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# **Mental Capacity**

Updating New Zealand's Law and Practice



Alison Douglass

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A Report for the New Zealand Law Foundation

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# **Mental Capacity**

## Updating New Zealand's Law and Practice

**Alison Douglass**

**New Zealand Law Foundation  
2014 International Research Fellow**



## Foreword

*Senior Judge Denzil Lush*

Before I became a lawyer I read history as an undergraduate and post-graduate, and have always approached the development of the areas of the law in which I specialise from a chronological perspective. I find it's the best way of understanding the trajectory along which ideas are moving when confronted by various forces.

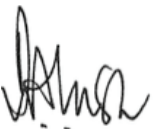
The Court of Protection, of which I was the last Master and the first Senior Judge, has a venerable history dating back to about 1270, but it has never been the quiet backwater that most people assume it is. For the last two hundred years it has been on the cutting-edge of public policy. As Alison Douglass mentions in Chapter 1C of this report, since the great Reform Act 1832, when, to all intents and purposes, Britain first became a modern parliamentary democracy, we have changed our mental capacity legislation at least once in a generation.

England and Wales last looked properly at mental capacity a generation ago, during the early 1990s. In April 1991 the Law Commission published a consultation paper, *Mentally Incapacitated Adults and Decision-Making: An Overview*, which provided an overview of this area of the law, assessed the necessity for reform, and explored the best ways forward. This paper discussed and approved New Zealand's recent legislation, the Protection of Persons and Property Rights Act 1988 (PPPR Act). The Law Commission produced three further consultation papers followed by a final report, *Mental Incapacity*, in 1995. The report contained a draft Mental Incapacity Bill, which was shelved for ten years before finally being enacted as the Mental Capacity Act 2005.

Alison Douglass is right when she says that "The PPPR Act is in need of review". It is nearly thirty years old and needs to be updated to reflect contemporary thinking about disability, human rights and cultural diversity. She is complimentary towards our Mental Capacity Act 2005. It is well-drafted, concise legislation and good to work with. It clearly explains the key concepts of "capacity", and "best interests" (understood as will and preferences), which are central to understanding the law. The Code of Practice has also been pivotal to the implementation of the Act by the wide range of people who use it.

But our legislation too, is in need of review. It is not fully compatible with the Convention on the Rights of Persons with Disabilities, which was adopted by the General Assembly of the United Nations on 13 December 2006, and ratified by New Zealand on 25 September 2008 and the United Kingdom on 8 June 2009. Abolishing adult guardianship law, as suggested by the UN Committee, would be a gigantic leap of faith into uncharted territory and may be one step too far this time around. However, I fully agree with Alison Douglass' finding that substituted and supported decision-making models for mental capacity law can coexist comfortably.

I congratulate Alison Douglass on this report. Her recommendations are easily achievable and, if New Zealand were to implement them, its new legislation would be state-of-the-art, just as the PPPR was a generation ago.



Denzil Lush  
Senior Judge of the Court of Protection  
England and Wales  
4 July 2016



*Professor Geneva Richardson*

The publication of this report is hugely welcome. It provides a most timely and lucid analysis of the dilemmas raised by mental capacity law and practice. Dilemmas that have a very real impact on the lives of many of the most vulnerable of our fellow citizens, on clinical practice and on the law. The report reviews developments in international human rights law and contemporary thinking in ethics. Against the background of the experience of law reform in England and Wales, it analyses the legal position in New Zealand and provides some thoughtful recommendations for change. In the present context of widespread and often polarised debate concerning the law's proper approach to decision-making, the report's thoughtful and considered style is of particular value. In this Foreword I have the space to identify just two of the many difficult issues that Alison Douglass covers with great skill and sensitivity: support and liberty safeguards.

Over the last decade the focus of international human rights has shifted from a concern to protect people with impaired decision-making capacity by making decisions for them, to a desire to place the person at the centre by respecting their decisions and empowering them to exercise their legal rights just like anyone else. Central to this shift in focus has been the notion of support or supported decision-making. In Chapter 2 Alison Douglass gives a wonderfully clear account of the evolution of this "support paradigm" in international human rights and considers how far it is reflected in the law in New Zealand and in England and Wales. Of particular interest, is her analysis of tikanga Māori and her suggestion that New Zealand has a unique opportunity to enrich the wider debate by illustrating the importance of cultural influences.

Since the turn of the century, the law in England and Wales has struggled with the question of how best to safeguard the interests of people who lack mental capacity and who are effectively detained in supported residential or hospital care for their own protection. It is known as the question of the Bournemouth gap after the case where it was first identified. The problem lies in trying to find the precise mechanisms for oversight and review that will provide real protection for an exceptionally vulnerable group of people without over regulation. In recognition of the very real need for proper oversight, we are working on improvements to our current system in England and Wales. In December 2016 the Law Commission is due to publish its report and is likely to recommend simplification of our existing Deprivation of Liberty Safeguards.

In Chapter 3 Alison Douglass reviews the law in England and Wales from the Bournemouth case to the present day. This history is directly linked to the requirements of the European Convention on Human Rights and the attempts in England and Wales to comply with them. But, as Alison Douglass explains, the right to be free from arbitrary detention is not unique to the European Convention. It is both widespread within human rights treaties and well established within the common law. The dilemma raised by the Bournemouth gap is not, therefore, limited to signatories of the European Convention and Alison Douglass concludes that the legal safeguards available in New Zealand are insufficient to plug it. With great insight and sensitivity she draws on the research she conducted in England and Wales to inform her recommendation that Liberty Safeguards be introduced through New Zealand's mental capacity legislation. Her understanding of the law in England and Wales, its origins and, most particularly, its practical implications has enabled Alison Douglass to produce a set of recommendations that are balanced and closely informed by experience elsewhere. The result perfectly reflects the value of careful comparative work and the recommendations that have emerged from it deserve the most serious attention.



Professor Geneva Richardson  
Kings College London  
4 July 2016

## Acknowledgements

Many people have contributed to this report. It would not have been possible to carry out this law reform project without the support and generosity I have received from a large number of people and organisations involved in the ever-expanding field of mental capacity law and practice. The multidisciplinary nature of this report is self-evident in the list of people set out in Appendix E, all of whom have willingly been interviewed or provided advice, resources and comments on various drafts of the report. I wish to thank them all for being so generous with their time and their knowledge.

I also acknowledge the people with impaired capacity, and their families, whom I have represented over the years and the valuable insights they have given related to the challenges they face in their lives.

I would like to thank the following people for hosting me as a visiting researcher while in England: Professor Geneva Richardson, Dickson Poon School of Law, Kings College of London; Senior Judge Denzil Lush, Court of Protection; Alex Ruck Keene, barrister, 39 Essex Street Chambers, London; and Dr Michael Dunn, Ethox Centre, University of Oxford.

In New Zealand, I would like to thank Professor John Dawson, Faculty of Law, University of Otago, for his advice and peer review of this report; Professor Ron Paterson and Justice Collins QC for supporting my fellowship application; Professor John McMillan and colleagues at the Bioethics Centre, University of Otago, for providing an academic base; Dr Greg Young, for our work together and making this a medico-legal project; Jessie Lenagh-Glue, for her able research assistance; Dr Royden Somerville QC and colleagues at Barristers Chambers, for their interest and support; Naomi O'Connor for editorial assistance; and my family, including the cover design by Emma Crampton.

Most of all, I would like to acknowledge the generous support of the New Zealand Law Foundation by awarding me the 2014 international research fellowship. Special thanks to Lynda Hagen and Dianne Gallagher for their practical advice and support.

*Naku te rourou, nau te rourou, ka ora ai te iwi.*<sup>1</sup>

With your basket and my basket the people will flourish.

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<sup>1</sup> Whakatauki (proverb) provided by Janine Kapa-Blair (Kāi Tahu, Kāti Māmoe, Waitaha) Associate Dean – Māori/Manutaki Tuarua - Māori, Otago Business School, University of Otago, sourced from M Mead and N Grove *Ngā Pēpeha a ngā Tipuna* 2003 (Victoria University Press, Wellington).



