a tenant. Connor and Nikki also helped Max to update their budget, set up an automatic payment for rent and investigate power and internet service providers.

#### *A Application of the SDM Bill to Max's circumstances*

Under the SDM Bill Max would meet the definition of disabled person included in cl 11 because he is autistic.

Max would also meet the capacity requirement in cl 13 because he is able to know and understand the consequences of his decisions when he has support from Connor and Nikki.

Connor and Nikki would be Max's "supporters" under cl 12 because they support Max to make decisions using SDM. The support Connor and Nikki provide Max meets the definition of SDM in cl 10 because they explain and provide information to Max in a format that he understands, and ensure Max has extra time to consider the information provided, ask questions, and do his own research.

The arrangement that Max has in place with Connor and Nikki would meet the definition of a SDM arrangement because there is an oral agreement between Max, Connor, and Nikki that Connor and Nikki will provide support to Max to make important decisions relating to his welfare and property.

Under cl 15, the effect of the SDM arrangement is that it enables Max to make decisions that he would not otherwise have capacity to make.

Additionally, the decisions made under the SDM arrangement are presumed to be valid unless cl 16 applies and are binding on Max under cl 17.

Connor and Nikki will generally not be liable for the consequences of a decision made under an SDM arrangement unless an exemption in cl 18 applies. These exemptions include where the SDM arrangement was entered into for an improper purpose, the disabled person was subjected to undue influence, or procured by fraud, misrepresentation, or mistake, and where the supporters should have reasonably known that the disabled person was unable to enter an SDM arrangement.

In this scenario there is no evidence that Connor and Max have been involved in the SDM arrangement for an improper purpose or exerted undue influence over Max. There is no evidence to suggest that Connor and Nikki entered the SDM arrangement with Max fraudulently, due to a misrepresentation or by mistake. Additionally, Max asked Connor and Nikki to be his supporters so they can be confident that Max was able to enter an SDM arrangement.

In these circumstances, despite the absence of a written SDM arrangement, Kāinga Ora can be confident that an SDM arrangement exists between Max, Connor, and Nikki because the trio attended meetings together. Kāinga Ora has had the opportunity to observe the way in which Connor and Nikki have supported Max to make this decision and be confident that Max has made an informed decision as a result of the SDM arrangement.

The SDM Bill provides certainty for Kāinga Ora that Max had capacity to make the decision to move into the social house offered because of the SDM arrangement. Kāinga Ora also knows that Max is personally liable for the consequences of the decision rather than Connor and Nikki.

For future interactions Kāinga Ora can make a file note confirming Max uses SDM to make his own decisions and that he is supported by Connor and Nikki to do so. Kāinga Ora could also have a discussion with Max about how he wants to be contacted, whether he would prefer that they

talk directly to Connor and Nikki in the first instance if any additional decisions need to be made, and how he would prefer to receive information.

## *II Pita*

Pita is 61 years old and lives with his partner in their own home in Whanganui. They have three adult children who live in Wellington, Christchurch, and Brisbane. Pita's wife holds EPOA and his daughter in Brisbane is the successor.

Three and a half years ago Pita was diagnosed with Parkinson's disease, a neurological condition which affects mobility and cognitive function. For Pita this means that he requires assistance for his personal cares, uses a walker to aid with movement, he increasingly has difficulty with speaking and processing information. He is required to take medication seven times a day between 7:00 am and 9:00 pm.

Pita receives assistance from a Care Support Worker for an hour and a half every day to assist with his personal care; this is funded via Whaikaha – Ministry of Disabled People. Living at home is becoming increasingly unsafe because the bathroom is not accessible, it is not easy for Pita to move around the house with his walker, and there is not someone at home 24/7 to ensure that he takes his medication or assist if he has a fall.

Recently, Pita has spent a month in hospital after suddenly becoming unwell and has recently been diagnosed with early stages of dementia. His specialist recommends that he consider moving into a residential care facility. Pita does not want to move into a residential care facility; he wants to live in his own home with his partner.

Pita seeks support from his partner and his three children to decide whether to be discharged back to home or move into a residential care facility. His primary objection to moving into a residential care facility is that they are designed for people much older than him and does not think

it will meet his needs. Pita is also concerned that the strict rules would impact on his independence.

*A Application of the SDM Bill to Pita's circumstances*

Under the SDM Bill Pita would meet the definition of disabled person included in cl 11 because he has Parkinson's disease and dementia. Pita would also meet the capacity requirement in cl 13 because he is able to know and understand the consequences of his decisions when he has support.