# Glossary

This glossary is a list of Māori and legal terms used throughout this report. It does not contain technical definitions of these terms, but simply describes how they are used in this report.<sup>2</sup>

**Māori terms** used in this Report have the meanings set out below:

|                      |   |
|----------------------|---|
| Hapū                 | Sub-tribal group.   |
| Hui                  | Gathering, meeting.   |
| Iwi                  | Tribal group.   |
| Kaitiakitanga        | Guardianship and protection based on the Māori world view.  |
| Kawa whakaruruhau    | Cultural safety, recognised in nursing practice as a patient-centred approach to healthcare.  |
| Ngā Kooti Rangatahi  | Youth courts held on marae (traditional meeting place).   |
| Mana                 | Upholding dignity for both personal and whānau.   |
| Pākehā               | New Zealander of European descent.  |
| Tangata whenua       | People of the land. Used to refer to Māori as the indigenous people of New Zealand, or to refer to iwi or hapū associated with a particular geographical area.            |
| Te Ao Māori          | A Māori world-view or the Maori dimension of understanding.   |
| Te Tiriti o Waitangi | The Treaty of Waitangi 1840.  |
| Tikanga Māori        | The customary system of Māori values and practices that have developed over time, sometimes defined in New Zealand legislation as “Māori customary values and practices”. |
| Tino rangatiratanga  | Self-determination, sovereignty, self-government.   |
| Wāhi tapu            | Sacred place, sacred site e.g. a burial ground.   |
| Whakapapa            | Genealogy, ancestral history, descent.  |
| Whakawhanaungatanga  | The process of establishing relationships and relating well to others.  |
| Whānau               | Family group. In the modern context, the term is sometimes used to include friends who may not have any kinship ties to other members.                                    |
| Whanaungatanga       | A relationship, kinship, sense of family connection, through shared experiences of working together which provides a sense of belonging.                                  |

<sup>2</sup> For further explanation of Māori terms see: [www.maoridictionary.co.nz/](http://www.maoridictionary.co.nz/).

**Legal Terms** used in this Report have the meanings set out below:

|  |   |
|--|---|
| Advance directive                        | A written or oral statement by which a person makes provision for healthcare decisions in the event that they become incompetent to make such decisions.  |
| Best interests                           | A standard to guide substitute decision-making that takes into account the will and preferences of the person for whom the decision is being made.  |
| Capacity                                 | A person's ability to make their own decisions, e.g. consent or refuse healthcare. The term "competence" is sometimes used with a similar meaning, as well as "decision-making capacity" and "mental capacity".   |
| Capacity assessment                      | A clinical interview undertaken by a health practitioner for the purpose of deciding whether a person has decision-making capacity in respect of a specific decision(s). The assessment involves examining the mental processes a person goes through in order to arrive at a decision. |
| Common law                               | Law that derives its authority from decisions of the courts (case law) rather than from legislation passed by Parliament.   |
| Court of Protection (COP)                | The specialised English court under the Mental Capacity Act which has jurisdiction over the property, financial affairs and the personal welfare of adults who lack capacity to make decisions for themselves.  |
| Cultural competence                      | A standard of practice for health practitioners that recognises cultural diversity and working in a culturally responsive manner.   |
| Deprivation of Liberty                   | When a person is under continuous supervision and control and is not free to leave, and the person lacks capacity to consent to these arrangements.   |
| Deprivation of Liberty Safeguards (DoLS) | Safeguards introduced under the Mental Capacity Act requiring certain deprivations of liberty to be reviewed and authorised, even if the person is not actively seeking to leave the care arrangement.  |
| Deputy                                   | A substitute decision-maker appointed by the Court of Protection for a person who lacks capacity to make property or personal welfare decisions.  |
| Donor                                    | A person who gives a power of attorney to someone else (an attorney) to make decisions on their behalf.   |
| Enduring Powers of Attorney (EPOA)       | A power of attorney made by a person with capacity which continues to operate, or endures, when the person loses capacity.  |
| Habeas corpus                            | An application for writ of habeas corpus is one of the common law's oldest causes of action that allows a person to challenge the legality of their detention.  |

|                                   |   |
|-----------------------------------|---|
| Impaired decision-making capacity | The inability to make legally binding decisions. The term “diminished capacity” is sometimes used with a similar meaning to reflect that capacity or incapacity is not an absolute concept and is decision specific.  |
| Lasting Powers of Attorney (LPA)  | The Mental Capacity Act equivalent to an enduring power of attorney (EPOA) under the PPPR Act.  |
| Learning disability               | A condition giving rise to learning difficulties, especially when not associated with physical disability, including intellectual disability.   |
| Legal agency                      | The ability to act within the framework of the legal system.  |
| Legal capacity                    | As understood in human rights law, this term refers to a person’s possession of rights and the ability to act on those rights on an equal basis with others. Legal capacity comprises both <i>legal standing</i> and <i>legal agency</i> .  |
| Legal standing                    | Being recognised as a person before the law.  |
| <i>Parens patriae</i>             | The inherent jurisdiction of the High Court to make orders in the best interests of individuals who lack capacity and who are unable to safeguard their own welfare.  |
| Power of Attorney                 | A document in which a person with capacity appoints another person to make nominated decisions for them.  |
| Property Manager                  | A substitute decision-maker appointed by the Family Court under the PPPR Act for a person who lacks capacity in respect of their property and financial affairs.  |
| Public Guardian                   | A statutory office set up under the Mental Capacity Act charged with establishing and maintaining a register of lasting powers of attorney, supervising deputies appointed by the court, and investigating complaints of abuse or referrals regarding adults who lack capacity.       |
| Substitute decision-maker         | A person or the court with legal authority to make decisions on behalf of someone else who is unable to make that decision.   |
| Supported decision-making         | A process of providing support to people whose decision-making ability is impaired, to enable them to make their own decisions.   |
| Undue influence                   | Where there is improper pressure or coercion by one person taking advantage of a position of power over another person who may be regarded as vulnerable. A court may set aside a contract or a will and take into account undue influence in deciding whether a person has capacity. |
| Vulnerable adult                  | In English law this term refers to an adult who has capacity and therefore is not subject to the Mental Capacity Act but who is nevertheless thought to need protection from abusive relationships under the inherent jurisdiction of the High Court.                                 |

|                  |  |
|------------------|--|
| Welfare Guardian | A substitute decision-maker appointed by the Family Court under the PPPR Act for a person who lacks capacity to make care and welfare decisions. |
|------------------|--|

**Abbreviations** used in this Report:

|             |  |
|-------------|--|
| Art         | Article of an international convention                                   |
| COP         | Court of Protection  |
| CRPD        | United Nations Convention on the Rights of Persons with Disabilities     |
| CTO         | Compulsory Treatment Order under the MH(CAT) Act                         |
| DHB         | District Health Board  |
| DoLS        | Deprivations of Liberty Safeguards                                       |
| ECHR        | European Convention on Human Rights 1950                                 |
| ECtHR       | European Court of Human Rights   |
| EPOA        | Enduring Power of Attorney   |
| HDC Code    | Code of Health and Disability Services Consumers' Rights Regulation 1996 |
| ICCPR       | International Covenant on Civil and Political Rights                     |
| IDCCR Act   | Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003    |
| MCA         | Mental Capacity Act 2005 (England and Wales)                             |
| MH(CAT) Act | Mental Health (Compulsory Treatment and Rehabilitation) Act 1992         |
| MHA         | Mental Health Act 1983 (England and Wales)                               |
| NZBORA      | New Zealand Bill of Rights Act 1990                                      |
| OPG         | Office of the Public Guardian (England and Wales)                        |
| PPPR Act    | Protection of Personal and Property Rights Act 1988                      |

# Executive Summary

Mental capacity is concerned with a person's decision-making ability. It focuses on whether the person retains that ability and, if not, who should decide on their behalf and on what basis.

The law affects a wide range of adults with impaired decision-making capacity, who are vulnerable for reasons such as dementia, learning disabilities, mental illness or acquired brain injury. The decisions in question may involve, for example, a younger adult with learning disabilities negotiating choices about their living arrangements; or, an older adult experiencing the onset of dementia who needs to work out their next steps. The increasing prevalence of dementia and Alzheimer's disease means there are now more people with impaired capacity in the community, and, there is a greater need to support them within the health system.

New Zealand's mental capacity law and practice needs updating and reform, as set out in the key findings below. This report provides a template for that reform. It tackles the challenge of how to provide a workable law that best protects and promotes the autonomy of people with impaired capacity. Specific recommendations are made for updating New Zealand's adult guardianship (or incapacity) legislation: the Protection of Personal and Property Rights Act 1988 (PPPR Act). The report also offers guidance to practitioners who are involved in assessing people's capacity, in the form of a toolkit, co-authored with a psychiatrist and an ethicist.

This report is the result of a legal research project undertaken by the writer as the 2014 recipient of the New Zealand Law Foundation International Research Fellowship. The project has involved analysis of relevant New Zealand law plus analysis of the legislative framework provided by the Mental Capacity Act 2005 (for England and Wales) and its associated Code of Practice. Key informants for this research include leading experts, academics and members of the judiciary in the United Kingdom, as well as a wide range of people working in the health and disability sector in New Zealand. A survey of doctors' educational needs was undertaken to inform the toolkit on assessing capacity.

## KEY FINDINGS AND RECOMMENDATIONS

### **The need to modernise the law**

The Protection of Personal and Property Rights Act 1988 (PPPR Act) is out of date and in need of review. The range of people to whom the legislation applies and the social environment in which it operates are now very different from when it was passed at the peak of the era of deinstitutionalisation of large psychiatric facilities. The legislation's weakness lies in its unnecessary complexity and lack of clarity about two essential concepts. These are capacity (or incapacity) – the legal “bright line” determining whether intervention is permitted in people's lives; and best interests – the standard upon which others should make decisions for people with impaired capacity, taking into account their will and preferences.

Importantly, the PPPR Act lacks an adequate mechanism for oversight of its implementation in keeping with the principles underpinning it. There has never been a public body that champions it and educates the public (and professionals working within the health and disability sector) about it. For the legal framework to have more integrity, there needs to be such a body and a clear and precise law that is accessible to all.



## **Supported decision-making – a legal principle taking into account tikanga Māori**

New Zealand lags behind comparable jurisdictions in its commitment to implementing the United Nations Convention on the Rights of Persons with Disabilities (CRPD) within our law. This important human rights convention offers new ways of thinking about capacity, particularly in its emphasis on *supported decision-making* and recognition of universal legal capacity. New Zealand's current legal framework, as with adult guardianship law in other jurisdictions, is based on a process of *substitute decision-making*, whereby mental capacity can be tested, and when found absent another person can make a decision on the person's behalf. However, not only is it important that good judgments are made about whether or not a person has decision-making capacity, there is also an equally important question about whether there are ways in which they can be supported to make their own decisions, and the extent to which the law reflects this aim.

The CRPD provides an opportunity to enhance and improve New Zealand's adult guardianship law by giving priority to supported decision-making as a legal principle. The positive obligation in the CRPD to recognise supportive relationships has synergies with tikanga Māori, where values of individual autonomy and collective decision-making work alongside each other. There is a need for clear statutory guidance about who bears the responsibility, and when, for providing support to people whose decision-making ability is impaired, to enable them to make their own decisions whenever possible.

## **Defining capacity – a single test**

As capacity or incapacity is the “bright line” for deciding whether the law permits intervention in people's lives, it is essential that there is a clear test for it. There are currently several tests for incapacity in the PPPR Act. At the same time there is no definition of incapacity in the Code of Health and Disability Services Consumers' Rights (HDC Code) for the purposes of deciding whether a person can give informed consent to, or refuse, healthcare.

Section 3 of the Mental Capacity Act 2005 (referred to as the English law, or MCA in this report) provides a single legal test, which defines a person as lacking capacity if they are unable to make a decision due to an inability to: understand information relevant to the decision, retain that information, use or weigh the information, or communicate the decision. This test is recommended for adoption in New Zealand.

## **Best interests – a standard for decision-making**

The “best interests” standard recognises that where supported decision-making options have been exhausted, decisions by others need to be made. It can provide a transparent basis for decision-making when a person is unable to fully exercise their legal capacity. It is an essential complement to a supported decision-making framework. As described in English case law, “capacity is not an off-switch to a person's rights and freedoms.”

In New Zealand the phrase “best interests” is found in both the PPPR Act and in Right 7(4) of the HDC Code, but it cannot be regarded as a specified legal standard for decision-making of the kind codified in the MCA. Section 4 of the MCA provides a checklist setting out a series of matters that must be considered when best interests decisions are made on behalf of a person by a substitute decision-maker. These include: the person with impaired capacity participating as much as possible in the process of determining their best interests; their present and past wishes and feelings (or will and

preferences) being recognised; and, taking into account beliefs and values that would likely have influenced their decisions if they had capacity.

## **Major gaps in current New Zealand law**

There are major gaps in New Zealand legislation that need urgent attention and English law provides models which New Zealand could adapt. The most significant development in English law that New Zealand can learn from has been the realisation that the doctrine of *necessity* under the common law – the principle that necessary treatment and care can be provided to a person who lacks capacity in their best interests – which is expressed in New Zealand through Right 7(4) of the HDC Code, provides inadequate legal safeguards for people who lack capacity and who are unable to consent or object to decisions about their healthcare and living arrangements, or to their participation in research.

This report provides a solution to filling these gaps. It recommends establishing a set of “liberty safeguards” where people lacking capacity appear to be detained, and specific legislation concerning research involving people who lack capacity.

## **Liberty safeguards**

Liberty and freedom of movement are values of fundamental importance in our society, yet currently in New Zealand there is no legal process governing loss of liberty for some people who lack capacity. In a broad range of settings, people who lack capacity are detained, under the continuous supervision and control of those caring for them. Yet, in many cases no process is automatically triggered to review the lawfulness or appropriateness of their detention. This is the case, for instance, when people are not under the authority of the Mental Health (Compulsory Treatment and Assessment) Act 1992, or an order made under the PPPR Act, but are detained. Moreover, in most cases, the PPPR Act does not provide an ongoing process for reviewing the detention of people who lack capacity where their detention has been authorised by a person holding an enduring power of attorney (EPOA).

This is the so-called “Bournewood gap” that has led to major, ongoing developments in English law under the MCA and in the European Court of Human Rights, including the establishment of “deprivation of liberty safeguards” (DoLS), to fill the gap.

Revised legislation should therefore provide what might be called “liberty safeguards” to cover the situation of such persons. These safeguards should include: a process to identify, authorise and monitor deprivations of liberty; a code of practice to guide providers and facilities when the safeguards apply; a clear and speedy authorisation process; and the powers and procedures of an independent monitoring body.

## **Research on people who lack capacity**

There is also currently no facility in the law to allow participation in research by adults incapable of giving informed consent. This report argues that ethics committees should be permitted to allow ethically sound research that will secure benefits, provided it adequately protects the interests of the research participants. Here too, the MCA provides a useful legal model for the development of New Zealand’s own statutory protections to guide ethics committees where none currently exist.

Sections 30–34 of the MCA provide lawful authority to carry out research on participants who lack capacity where approved by a research ethics committee, as long as various safeguards are complied with. These safeguards relate both to the characteristics of the research and the participation of individuals in it. Among the numerous protections, the MCA provides that the research must have the potential to benefit the patient without imposing a burden that is disproportionate to that benefit, or be of wider benefit for persons affected by the same or a similar condition, and must impose no more than negligible risk to the patient.

## **A Code of Practice**

The MCA Code of Practice has been pivotal in making the English law accessible. The English experience shows it is vital that the professionals involved with an individual, as well as their informal carers, know what the law is and how to implement it. New Zealand should establish a Code of Practice concurrently with reform of the legislation.

The Toolkit for Assessing Capacity, annexed to this report, is a first step towards providing a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting. It is intended to contribute to such a Code of Practice.

## **A checklist for reform**

The report also identifies other useful aspects of the MCA that could form part of a wider review of New Zealand law. A key factor promoting the success of the English mental capacity legislation has been a national register of lasting powers of attorney (LPAs), which are like enduring powers of attorney (EPOA) in New Zealand. The national register is supported by a public agency – the Office of the Public Guardian – which ensures more effective supervision of attorneys. This report recommends that an electronic register of EPOAs and advance directives should be established in New Zealand.

These measures are now recognised in the United Kingdom as instruments of support and safeguards against abuse that are compliant with article 12 of the CRPD. Another measure is supporting effective access to independent advocates for people with impaired decision-making capacity.