Pita's wife and children would be his "supporters" under cl 12 because they support him to make decisions using SDM. The support provided to Pita meets the definition of SDM in cl 10 because his supporters explain and provide information to Pita in a format that he understands, ensure he has extra time to consider the information provided, and check in with him a couple of times during the decision-making process.

The arrangement that Pita has in place with his wife and children would meet the definition of a SDM arrangement because there is an oral agreement between Pita, his wife and children to support him to make important decisions about his welfare and property.

Under cl 15, the effect of the SDM arrangement is that it enables Pita to make decisions that he would not otherwise have the mental capacity to make. Additionally, the decisions made under the SDM arrangement are presumed to be valid unless cl 16 applies and are binding on Pita under cl 17.

Pita's wife and children will generally not be liable for the consequences of a decision made under an SDM arrangement unless an exemption in cl 18 applies. These exemptions include where the SDM arrangement was entered into for an improper purpose, the disabled person was subjected to undue influence, or procured by fraud, misrepresentation, or mistake, and where the supporters should have reasonably known that the disabled person was unable to enter an SDM arrangement.

## *B Intersection with the PPPR Act*

As Pita has dementia, his mental capacity will progressively diminish over time. He will become increasingly reliant on support from his wife and children to make his own decisions. As the disease progresses, Pita's mental capacity may also vary greatly day to day depending on many factors, including how well rested he is and whether he has taken his medication on time.

Eventually, there will be a point in time where he is determined to lack the mental capacity to make his own decisions even via SDM. When Pita's wife's EPOA came into force for Pita this would limit the ability to use SDM and instead the obligations and regime set out in the PPPR Act would apply.

Part 5 of the SDM Bill contains provisions to resolve disputes between the parties to an SDM arrangement. In this scenario, Pita relies on his wife and three children to support him to make decisions. Given the number of supporters Pita has and the supporter's emotional investment in his welfare as family members there is considerable risk of a dispute arising.

If a dispute arose one of the parties to the SDM arrangement could apply under cl 19 for the dispute to be resolved via alternate dispute resolution methods such as mediation, arbitration or by an independent panel. Alternatively, a third party could make an application under cl 20 for dispute resolution such as one of Pita's health practitioners or his lawyer.

If alternate dispute resolution did not assist the parties to the SDM arrangement to resolve the dispute an application can be made to the Family Court under cl 20. This avenue is a tool of last resort to encourage disputes to be resolved between the parties so as to enable the SDM arrangement to continue. Clause 20 empowers the Family Court to make a determination about the dispute and direct the parties to the SDM arrangement on how to proceed. Clause 21 provides mechanisms to appeal the determination of the Family Court to the High Court, Court of Appeal and Supreme Court.

Applications to the Family Court and appeals to the High Court, Court of Appeal and Supreme Court are free and do not incur liability for costs except if the application is frivolous, vexatious, made in bad faith or for an improper purpose.<sup>275</sup> This is to ensure that cost is not a barrier to ensuring that genuine disputes arising under SDM arrangements, that cannot be resolved via alternate dispute resolution methods, can be resolved. Additionally, the fact that costs liability can be imposed in limited circumstances is designed to disincentivise disingenuous applications to the Court.

### *III Manaia*

Manaia is 18 years old and lives with her whānau (mother, three sisters and brother) in Whāngarei. Manaia was involved in a car accident 8 years ago which left her with a traumatic brain injury, chronic pain and other physical injuries which impact on mobility.

Manaia's brain injury has impacted her short-term memory and the way that she learns and interprets information. Additionally, Manaia experiences chronic fatigue. While Manaia's chronic pain is treated with medication, pain flares can impact on her mood and ability to do her personal care independently meaning that she needs extra support which is provided by her mother. Manaia's mobility varies depending on her pain levels and she sometimes uses walking mobility aids such as crutches.

Manaia receives in-home assistance from a care support worker provided by the ACC for 3 hours every week to help with household management tasks like cooking meals when Manaia's mother is at work, doing laundry and cleaning the house. Manaia also sees her doctor regularly to review her pain medication and sees a physiotherapist on a weekly basis. She also receives a lump sum payment from ACC every five years recognising the financial impact of her permanent disability.

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<sup>275</sup> Supported Decision-Making Bill 2022, cls 20 and 21.

Manaia has recently turned 18 and is finishing her last year of high school. Manaia has important decisions to make about what she will do after finishing school. She has been volunteering at Riding for the Disabled for a year. Manaia is interested in studying to become a teacher or nurse at Auckland University next year.

Manaia has never made important decisions like this on her own before. Manaia's mother had guardianship until she turned 18 in accordance with the Care of Children Act 2004.<sup>276</sup> Now that Manaia is 18 years old the legal ground rules have changed.

Manaia is determined to study at Auckland University, and she wants to move out of home to be independent. Manaia's mother is concerned that she will not be able to live independently without significant support because of her disabilities. Manaia has not had much experience making decisions on her own and has not had the same opportunity as peers to develop these skills because she spent two years in hospital after her accident.

#### *A Application of the SDM Bill to Manaia's circumstances*

Under the SDM Bill Manaia would meet the definition of disabled person included in cl 11 because he has an intellectual and physical disability.

Manaia would also meet the capacity requirement in cl 13 because she is able to know and understand the consequences of his decisions when she has support. There are also likely to be many decisions that Manaia can make on her own without using SDM.

Currently, Manaia's mother would be her "supporter" under cl 12 because she supports her to make decisions using SDM. The support provided by Manaia's mother would meet the definition of SDM in cl 10 because she explains and provides information to Manaia as early as possible, ensures she has information she can refer to easily and ensures she has extra time to consider the information provided before deciding.

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<sup>276</sup> Sections 15-16.



The arrangement that Manaia has in place with his mother would meet the definition of a SDM arrangement because there is an oral agreement between Manaia to support her to make important decisions about her welfare and property.

Under cl 15, the effect of the SDM arrangement is that it enables Manaia to make decisions that she would not otherwise have the mental capacity to make. Additionally, the decisions made under the SDM arrangement are presumed to be valid unless cl 16 applies and are binding on her under cl 17.

Manaia's mother would generally not be liable for the consequences of a decision made under an SDM arrangement unless an exemption in cl 18 applies. These exemptions include where the SDM arrangement was entered into for an improper purpose, the disabled person was subjected to undue influence, or procured by fraud, misrepresentation, or mistake, and where the supporters should have reasonably known that the disabled person was unable to enter an SDM arrangement.

#### *IV Lorna*

Lorna is 93 years old and lives alone in their own home in Ōtautahi / Christchurch. Her husband died 6 years ago, and her only child Jane lives in Auckland. Lorna is legally blind, hard of hearing and has depression.

Lorna receives a pension from the Ministry of Social Development and has meals delivered by Meals on Wheels 3 times a week. She does not receive any other disability support services from Whaikaha – Ministry of Disabled People or Te Whatu Ora – Health New Zealand.

Jane holds an EPOA for Lorna and is concerned about her mother's welfare because they have recently observed that she is unable to cook for herself. Additionally, she is having difficulty maintaining good personal and ensuring the house is clean and tidy. They think it is time that Lorna moves into a retirement village where they will be able to socialise with other elderly people, receive in-home support, and regular cooked meals.

Lorna's doctor has assessed her mental capacity recently and determined that she is "of sound mind". As a result, Jane is unable to exercise their powers under the EPOA and is unable to apply to the Family Court for a welfare guardianship order under the PPPR Act.

Lorna is fiercely independent and adamant that she wants to remain in her own home. She also appears to be unaware of the welfare, safety, and hygiene issues. Jane is concerned that remaining in her own home is no longer in her mother's welfare and best interests because she is not able to feed herself, do her personal cares or ensure the house is clean and tidy. Additionally, Jane is concerned that Lorna is becoming increasingly socially isolated because most of her friends have died and she does not have regular social contact apart from when Jane comes to visit.

*A Application of the SDM Bill to Lorna's circumstances*

Under the SDM Bill Lorna would meet the definition of disabled person included in cl 11 because she is legally blind, hard of hearing and has a mental health condition. Lorna would also meet the capacity requirement in cl 13 because she is able to know and understand the consequences of his decisions when she has support.

Currently, Jane would be Lorna's "supporter" under cl 12 because she supports her to make decisions using SDM. Jane's support would meet the SDM definition in cl 10 because she explains information to Lorna as early as possible, ensures information is provided in audio format where possible and ensures she has extra time to consider the information provided before making a decision.

The arrangement that Lorna has in place with Jane would meet the definition of an SDM arrangement because there is an oral agreement with Jane to support her to make important decisions about her welfare and property.

Under cl 15, the effect of the SDM arrangement is that it enables Lorna to make decisions that she would not otherwise have the mental capacity to make. Additionally, the decisions made under the SDM arrangement

are presumed to be valid unless cl 16 applies and are binding on her under cl 17.