The legal landscape of mental capacity law in New Zealand is fragmented. Reform of the law is urgently needed. It will require a coordinated approach across the social, health and legal sectors. This is likely to get full support from those working within the health and disability sector who want to make positive changes that will benefit people with impaired capacity for decision-making.

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# INTRODUCTION

## Capacity and decision-making

1. Decision-making capacity is a person's ability to make their own decisions based on their personal values and, where possible, to make meaningful choices. It goes to the heart of a person's autonomy and respect for their self-determination. The ability to make a specific decision or take actions that influence a person's life can range from a simple everyday decision about what to have for breakfast, to far-reaching decisions about medical treatment or financial investments. For example, how does a young adult with learning disabilities negotiate choices about their living arrangements, or how do we support an older adult experiencing onset of dementia to decide their next steps? In some instances, where a person is in a coma on life support, for example, the extent of a person's incapacity means they are unable to participate in the decisions made about them. Many people with significant intellectual, cognitive and mental disabilities face substantial or total restrictions in making their own decisions.
2. In a legal context, capacity (sometimes referred to as "competence") is concerned with whether a person's decision-making ability is recognised as valid and, if not, there is the question of who should make decisions on their behalf and on what basis those decisions should be made. When lack of capacity is temporary it may be possible to defer decisions until capacity is restored. But if a person's incapacity is of lasting duration or permanent, or if an urgent decision otherwise needs to be made, there must be some legally recognised procedure whereby necessary decisions can be made by some other person or body. Getting the process for these decisions right is essential to the protection and promotion of an incapacitated person's rights and in determining the legal consequences that follow.
3. New Zealand's current legal framework, as with adult guardianship law in other jurisdictions, is based on a process of "substitute decision-making", whereby mental capacity can be tested, and when found absent another person can make a decision on the person's behalf. This approach is now under scrutiny in light of the United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD). This important human rights convention advocates a shift from substituted to supported models of decision-making for people who lack capacity. Not only is it important that good judgments are made about whether or not a person has decision-making capacity but there is an equally important question about whether there are ways in which they can be supported to make their own decisions, and the extent to which the law reflects this process. How the State best protects and supports people with diminished capacity for decision-making and the tension between protection and autonomy is a key aspect of the law concerning mental capacity.

## Purpose of the report

4. The overall purpose of this report is to bring attention to the need to review and update New Zealand's adult guardianship (or incapacity) legislation: the Protection of Personal and Property Rights Act 1988 (PPPR Act). This is the main legislation governing these questions of capacity and decision-making for others. Such a legislative review is necessary to ensure New Zealand complies with international human rights conventions and keeps pace with contemporary thinking about mental capacity law and practice. New Zealand is well placed to develop its own legal and cultural perspective in this important area of social policy and align itself with reform in other jurisdictions.

5. The basis of the report is an investigation and description of the developments in England and Wales that are ongoing under their Mental Capacity Act 2005 (MCA).<sup>1</sup> There has been a comprehensive overhaul of this area of law in England and Wales with the introduction of the MCA and a Code of Practice for the guidance of health professionals, lawyers and a range of people involved with adult incapacity.
6. This analysis of the English legislation can provide New Zealand with the foundation for modernising our law and practice based on the English experience. I have identified key provisions in the MCA that could be used and adopted into a review of New Zealand's legislation. I also raise some important questions that require closer scrutiny for any future review. A summary of the problems with the PPPR Act that I consider include: a lack of attention to supported decision-making; a gap in procedural safeguards for people who are detained but not subject to the mental health legislation; multiple tests for (in)capacity with no clear definition; the absence of a best interests standard for decision-making; no legislative safeguards regarding research on people who lack capacity; and lack of an accompanying Code of Practice.

## Background

7. New Zealand's PPPR Act was progressive legislation for its time, but the range of people to whom the legislation applies and the social environment in which it operates are now very different. Over the past 28 years there has been a shift in the application of the legislation from people with intellectual disabilities to our aging population, without corresponding developments in the policy supporting it. The increasing prevalence of dementia and Alzheimer's disease is a major factor in the growth in numbers of people with impaired decision-making capacity in the community. This increased burden on providers affects older people's experience with social care and in the health system. Increasingly, cases before the Family Court are concerned with decisions about the living arrangements and the healthcare of older adults who lack capacity, and how those decisions are made and by whom.
8. Capacity is a legal concept that historically has emerged from three main legal areas: property rights, medical law and the law of consent. The three areas inform the concept, but it is only the latter two that form the focus of this report. In that regard, the PPPR Act was enacted in 1988, the year of the report of the Cartwright Inquiry, and predates significant developments of the law relating to patients' rights following the Cartwright Inquiry and leading to the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Services Consumers' Rights (the HDC Code).<sup>2</sup> The HDC Code is now a central part of New Zealand's health and disability regulatory framework, as are the Commissioner's opinions on the standards of care and treatment by health and disability providers. The interface between the PPPR Act and the HDC Code for people who lack capacity is not well understood, yet it is very important for understanding how and by whom decisions can be made for people who lack capacity – whether for everyday health and welfare decisions through to more profound decisions at the end of life.
9. In 2008 New Zealand ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD). The CRPD, as well as the European Convention on Human Rights,

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<sup>1</sup> The Mental Capacity Act 2005 (England and Wales), was passed into law by the United Kingdom Parliament on 7 April 2005. The Act only applies to England and Wales and is referred to in this report as the "MCA". The term "English law" is intended to refer to both England and Wales. The MCA also gives effect in England and Wales to the Convention on the International Protection of Adults signed at The Hague on 13 January 2000: MCA, Preamble, s 63 and Schedule 3.

<sup>2</sup> The Code of Health and Disability Services Consumers' Rights is referred to as the HDC Code in this report to distinguish it from the MCA Code of Practice.



(ECHR), has had a major impact on interpretation of mental capacity law concepts internationally, particularly in the United Kingdom, raising important issues around the role of the law in ensuring equality before the law for those people with mental disabilities who lack capacity.

## Law reform in England and Wales

10. Despite the MCA being described as a visionary piece of legislation, a 2014 post-legislation scrutiny report from the House of Lords (House of Lords report)<sup>3</sup> described the MCA as not fit for purpose, and revealed significant problems with the implementation of the law and its interface with mental health law. The key problem that has emerged in England concerns how the law should regulate the liberties of people who lack capacity to consent to their care and treatment arrangements, and who are not receiving compulsory mental health treatment under the Mental Health Act (MHA). A crucial decision in the European Court of Human Rights (ECtHR)<sup>4</sup> overturned a decision of the House of Lords,<sup>5</sup> and exposed a gap in legal protections and held that healthcare providers could not rely on the common law doctrine of necessity to justify detention of “informal” patients (known as the “Bournewood gap”).
11. The law was amended in 2007 and procedural safeguards, called “Deprivation of Liberty Safeguards” (DoLS), were subsequently introduced in England. However, the DoLS have been described in the House of Lords report as an “administrative nightmare” and “fundamentally flawed”.<sup>6</sup> Meanwhile, a decision of the Supreme Court, *Cheshire West*,<sup>7</sup> broadened the ambit of the DoLS scheme beyond hospitals and care homes so that its procedural requirements must be followed even, in some cases, where people are living in the community, thereby placing pressure on the English government to revise the scheme. The Law Commission of England and Wales (Law Commission) is currently consulting on replacing the DoLS scheme and draft legislation will be available by the end of 2016.
12. The reform of the MCA to ensure it is compliant with international human rights conventions is current and ongoing. It provides a vast pool of information and experience for New Zealand to draw upon, critically consider, and so use to progress our own law and related practice. The proposed revised DoLS regime in England raises a fundamental question for New Zealand: in the absence of procedural safeguards where people are detained in these circumstances, is there a significant gap in our law to protect those people who lack capacity where the State is involved with the provision of health and social care? And if so, how should New Zealand fill this gap through a review of the law?
13. These world-leading developments in England, including the first decisions under the MCA from the Supreme Court, provide valuable insights into the lessons learned in trying to embed a new law and corresponding practice. In view of the English experience, it is timely to promote discussion on possible areas for law reform and on the formulation of standards for best practice for New Zealand.

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<sup>3</sup> House of Lords Select Committee *Mental Capacity Act 2005: post-legislative scrutiny* (TSO, London, 13 March 2014).