Jane would generally not be liable for the consequences of a decision made under an SDM arrangement unless an exemption in cl 18 applies. These exemptions include where the SDM arrangement was entered into for an improper purpose, the disabled person was subjected to undue influence, or procured by fraud, misrepresentation, or mistake, and where the supporters should have reasonably known that the disabled person was unable to enter an SDM arrangement.

In this scenario, Lorna's will, and preference is that she remain in her own home. Lorna is refusing to take Jane's advice about making a decision about her current living situation and moving into a supported living environment. Lorna is not required to agree with Jane's advice as her supporter, providing that Lorna can know and understand the consequences of the decision being made with Jane's support.

This would be an example of where Lorna would have "dignity of risk" and is able to make decisions that seem unwise. In the context of an SDM arrangement Lorna has the capacity to make her own decisions with support and a medical practitioner has determined she is "of sound mind". This means that the exemption would not catch Jane in cl 18 because, considering the recent assessment by a medical practitioner, Jane could not have reasonably known that Lorna was unable to enter an SDM arrangement. However, if Jane sought to place significant pressure on Lorna to decide to move into a supported living environment, then under the SDM Bill Jane would become jointly liable for the consequences of that decision under cl 18.

Perhaps Jane or a permitted third party could potentially apply for the dispute to be resolved via an alternative dispute resolution process like in Pita's example above.<sup>277</sup> There may be a genuine question about whether there is a dispute between the parties to the agreement. It is likely Lorna would argue that there was not a dispute because she

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<sup>277</sup> Above n 277, cl 19.

considered Jane's advice and was supported to make an informed decision that was contrary to the advice given and in accordance with her will and preference to remain in her own home.

#### *B Intersection with the PPPR Act*

There may come a point where Lorna is unable to make decisions due to a lack of mental capacity arising from being in an acute mental health crisis or with the onset of another condition like Alzheimer's disease or dementia. When Jane's EPOA comes into force for Lorna this would limit the ability to use SDM and instead, the obligations and regime set out in the PPPR Act would apply to Lorna's circumstances.

Despite the existence of an SDM arrangement, Jane could apply to the Family Court for an order under s 10 of the PPPR Act requiring Lorna to be placed into a supported living environment contrary to Lorna's will and preference. The Family Court would have to find that Lorna was wholly or partially unable to make the specific decision about her housing circumstances on her own with support. This is unlikely given that a medical practitioner has recently determined that Lorna is "of sound mind".

#### *V Tuī*

Tuī is 30 years old and lives in a residential care facility in Palmerston North for disabled people with intellectual and physical disabilities who have high or complex care needs. Her mother Kora has been her carer since birth and shares care responsibility for Tuī with staff at the residential care facility who rotate regularly.

She has a long-term health condition that impacts their cognitive function, ability to communicate and her motor function. In particular, Tuī uses Easy Read information and special computer software to help her to communicate with others because she has difficulty vocalising and being understood by others. Tuī also has an electric wheelchair to aid with mobility and independence.

She receives disability support from Whaikaha – Ministry of Disabled People via the Enabling Good Lives pilot Manawhaikaha discussed above in Chapter 3. Additionally, she receives financial assistance from the Ministry of Social Development through the Supported Living Payment and Disability Allowance.

Tuī’s mother Kora is her Court-appointed property manager and welfare guardian under the PPPR Act; however, Kora supports Tuī to make her own decisions on a regular basis. This arrangement has been in place for important property and welfare decisions since Tuī was 18 years old in the event that Tuī was unable to make a decision with support in place.

Tuī went to a school specialised in educating disabled people, obtained University Entrance, and completed National Certificate in Educational Achievement Level 2. In the last six months, Tuī has expressed a desire to begin studying coding so that she can develop software that helps other disabled people who are non-verbal.

#### *A Application of the SDM Bill to Tuī’s circumstances*

Under the SDM Bill, Tuī would meet the definition of disabled person included in cl 11 because she has a long-term health condition affecting her cognitive function, communication, and mobility.

Tuī would also meet the capacity requirement in cl 13 because she is able to know and understand the consequences of most day-to-day decisions when she has support. In Tuī’s circumstances, there may be times where she would not meet the capacity requirement in the SDM Bill. This is discussed below.

Kora would be Tuī’s “supporter” under cl 12 because she supports her in making decisions using SDM. The support provided by Tuī would meet the definition of SDM in cl 10 because Kora explains information to Tuī in a way she understands as early as possible, ensures information is provided in Easy Read format where possible and ensures Tuī has extra time to consider the information provided before making a decision.

The arrangement that Tuī has in place with Kora would meet the definition of an SDM arrangement because there is an oral agreement with Kora to support her in making day-to-day decisions about her welfare and property.

Under cl 15, the effect of the SDM arrangement is that it enables Tuī to make decisions that she would not otherwise have the mental capacity to make. Additionally, the decisions made under the SDM arrangement are presumed to be valid unless cl 16 applies and are binding on her under cl 17.

Kora would generally not be liable for the consequences of a decision made under an SDM arrangement unless an exemption in cl 18 applies. These exemptions include where the SDM arrangement was entered into for an improper purpose, the disabled person was subjected to undue influence or procured by fraud, misrepresentation, or mistake, and where the supporters should have reasonably known that the disabled person was unable to enter an SDM arrangement.

The residential care facility is likely to accept the SDM arrangement in this context because Tuī's supporter is also her welfare guardian and property manager. The facility may insist on the SDM arrangement being in writing for their records to ensure that they are able to rely on decisions that Tuī makes under the SDM arrangement. However, the facility may choose to accept the oral agreement because Kora is also Tuī's welfare guardian and property manager under the PPPR Act.

If Tuī had a different supporter, then it would be reasonable for the facility to insist that the SDM arrangement be in writing to clarify the scope and nature of decisions that Tuī can make using SDM and where decisions would need to be made by Kora as Tuī's welfare guardian and property manager.

Under the SDM Bill, if Tuī had a different supporter, Kora would be able to apply for alternative dispute resolution or to the Family Court if a dispute arose between Tuī and her supporter. Kora is Tuī's welfare

guardian and property manager therefore, she is entitled to make an application under cl 20(b).

If Kora was not Tuī's welfare guardian and/or property manager, she would be statutorily barred from applying to resolve a dispute between Tuī and the supporter.<sup>278</sup> In this situation, Tuī's health practitioner or lawyer could make an application for dispute resolution instead if the circumstances required it.

This statutory bar exists to ensure that family and whānau members who do not have supporter status under an SDM arrangement cannot use the dispute resolution processes to undermine the autonomy, dignity, will and preference of the disabled person. This protects the disabled person's right to choose who their supporters are under an SDM arrangement.

#### *B Intersection between the SDM Bill and the PPPR Act*

There could be circumstances where the decisions would be of a level of complexity that Tuī may not be able to exercise her mental capacity even with support via SDM. In these circumstances, Kora's role as Tuī's welfare guardian and property manager under the PPPR Act would enable Kora to make decisions on Tuī's behalf.

Kora has a responsibility as Tuī's welfare guardian and property manager under the PPPR Act to encourage Tuī to develop and exercise her mental capacity to the extent she can. The SDM Bill would enable Kora to support Tuī in making her own decisions, with support, on day-to-day matters.

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<sup>278</sup> Above n 277, cl 20(3).

## *VI Concluding Observations*

The SDM Bill fills an important gap in our existing legal frameworks by providing disabled people with a legislative framework to exercise their mental capacity and make decisions with appropriate support in place.

The SDM arrangement definition is deliberately flexible to enable SDM to be used in a variety of circumstances. Currently, the definition includes the ability for an SDM arrangement to be entered into orally or in writing. To give organisations confidence in their ability to rely on decisions made by a disabled person using SDM it may be more appropriate to have an SDM arrangement recorded in writing. Indeed, this may be required by other statutes which require agreements to be in writing for evidential purposes. Residential care facilities and supported living environments may require SDM arrangements to be in writing for record-keeping purposes.

There will be circumstances where disabled people will be able to make their own decisions without using the SDM Bill. Equally, there will be circumstances where no amount of support provided to a disabled person will be enough to enable them to make their own decisions and exercise their mental capacity and the PPPR Act will come into play.

It is important to note that disabilities can impact on mental capacity in different ways and the extent to which mental capacity is impacted can vary greatly day to day and decline over time. The SDM Bill could be used in conjunction with welfare guardianship and property managers to encourage disabled people to develop and exercise their mental capacity to the extent appropriate in the circumstances.



## **Chapter 10: Conclusions**

This dissertation has contributed to Aotearoa New Zealand's legal scholarship on SDM by producing a draft SDM Bill. It has demonstrated that there is a significant gap in our existing decision-making capacity law that is currently being filled by ad hoc use of SDM at an operational level without a clear legislative basis. As a result, there is a lack of clarity for disabled people, their supporters and third parties relying on decisions made under SDM arrangements about the status of those decisions.

Our law is clear about when a person is presumed to have capacity and what happens when a person has partially or wholly lost their capacity to make their own decisions. Our law is unclear about what happens when a disabled person has capacity to make their own decisions but requires support from others to make them. SDM occupies a middle ground and should have an overarching legal framework supporting and encouraging the use of SDM arrangements to enable disabled people to make their own decisions in accordance with their will and preference.