<sup>4</sup> *HL v United Kingdom* (2004) 40 EHRR 32.

<sup>5</sup> *R v Bournewood Community and Mental Health NHS Trust, Ex p. L* [1999] 1 AC 458.

<sup>6</sup> House of Lords, above n 3 at summary and [256] – [259].

<sup>7</sup> *P v Cheshire West and Chester Council and P v Surrey County Council* [2014] UKSC 19, [2014] AC 896.



## Objectives of the report

14. This report has three objectives aimed at assisting with the improvement of New Zealand law and practice. Firstly, the report provides a high level analysis of contemporary thinking about mental capacity law to inform potential law reform in New Zealand. It considers the impact of CRPD and the paradigm shift from substitute to supported decision-making regimes, and what supported decision-making might mean for New Zealand from a legal, ethical and cultural perspective. A wider review would require an analysis of developments in other Commonwealth jurisdictions, particularly in Australia and Canada, and a closer consideration of how supported decision-making could be integrated into law reform.
15. Secondly, there is a legal analysis of specific provisions of the English MCA that could be adopted and incorporated in an update of New Zealand law. The report compares key legal aspects of the MCA with the PPPR Act and the HDC Code<sup>8</sup> including: the core principles that underpin the English and the New Zealand legislation; the legal tests for capacity; the role of “best interests” as a standard for decision-making; and the specific provisions of the English law concerning research on people who lack capacity.<sup>9</sup> More generally, some specific features of the MCA that are absent in New Zealand legislation are highlighted as worthy of attention in a review of our law.<sup>10</sup>
16. Thirdly, the report takes a multi-disciplinary first step towards a Code of Practice by providing guidance for doctors assessing capacity in the form of a “toolkit”. In New Zealand, there is no specific guidance for medical or legal practitioners and others in this field, yet incapacity permeates all aspects of law and healthcare practice. The possibility of a wider review of the PPPR Act means it would be premature to draft a complex Code of Practice at this stage, however, a clear indication is given of what such a Code of Practice might look like.
17. An important part of this project has been to collaborate with Dr Greg Young, consultant psychiatrist, and Professor John McMillan, bioethicist. We have consulted with medical colleagues and conducted a survey of doctors, including general practitioners (GPs), about the guidance and education needed to promote good practice in the clinical assessment of capacity. This work aims to contribute to professional education and provide guidance for health practitioners and others who work with people who lack or have impaired capacity. We hope the guidance will be taken forward by the medical colleges and other healthcare professions.<sup>11</sup> Professional education of lawyers is equally important. In England, there has been a move by the Law Society to develop an accreditation programme for lawyers who specialise in capacity law and who appear in the specialised jurisdiction of the Court of Protection.<sup>12</sup>

## Method

18. The Bioethics Centre and Faculty of Law, University of Otago, provided an academic base for this research. Support for the project was received from a wide range of key informants

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<sup>8</sup> The Code of Health and Disability Services Consumers' Rights (the HDC Code).

<sup>9</sup> The key provisions of the Mental Capacity Act 2005 (England and Wales) referred to in this report are set out in Appendix C.

<sup>10</sup> See Chapter I Overview of the MCA and Chapter 8 Conclusion and Checklist for Reform.

<sup>11</sup> The New Zealand Nurses Organisation supported this project. Nurses and other health practitioners are interested in training and education in the assessment of capacity.

<sup>12</sup> S Miles, “Time to accredit mental capacity work” [2015] Eld LJ 3. See also, *British Medical Association and the Law Society, Assessment of Mental Capacity, A Practical Guide for Doctors and Lawyers*, 2010, Third Edition (The Law Society, London).

and stakeholder organisations in New Zealand.<sup>13</sup> This is primarily a legal research project that combines law, medicine and ethics in addressing the key research question: *how is the current New Zealand legal process working and what changes are needed to the law governing mental capacity in New Zealand to ensure consistency with contemporary thinking and best practice standards?* The project has involved an analysis of the relevant New Zealand law and a comparative analysis of issues identified for law reform from the Mental Capacity Act 2005 (England and Wales) and Code of Practice.

19. The New Zealand Law Foundation 2014 international research fellowship enabled me to visit and consult leading experts and academics in Singapore, England, Scotland, and Ireland to inform the research and recommendations in this report.<sup>14</sup> During April to June 2015, I was a visiting researcher and hosted at the Centre for Biomedical Ethics at the National University of Singapore (Professor Alastair Campbell), the Dickson Poon School of Law, Kings College of London (Professor Genevra Richardson) and the Ethox Centre Oxford University, (Dr Michael Dunn). In England I interviewed members of the judiciary who have delivered leading judgments under the mental capacity law including: Lady Brenda Hale, Deputy President of the Supreme Court of the United Kingdom; Mr Justice Charles, Deputy President of the Court of Protection; and Senior Judge Denzil Lush of the Court of Protection. Ethical approval for the purpose of formal interviews was obtained from the Human Ethics Committee, University of Otago.<sup>15</sup>
20. Informants in England and Scotland included medical law and ethics experts (both academics and practising lawyers), Law Commissioners, lawyers in the offices of the Official Solicitor, and the Public Guardian, as well as psychiatrists and Chairs of research ethics committees. Alex Ruck Keene, a leading barrister in this field of law and consultant to the Law Commission on current law reform of the MCA, has provided extensive resources and made an invaluable contribution to this report.
21. A mixed methods research methodology and thematic analysis was used for the survey of doctors undertaken with medical and ethics colleagues to inform the Toolkit for Assessing Capacity.<sup>16</sup> Preliminary findings of the research were disseminated through seminars in Singapore, England and New Zealand.<sup>17</sup>

## Legal practice and bioethics perspective

22. I take full responsibility for the synthesis and analysis of the work presented here. I come to this topic as a practising lawyer with a background in bioethics. To inform this report, I have drawn on my experience in cases where I have represented people who lack capacity and/or their families under the PPPR Act and under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act), as well as my involvement with clinical ethics and medical education. In doing so, I provide examples in real-life practice and cases to illustrate some of the challenges that are encountered. I have also drawn on the wisdom

<sup>13</sup> A list of people and organisations that provided letters of support and references for my application to the New Zealand Law Foundation as well as people interviewed in the United Kingdom is set out in Appendix E.

<sup>14</sup> I also attended the Capacity Australia conference in Sydney, Australia, in November 2015.

<sup>15</sup> Ethics Reference D15/105, 23 March 2015. A limitation of this research is that while I was able to interview a number of key informants whilst visiting England, in the timeframe and resources available to me I have undertaken only a limited number of interviews in New Zealand.

<sup>16</sup> The findings of this survey entitled, "Assessing capacity: what do you know and what would help you do it better?" are discussed in Chapter 7 Code of Practice. Ethical approval was obtained from the Human Ethics Committee, University of Otago D15/213.

<sup>17</sup> The draft toolkit for assessing capacity was presented at a workshop on Capacity Assessments in Auckland on 24 February 2016 attended by 24 health practitioners, mainly geriatricians and psychiatrists, as well as social workers. The toolkit was circulated widely for consultation among doctors and some lawyers as described in Chapter 7 Code of Practice.

and experience shared by colleagues including lawyers, judges, doctors, nurses and social workers in New Zealand and overseas while I was carrying out this research.

23. Bioethics provides a multi-disciplinary approach to critical thinking about moral issues in medicine and healthcare. It is important to recognise that often decisions about a person's capacity may involve multiple professionals and others involved in a person's care, in situations where decisions are not clear cut, and may be decisions not only about whether a person lacks capacity but also whether any intervention is necessary. Recognition of these challenges reinforces to me the need to have a legal framework supportive and respectful of the people subject to them. The process of applying the law and the experiences of people affected may be as important as the outcome itself. To this end, the current movement towards therapeutic jurisprudence in New Zealand<sup>18</sup> has a lot to offer in the design and application of revised mental capacity law, especially for embedding supported decision-making into practice.