The draft SDM Bill provides an overarching legal framework to enable disabled people, supporters and third parties to confidently engage in SDM arrangements and rely on decisions made using SDM arrangements by clarifying the roles, responsibilities, and liability in SDM arrangements. Additionally, enacting an SDM Bill would demonstrate that the New Zealand Government has taken action to address the comments made by the UNCRPD Committee on New Zealand's compliance with art 12 of the UNCRPD.

Enacting the SDM Bill would bring New Zealand's law closer to complying with obligations under art 12 of the UNCRPD. It would ensure that disabled people were empowered to make their own decisions in accordance with their will and preference. It will also ensure that disabled people are supported to develop their decision-making skills in a way that is appropriate for the context. Over time the use of SDM arrangements could enable disabled people who may not have otherwise

been encouraged to develop their decision-making skills to make fully independent decisions in certain circumstances.

Contrary to the UNCRPD Committee's General Comment on Art 12, the SDM Bill retains but significantly limits the operation of substitute decision-making options under the PPPR Act. This recognises that there will be hard cases where a person will not be able to make their own decisions even with significant support. As a result, substitute decision-making options are retained as a tool of last resort with SDM arrangements to be preferred to the extent reasonably practicable.

Retaining the PPPR Act and substitute decision-making as a legal tool of last resort would still likely result in the UNCRPD Committee concluding that New Zealand is not fully compliant with art 12. The PPPR Act requires amendment to take into account tikanga Māori and give greater weight to the views of the person subject to an order under the Act.

Finally, enacting the SDM Bill would be an important step towards a future for disabled people where they are empowered to make their own decisions. It will signal and facilitate a cultural shift within society towards recognising that disabled people deserve to live good lives in accordance with their will and preference and that society's role is to support disabled people to live freely and equitably in dignity and rights. Additionally, any law change would need to be accompanied by education and support programmes to ensure disabled people and supporters are equipped to utilise any new law to its full potential.

Ehara tāku toa i te toa takitahi, engari takimano, nō āku tīpuna – My strength is not the strength of one, it is the strength of many.<sup>279</sup>

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<sup>279</sup> Pāterangi (Ngāti Kahungunu).

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# **Appendix A – Draft Supported Decision-Making Bill 2022**

*Hon Poto Williams*

## **Supported Decision-Making Bill 2022**

Government Bill

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#### **Schedule 1**

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**The Parliament of New Zealand enacts as follows:**

**1 Title**

This Act is the **Supported Decision-Making Act 2022**.

**2 Commencement**

This Act comes into force on 1 July 2023.

**Part 1**

**Preliminary provisions**

**3 Purpose of this Act**

(1) The purpose of this Act is to enable disabled people to enter into supported decision-making arrangements in order to—

(a) enable disabled people to live freely in dignity and rights:

(b) provide a mechanism for disabled people to exercise legal capacity on an equitable basis to non-disabled people:

(c) provide safeguards against abuses of power or special relationship status.

(2) This Act supplements existing adult decision-making law in—

(a) the **Protection of Personal and Property Rights Act 1988**;

(b) the **Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996**;

(c) the common law doctrine of necessity;

(d) the inherent jurisdiction of the High Court of New Zealand; and

(e) other relevant enactments and rules of law.

#### 4 **Interpretation**

In this Act, unless the context otherwise requires, -

**capacity** is defined by **section 13**.

**disabled person** is defined by **section 11**.

**supported decision-making** is defined by **section 10**.

**supported decision-making arrangement** is defined by **section 14**.

**supporter** is defined by **section 12**.

#### 5 **Guide to this Act**

- (1) **Part 1** – Preliminary provisions
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- (3) **Part 3** - Effect of supported decision-making arrangements
- (4) **Part 4** - Liability for decisions made under a supported decision-making arrangement
- (5) **Part 5** - Resolution of disputes between parties to a supported decision-making arrangement
- (6) **Part 6** - Appeals where disputes between parties to a supported decision-making arrangement are resolved by the Family Court
- (7) This section is intended as a guide only.

#### 6 **Te Tiriti o Waitangi (the Treaty of Waitangi)**

In order to provide for the Crown's intention to give effect to the principles of Te Tiriti o Waitangi (the Treaty of Waitangi), this Act –

- (a) requires parties to a supported decision-making arrangement to act in a way that is consistent with Te Tiriti o Waitangi;
- (b) requires those acting on decisions made under a supported decision-making arrangement to act in a way that is consistent with Te Tiriti o Waitangi;
- (c) requires those reviewing supported decision-making arrangements in accordance with this Act to specifically consider Te Tiriti o Waitangi and te ao Māori when

adjudicating on issues arising within the context of a supported decision-making arrangement.