### Scope of the report

24. After 28 years New Zealand's PPPR Act is in need of review. However, a full review is beyond the scope of this report. Indeed it would be impossible for a sole barrister to review all aspects of the PPPR Act and undertake a complete comparative analysis with English and international law. So, by necessity, there are some important limitations in my approach to a review of the law, as noted below.
25. The interface between mental capacity law and mental health law is complex. While I raise important questions about the rights of people who lack capacity and who are not subject to the compulsory treatment under mental health legislation, this report does not extend to a review of the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH(CAT) Act). The focus of this project is on health and disability law and practice as it applies to adults (not children) with impaired capacity in general, whether or not they are under the MH(CAT) Act. Equally, while issues of capacity for financial and property decision-making and to make a will often overlap with the care and welfare of the person who lacks capacity, that kind of decision-making is not a focus of the report. It is more concerned with decisions about personal care. With regard to testamentary capacity, there is a solid body of common law jurisprudence that has developed in England and New Zealand<sup>19</sup> and I do not consider there is a need to codify these aspects of common law into legislation.
26. The recent restructuring of the Family Court with its focus on child law and domestic violence has had the effect of taking the spotlight off other areas of the Family Court's wide jurisdiction, including mental health law and the operation of the PPPR Act. The problems encountered with the increase of self-representation in courts generally, as identified by Justice Winklemann,<sup>20</sup> compound the current limitations of the legislation designed to protect the interests of vulnerable adults who are often caught up in complex family relationships and are ill-equipped to initiate or progress resolution in court proceedings.<sup>21</sup>

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<sup>18</sup> W Brookbanks (ed) *Therapeutic Jurisprudence: New Zealand Perspectives*, 2015 (Thomson Reuters, Wellington).

<sup>19</sup> Recent New Zealand examples include: *Woodward v Smith* [2009] NZCA 215; *Moleta v McFadzean* [2013] NZHC 2694, Collins J; and *Green v Green* [2015] NZHC 1216, Winklemann J.

<sup>20</sup> Justice Winklemann, "The New Zealand Law Foundation Ethel Benjamin Commemorative Address 2014, Access to Justice - Who Needs Lawyers?" (2014) 13 Otago Law Review 229.

<sup>21</sup> Access to justice through the Court system by people with intellectual disabilities has recently been the subject of a New Zealand Law Foundation research project: B Mirfin-Veitch, S Gates, K Diesfield, and others *Developing a more responsive legal system for people with intellectual disability in New Zealand* (Donald Beasley Institute, Dunedin, 2014).

27. This report is concerned mainly with substantive law and the conceptual thinking that underpins it. An important follow-on of a review of the law will be the very practical challenges of implementing and embedding workable laws *in practice*. It will require substantial input from the legal profession as well as health professionals, social workers and the many people involved in the health and disability sector who are working with and supporting people with impaired capacity for decision-making, and their families, on a daily basis. The incredible support I received for this project from a wide range of people and professions is testament to the fact there many committed and dedicated people working in the health and disability sector who see the need to act *now* to improve the experiences of people with impaired capacity within the law and practice in New Zealand.

## Structure of the report

28. **Chapter 1: Setting the Context – An Overview of New Zealand and English Mental Capacity Law** is an introduction to capacity as a legal concept. It outlines the history, context and an overview of the legal landscape of capacity law, and of related law reform to date in New Zealand and in the United Kingdom and Ireland.
29. **Chapter 2: Supported Decision-making** describes the impact and challenges of the United Nations Convention on the Rights of Persons with Disabilities (CRPD). It draws threads together between: supported decision-making as understood in human rights law; legal principles; an understanding of autonomy in ethics; and New Zealand’s own cultural dimension, incorporating tikanga Māori. While the CRPD has challenged thinking about substitute decision-making within adult guardianship law, there is no need to abolish the PPPR Act in New Zealand; rather, the CRPD provides an opportunity to enhance and improve the law by giving priority to supported decision-making as a legal principle, within the decision-making mechanisms of the legislation itself. English case law examples show that supported and substitute decision-making can coexist.
30. **Chapter 3: Liberty Safeguards** explains the developments in England following important decisions of the European Court of Human Rights and the United Kingdom Supreme Court, and following the creation of a special set of procedural safeguards for people who lack capacity but are detained, known as Deprivation of Liberty Safeguards (DoLS). This chapter identifies the existence of the so-called “Bournewood gap” in the New Zealand context and considers its implications within the international human rights context. It recommends further steps to protect the liberties of people with diminished capacity who are not subject to, or do not have the benefit of, the safeguards contained in the mental health legislation.
31. **Chapter 4: Defining Capacity** identifies the problems and complexity of the multiple tests for capacity found in the PPPR Act and the lack of a definition of incapacity within the HDC Code for the purposes of informed consent or refusal of healthcare. It recommends that a single legal test should be adopted as set out in section 3 of the MCA.
32. **Chapter 5: Best Interests – A Standard for Decision-making** explains that New Zealand has no statutory standard governing subsequent decision-making where a person lacks capacity, and our jurisdiction is reliant on an outdated understanding of “best interests” developed in case law. Understanding supported decision-making as a continuum creates an imperative for having a transparent decision-making process where substitute decisions are made, involving the person with diminished capacity where possible. A standard, modelled on section 4 of the MCA, with wrap-around provisions for supported decision-making, is recommended.
33. **Chapter 6: Research on People who Lack Capacity** examines sections 30–34 of the MCA, there being no similar protections for research participants in New Zealand who are unable to consent to health and disability research. It provides examples of research

undertaken in both England and New Zealand and considers how these MCA provisions could be adopted within the New Zealand ethical review framework.

34. **Chapter 7: Code of Practice** advocates a Code of Practice for New Zealand, as subordinate legislation to revised mental capacity law. It describes collaborative work undertaken with medical and bioethics colleagues regarding the clinical assessment of capacity. A Toolkit for Assessing Capacity is annexed to this report.
35. **Chapter 8: Conclusion – A Checklist for Reform** summarises the key recommendations within the scope of this report and highlights additional areas of the PPPR Act that need attention in a review of the law.

# Chapter 1

## **Setting the Context**

# Chapter 1: Setting the Context – an Overview of New Zealand and English Mental Capacity Law

Chapter 1 is in three sections:

- A. Setting the context and understanding the legal concept of capacity.
- B. An overview of mental capacity law in New Zealand, with a particular focus on the jurisdiction under the Protection of Personal and Property Rights Act 1988.
- C. An overview of the historical origins of the Mental Capacity Act (England and Wales) 2005, the law reform that produced it, and the jurisdiction it creates.

## 1A: THE LEGAL CONCEPT OF CAPACITY

### Understanding capacity

- 1.1 Decision-making capacity (or simply “capacity”) refers to individuals’ ability to make particular decisions or take actions that influence their lives. In a legal context, capacity is concerned with whether a person’s decision-making ability is recognised as valid and, if not, who should make decisions on their behalf and on what basis should such substitute decisions be made.
- 1.2 Capacity or incapacity is the “bright line” determining whether the law permits intervention in people’s lives, and on what basis.<sup>24</sup> Those who lack capacity are deemed unable to make decisions for themselves thereby justifying intervention in their lives. Decisions are then made by others based on an assessment of what is in the best interests of the person lacking capacity. Those with capacity are free to make decisions about their lives, even decisions that may be regarded as unwise, subject to the constraints of the law.<sup>25</sup> Concerns may still arise as to whether an individual is competent to make a particular decision, or is merely acquiescing under pressure from others (referred to in law as “undue influence”), and concerns may exist as to the extent to which such influence affects their capacity for decision-making.
- 1.3 Capacity is decision and time specific. Lack of capacity may arise for a variety of reasons and may be partial or total. When lack of capacity is temporary or fluctuating it may be possible to defer decisions until capacity is restored. But if it is of lasting duration or permanent, or if an urgent decision otherwise needs to be made, there must be some legally recognised procedure whereby necessary decisions can be made by some other person or body.<sup>26</sup>

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<sup>24</sup> M Donnelly “A Legal Overview” in C Foster, J Herring and I Doron (eds) *Law and Ethics of Dementia* (Hart Publishing, Oxford and Portland, 2014) 271 at 278.

<sup>25</sup> I Goold and J Herring “Palgrave Great Debates in Law” in J Herring (ed) *Medical Law and Ethics* (5<sup>th</sup> edition, Oxford University Press, Oxford, 2014).

<sup>26</sup> G Ashton *Mental Capacity Law and Practice* (2<sup>nd</sup> ed, Jordans, Bristol, 2012) at 2.