**7 Supported decision-making principles**

For the purpose of this Act, the supported decision-making principles are as follows:

- (a) to empower disabled people to live freely and equally in dignity and rights;
- (b) to empower disabled people to exercise their legal capacity on an equitable basis with non-disabled people; and
- (c) to enable disabled people to make their own decisions in a way that enables them to build their skills within a safe environment free from undue influence and abuses of power.

**8 Transitional, savings and related provisions**

The transitional, savings, and related provisions set out in **Schedule 1** have effect according to their terms.

**9 Act binds the Crown**

This Act binds the Crown.

**Part 2**

**Key definitions and roles**

**10 Definition of supported decision-making**

For the purposes of this Act, **supported decision-making** is defined as:

- (1) A process which supports and enables disabled people to exercise their legal capacity to make decisions on an equitable basis with non-disabled people through:
  - (a) providing information in accessible and alternative formats appropriate for the disabled person having regard to their disabilities;



- (b) allowing disabled person extra time to consider all relevant information to ensure they have an equitable opportunity to give informed consent;
  - (c) providing any other reasonable accommodations reasonably necessary to enable the disabled person to make their own decisions on an equitable basis with non-disabled people.
- (2) For the avoidance of doubt, supported decision-making does not include substitute decision-making arrangements under the **Protection of Protection of Personal and Property Rights Act 1988** and other relevant rules of law.

#### 11 **Definition of disabled person**

For the purposes of this Act, a person (Person A) is a **disabled person** if one or more apply:

- (a) physical disability or impairment:
- (b) physical illness:
- (c) psychiatric illness:
- (d) intellectual or psychological disability or impairment:
- (e) any other loss or abnormality of psychological, physiological, or anatomical structure or function:
- (f) rely on a disability assist dog, wheelchair, or other remedial means: or
- (g) the presence in the body of organisms capable of causing illness.

#### 12 **Definition of supporter**

- (1) For the purposes of this Act, a person or persons (Person B) is a **supporter** where they support a disabled person to make decisions in accordance with sections 10 (definition of supported decision-making) and 14 (definition of supported decision-making arrangement) of this Act.
- (2) To be eligible to be a supporter a person must:
  - (a) be at least 18 years old;
  - (b) have capacity to make their own decisions without using supported decision-making under a supported decision-making agreement; and

- (c) be free from conflicts of interest or undue influence.

13     **Definition of capacity**

For the purposes of this Act, a disabled person has **capacity** to enter into a **supported decision-making arrangement** if:

- (a) they know and understand the consequences of the decisions being made; and
- (b) need support to exercise their legal capacity.

14     **Definition of a supported decision-making arrangement**

For the purposes of this Act, a **supported decision-making arrangement** is defined as:

- (a) an agreement, whether oral or in writing, between:
  - (i) a disabled person; and
  - (ii) their supporter(s):
- (b) where a disabled person relies on their supporter(s) to supported them to make decisions relating to:
  - (i) welfare; and
  - (ii) property.

### **Part 3**

#### **Effect of supported decision-making arrangements**

15     **Effect of a supported decision-making arrangement**

Where a disabled person and supporter(s) enter into a supported decision-making arrangement it has the following effect:

- (a) the supported decision-making arrangement enables the disabled person to make decisions that they would not otherwise have capacity to make; and
- (b) decisions made by a disabled person in accordance with a valid supported decision-making arrangement are

binding on a disabled person in accordance with **section 17** unless **section 18** applies; and

- (c) supporter(s) liability for decisions made by a disabled person in accordance with a supported decision-making arrangement is determined in accordance with **sections 17 and 18** of this Act.

16     **Validity of a supported decision-making arrangement**

- (1) A supported decision-making arrangement is considered valid unless there is information to the contrary which indicates that the supported decision-making arrangement was entered into for an improper purpose.
- (2) For the purposes of this provision, **improper purpose** is defined as including circumstances where the supporter(s) benefit from a decision made under a supported decision-making arrangement without the prior knowledge or consent of the disabled person.

**Part 4**  
**Liability for decisions made under a supported decision-making arrangement**

**17 Liability of disabled person**

- (1) A disabled person who makes a decision in accordance with a supported decision-making arrangement is personally liable for the consequences of decisions.
- (2) A disabled person will not be personally liable for a decision made under a supported decision-making arrangement if an exemption in **section 18** applies.
- (3) Nothing in this provision affects the application of remedies available in common law, equity or any other enactment or rule of law.