## Conditions affecting capacity

- 1.4 Decision-making capacity can affect people of all ages and arises in a variety of social environments and healthcare settings. A range of conditions and disabilities can impair capacity; the most common of these, in the context of community care of older people, is dementia.<sup>27</sup> It is difficult to predict from the stage of dementia whether a person retains or has lost the capacity to make a particular decision. Measures of dementia severity correspond only approximately with capacity. It is important to recognise that different types of dementia may impair capacity in different ways. The most common form of dementia, Alzheimer's disease, affects memory in the first instance, whilst dementia secondary to vascular disease of the brain tends to impact on frontal and subcortical systems, causing problems with higher cognitive functions.
- 1.5 Delirium is a disorder that is seen more commonly in residential care and hospital settings and is characterised by a relatively sudden decline in cognitive function, or fluctuations in such function, and impaired attention. It occurs in the context of physical illness or toxic states and may represent the first time a capacity assessment is required. Head injury (or acquired brain injury) and intellectual disability (in England referred to as learning disability) are usually chronic, stable states where it is more likely the person's abilities will be understood and the focus should be on optimising the person's capacity.
- 1.6 Mental incapacity is not the same as mental disability. Mental disability, including mental illnesses such as depression, anxiety and psychosis, can impair capacity in a number of ways, including by causing forgetfulness or reducing the person's ability to think through complex issues, through inattention, or by causing a bias in reasoning to the point of impairing capacity. In psychiatry, there are approaches for making self-binding directives (the Ulysses Contract) by which patients with bipolar affective disorder commit themselves to treatment during episodes of mania, even if unwilling. For certain individuals, this can seem the most rational way to deal with their fluctuating condition.<sup>28</sup>
- 1.7 The prevalence of patients who lack capacity in New Zealand hospitals and care facilities is unknown. A recent review of 58 international studies of capacity found 45% of patients in psychiatric settings and 34% of patients in general medical settings lacked decision-making capacity.<sup>29</sup> Two million people in the UK are estimated to lack capacity through illness.<sup>30</sup> There is nothing to suggest that the proportion of people that lack capacity throughout the healthcare institutions in New Zealand is dissimilar; nearly a third of patients may be regarded as not having legal capacity for decision-making.

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<sup>27</sup> Dr Greg Young, consultant psychiatrist, Capital and Coast District Health Board.

<sup>28</sup> G Owen and T Gergel "Fluctuating Capacity and Advanced Decision Making in Bipolar Affective Disorder – Self-Binding Directives and Self Determination" (2015) 40 Int J Law Psychiatry 92 at 95.

<sup>29</sup> P Lepping, T Stanly and J Turner "Systematic review on the prevalence of lack of capacity in medical and psychiatric settings" (2015) 15 Clin Med (JRCF) 337. The study looked at the average proportion of patients and showed that psychiatric patients with psychosis, dementia and mania are more likely to lack decision-making capacity than those with depression or personality disorder. Likewise, in general medical settings, patients with learning disabilities, delirium and neurological disease were most likely to lack capacity.

<sup>30</sup> T Nicholson, W Cutler and M Hotopf "Assessing mental capacity: the Mental Capacity Act" (2008) 336 BMJ 322 at 322.



## Assessment of capacity

- 1.8 Deciding whether a person has the capacity or competence to make particular decisions is a legal, and in some cases judicial, determination, informed by medical evidence.<sup>31</sup> Capacity can be difficult to assess, may not be clear-cut and involves value judgments about people's preferences and beliefs. To deprive people who are capable of making their own decisions of the right to do so would be an abuse, yet failure to recognise lack of capacity results in continuing vulnerability.
- 1.9 The careful assessment of the individual's capacity to make particular decisions is crucial. This turns on an understanding of the kinds of decisions to be made, the legal thresholds for capacity, and a judgment of the point at which a person is considered incompetent or lacking capacity. Getting the process for these decisions right is essential to the protection of a person's rights and in determining the legal consequences that follow.

## Legal capacity

- 1.10 The term "legal capacity" recognises the legal right to exercise rights and legal status.<sup>32</sup> Legal capacity has a particular meaning in the context of international conventions such as the Convention on the Rights of Persons with Disabilities (CRPD), where it is understood to refer to a person's possession of rights and the ability to act on those rights on an equal basis with others without discrimination on the grounds of disability. The right to legal capacity includes, for example, having the right to choose where and with whom you wish to live, and most importantly, having those choices respected. The concept is relevant to all areas of an individual's life, including the exercise of legal capacity to enter a contract, to marry, to vote, to deal with property and to make personal life, personal care and healthcare decisions.<sup>33</sup>
- 1.11 Under New Zealand law, people who lack capacity and are subject to the adult guardianship legislation (the PPPR Act) may be regarded as having the same legal rights as others except to the extent their rights are expressly limited by the PPPR Act or other legal principles.<sup>34</sup>
- 1.12 "Legal capacity" is distinct from "mental capacity", the latter being the cognitive ability considered necessary to exercise one's legal rights. In discussing mental capacity, the terms "decision-making capacity" or "competence" are often used in the clinical context<sup>35</sup> as a descriptor of the mental or cognitive characteristics considered necessary to exercise legal capacity.<sup>36</sup> Despite the potential to confuse legal capacity (a legal concept) and mental

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<sup>31</sup> In *McFadzean v Moleta* [2013] NZHC 1601, a case involving the assessment of a person's testamentary capacity, Collins J observed at [7]: "Unfortunately, while the law and medicine intersect, the two disciplines are not synchronised".

<sup>32</sup> R Firmston and A Ruck Keene *The International Protection of Adults* (Oxford Press, Oxford, 2015) at 67.

<sup>33</sup> M Bach and L Kerzner "A new paradigm for protecting autonomy" (2014) Ontario Law Commission <http://repositoriocdpd.net:8080/handle/123456789/449> at 16.

<sup>34</sup> Protection of Personal and Property Rights Act 1988. Section 4 provides that the legal capacity of a person who may be subject to the Court's jurisdiction and in respect of whom an order is made may be regarded as having the same legal rights as anyone else unless those rights are expressly limited, varied, or taken away under the Act or some other Act.

<sup>35</sup> These terms also get confused with the legal concept of capacity. C Duncan, psychiatrist Capital and Coast District Health Board, "The Red Flags and Pitfalls of Assessing Capacity", presentation to Bioethics Centre, University of Otago, 7 September 2015. Interview with G Owen, psychiatrist, Kings' College London (A Douglass, London, 22 April 2015). In the United States, "competence" is generally used as the legal term: Buchanan Brock *Deciding for Others, The Ethics of Surrogate Decision Making* (Cambridge University Press, 1990).

<sup>36</sup> The Protection of Personal and Property Rights Act 1988 uses "capacity" and "competence" interchangeably and the Code of Rights refers exclusively to "competence". For ease of reference I use the terms "capacity" or "mental capacity".

capacity (the cognitive abilities required), the term “mental capacity” is the one used in the legislation in the United Kingdom.<sup>37</sup>

## 1B: OVERVIEW OF MENTAL CAPACITY LAW IN NEW ZEALAND

### The Protection of Personal and Property Rights Act 1988 (PPPR Act) – background

- 1.13 In New Zealand, the PPPR Act is the guardianship law for adults who may permanently or temporarily lack capacity. The PPPR Act is the main legislation that applies to people who lack capacity and is a vitally important piece of legislation. It has played a key role over the last 28 years by recognising the vulnerability of adults with impaired capacity and the concern of the State to “protect and promote” the rights of those who cannot manage their own affairs.
- 1.14 The passing of the PPPR Act in 1988 responded to the needs of the community at a time when there was no guardianship law in place for adults who lacked capacity. The PPPR Act mainly grew out of the need to protect adults with intellectual disabilities in the community during deinstitutionalisation of psychiatric institutions in the 1980s, and was intended to remove them from under the control of “the murky stream of mental health law”.<sup>38</sup> Until the introduction of this Act in 1988, it was not possible to provide guardianship of people over 20 and, as a result, people over that age were often committed under the Mental Health Act 1969 (MHA 1969).
- 1.15 The PPPR Act created a new and expanded jurisdiction for the Family Court and in doing so relieved the High Court of a significant part of its first instance jurisdiction for people who lack capacity. The legislation adopted the social philosophy of the United Nations Declaration on the Rights of Mentally Retarded Persons 1971. It reformed aspects of the law governing both personal and property rights, and repealed the prior legislation dealing with administration of the property of people who lacked capacity: that is, the Aged and Infirm Persons Protection Act 1912 and property-related aspects of the MHA 1969.<sup>39</sup>
- 1.16 Early decisions of the Family Court under the PPPR Act, notably decisions by the late Judge Inglis QC, were largely concerned with testing the waters of the new jurisdiction, including the tests for incapacity and the power to authorise treatment decisions,<sup>40</sup> as well as the basis upon which people with intellectual disabilities could live in the community with an appointed substitute decision-maker.<sup>41</sup> With the changes in the social environment and burgeoning older

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<sup>37</sup> Mental Capacity Act 2005 (England and Wales), Mental Capacity Bill (currently before the Northern Ireland Parliament), Adults with Incapacity Act 2000 (Scotland) and the Supported Decision-Making (Capacity) Act 2015 in the Republic of Ireland. Note also the Mental Capacity Act 2010 (Charter 177A) Singapore which almost entirely adopts the English legislation.