**18 Liability of supporter(s)**

- (1) Supporter(s) are not personally liable for a decision made by a disabled person under a supported decision-making arrangement if **section 17** applies.
- (2) A supporter who supports a disabled person to make a decision in accordance with a supported decision-making arrangement is personally liable for the consequence of a decision where:
  - (a) section 16(1) relating to entering into a supported decision-making arrangement for an improper purpose applies;
  - (b) the supported decision-making arrangement was entered into at a time when one or more parties was under undue influence;
  - (c) the supported decision-making arrangement was procured by fraud or misrepresentation;
  - (d) the supported decision-making arrangement was entered into by mistake;
  - (e) the supporter(s) knew or should have reasonably known that the disabled person was unable to enter

into a supported decision-making arrangement of that nature.

- (3) Nothing in this provision affects the application of remedies available in common law, equity or any other enactment or rule of law.

## **Part 5**

### **Resolution of disputes between parties to a supported decision-making arrangement**

#### **19 Disputes between parties to a supported decision-making arrangement**

- (1) Where there is a dispute between the parties to the supported decision-making arrangement, relating to a decision made under a supported decision-making agreement, disputes can be resolved using the following mechanisms:

- (a) mediation provided by the responsible agency;
- (b) mediation provided by an agent of the responsible agency;
- (c) arbitration;
- (d) an independent panel appointed by the responsible agency.

#### **20 Applications can be made by the parties themselves or select third parties**

- (1) An application to resolve a dispute between the parties to a supported decision-making agreement may be made by:
- (a) the disabled person: or
  - (b) their supporter(s).
- (2) Additionally, an application to resolve a dispute between parties to a supported decision-making arrangement may be made by:
- (a) a person holding Enduring Power of Attorney with respect to any of the parties;

- (b) a person who has been appointed a welfare guardian in accordance with the **Protection of Personal and Property Rights Act 1988**;
  - (c) a lawyer defined in accordance with **Lawyers and Conveyancers Act 2006**;
  - (d) an advocate being a person who has been admitted and enrolled as a barrister and solicitor of the High Court of New Zealand who is entitled to hold a practising certificate but does not hold a valid practising certificate;
  - (e) a health practitioner defined in accordance with **Health Practitioners Competence Assurance Act 2003**;
  - (f) the Disability Commissioner appointed in accordance with the **Human Rights Act 1993** where the Attorney-General consents to the application on behalf of the Crown; or
  - (g) a person or class of persons in accordance with operational policy made by the responsible agency and approved by the Minister under this Act.
- (3) Nothing in this Act permits a whānau or family member or any other person to make an application on behalf of a disabled person to resolve a dispute between the parties to a supported decision-making arrangement.

## **Part 6**

### **Appeals where disputes between parties to a supported decision-making arrangement are resolved by the Family Court**

#### **21 Applications to the Family Court to resolve disputes a tool of last resort**

- (1) Applications to the Family Court are an option of last resort if an option in **section 19(1)** has not adequately resolved the dispute.
- (2) Applications to the Family Court may be made without notice or on notice in accordance with the **Family Court Rules 2002**
- (3) Applications lodged in accordance with this provision do not attract filing fees or incur costs liability unless the application is:
  - (a) frivolous:
  - (b) vexatious:
  - (c) made in bad faith: or
  - (d) made for an improper purpose.

#### **22 Appeals relating to disputes resolved via the Family Court**

- (1) Where a dispute between a disabled person and their supporter(s) is resolved through the Family Court an appeal may be heard in the High Court of New Zealand in accordance with **High Court Rules 2016**.
- (2) Applications made under subsection (1) may be determined *de novo* in accordance with the inherent jurisdiction of the High Court to determine matters.
- (3) Where a dispute is appealed to the High Court in accordance with subsection (1), a further appeal may be made with leave

of the Court of Appeal granted in accordance with **Court of Appeal (Civil) Rules 2005**.

(4) Where a dispute is appealed to the Court of Appeal in accordance with subsection (3), a further appeal may be made with leave of the Supreme Court granted in accordance with **Supreme Court Rules 2004**.

(5) Appeals lodged in accordance with this provision do not attract filing fees or incur costs liability unless:

- (a) frivolous:
- (b) vexatious:
- (c) made in bad faith: or
- (d) made for an improper purpose.

#### **Schedule 1**

#### **Transitional, savings, and related provisions**

#### **Schedule 2**

#### **Consequential amendments to enactments**