<sup>38</sup> AC Hughes-Johnson “The Protection of Personal and Property Rights Act 1988: An analysis, commentary and answers to likely questions”. (A seminar by the New Zealand Law Society, October 1988) at 11.

<sup>39</sup> Australian legislation, the Victorian Adult Guardianship Act 1987, provided the adult guardianship law model for the Protection of Personal and Property Rights Act 1988.

<sup>40</sup> In *Re S (Shock Treatment)* [1992] NZFLR 208 Judge Twaddle declined to order shock treatment therapy for a person with intellectual disability and instead ordered that they live in a community trust home and receive supported rehabilitative therapy.

<sup>41</sup> In *Re E* [1992] 9 FRNZ 393, the Court declined jurisdiction to make a residential care order for a 28-year-old with severe physical disability, as she did not “wholly” lack the capacity to communicate, and she clearly had the capacity to understand the nature of her decision. In *Re “Tony”* [1990] 5 NZFLR 609 Judge Inglis declined jurisdiction to make welfare guardian and property orders in respect of a man with schizophrenia who lived in a home described as a “protected environment”, where it was only a

population, many of the more recent cases before the Family Court are concerned with older adults who lack capacity.<sup>42</sup>

- 1.17 As a matter of social policy, a consistent theme emerges: the most significant decision for people who lack capacity, young or old, is where they are to live. All other decisions, healthcare, welfare, financial and property are important, but tend to be secondary to their living arrangements – whether supported in the community or in more institutionalised models of care and support.

## The PPPR Act – an overview

- 1.18 The PPPR Act and its Regulations provide the mechanisms for the making and use of an enduring power of attorney (EPOA), which a person can execute in advance to authorise another person to make decisions about their care, welfare or property if they later become mentally incapable of making those decisions.<sup>43</sup> It authorises the Family Court to appoint substitute decision-makers, known as welfare guardians and property managers, and make personal orders that can be tailored for specific interventions, such as treatment decisions, therapeutic services or living arrangements.<sup>44</sup>
- 1.19 The primary objectives of the PPPR Act are to make the least restrictive intervention and to maximise a person's decision-making capacity where possible.<sup>45</sup> Another principle that underpins the Act is the presumption of competence: a person must be assumed to have capacity unless proved otherwise.<sup>46</sup> A limitation on any intervention by the court is the principle that people are entitled to make imprudent or unwise decisions so long as they are considered to have the capacity to do so.<sup>47</sup> As such, the Act has good bones: it is intended to be enabling and supportive of people who lack capacity, not unnecessarily restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or participate in decision-making, as far as they are able to do so.
- 1.20 The Family Court is assigned this protective jurisdiction but it is a creature of statute and its jurisdiction in matters involving mental capacity is limited in scope by the legislation. There is a right of appeal and the ability to transfer Family Court proceedings to the High Court in certain circumstances.<sup>48</sup>
- 1.21 The High Court's inherent *parens patriae* jurisdiction in relation to vulnerable adults operates as a safety net to provide a remedy beyond the scope of the statutory scheme.<sup>49</sup> This

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hypothetical possibility he might leave. *Re A and Others* [1993] 10 FRNZ 537, Judge Inglis made an order allowing for the joint appointment of the care centre and a parent for each of five long-term institutionalised individuals with intellectual disability.

<sup>42</sup> See for example, *Wilson v Wilson* [2015] NZFLR 104, where a personal order was necessary to mitigate perceived undue influence for an elderly man with partial incapacity. In *Hutt Valley District Health Board v MJP* [2012] NZFLR 458 the Court held that it had jurisdiction to order an elderly woman with dementia to reside in a care facility despite her vehement objections.

<sup>43</sup> Changes to Part 9 of the PPPR Act are discussed below. An EPOA is a grant by a donor when they are mentally capable to another person (the donee) which allows that person to make welfare and/or property decisions when they become mentally incapable or lack capacity for decision-making.

<sup>44</sup> There are statutory limitations on substitute decision-makers' powers; Protection of Personal and Property Rights Act 1988, ss 18 and 98.

<sup>45</sup> Protection of Personal and Property Rights Act 1988, ss 8(a) and 8(b).

<sup>46</sup> Protection of Personal and Property Rights Act 1988, s 5.

<sup>47</sup> Protection of Personal and Property Rights Act 1988, s 8(3).

<sup>48</sup> Protection of Personal and Property Rights Act 1988, s 83; Family Courts Act 1980 s 14.

<sup>49</sup> *Carrington v Carrington* (2014) NZHC 869 Katz J at [103]. The *parens patriae* jurisdiction is expressly contemplated by s 114 of the PPPR Act. Section 17 Judicature Act 1908 applies to "Persons and

jurisdiction is rarely used but has some application, where, for example, there are limitations on the powers of an appointed welfare guardian,<sup>50</sup> or where disputes arise about end of life decision-making for fully incapacitated persons.<sup>51</sup>

- 1.22 The PPPR Act contemplates a two-stage procedure in which the Court must first determine whether there is jurisdiction and then determine the degree of intervention, if any, that is necessary.<sup>52</sup> In *KR v MR*, Miller J held:<sup>53</sup>

The question of capacity to make the decision that is the subject of an application (under the Act) is a threshold question and must be considered in every case; because jurisdiction to make an order ... depends on it.

- 1.23 The Act provides no single test for incapacity, which makes it complex legislation to follow and apply.<sup>54</sup> In general terms, however, the Act says a person lacks capacity if they do not understand the nature or cannot foresee the consequences of decisions, or are unable to communicate them.<sup>55</sup> As the Family Court can only intervene where a person lacks capacity, this concept of capacity and how it is assessed and considered by the court is central to the workings of the Act.

- 1.24 Although often assumed to be relevant, the further principle of the person's "best interests" is neither a primary objective of the PPPR Act nor defined in it. Substitute decision-makers appointed by a court order or by an EPOA are charged with making decisions in the person's "best interests and welfare", but there is no clear direction for the court to do so. The legislative intent in this area was discussed in an early decision by a full Court which warned against adopting:<sup>56</sup>

... a narrow, legalistic approach to the Act where the welfare and best interests of the person the subject of the application are part of a hidden rather than stated objective.

- 1.25 The absence of a best interests standard and lack of clarity as to its significance (a "hidden objective") has led to a confused understanding of best interest's role within the legislation and risks conflating matters of best interests with the legal tests for capacity.<sup>57</sup>
- 1.26 The Act provides a number of safeguards for the person who is subject to the Act (referred to as the "subject person"), including ensuring their right to be heard and the appointment of a

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estates of mentally disordered persons and persons of unsound mind". See also *Dawson v Keesing* [2004] 23 FRNZ 493.

<sup>50</sup> Protection of Personal and Property Rights Act 1988, s 18, Limitation on the powers of welfare guardians. In *Re W* [1994] 3 NZLR 600 the High Court held that it had inherent jurisdiction to declare W's marriage void on the basis of absence of consent through lack of intellectual capacity.

<sup>51</sup> The High Court's jurisdiction is used where there is withdrawal of life support from incapacitated patients in coma or persistent vegetative state (PVS). The continued existence in New Zealand of the Court's *parens patriae* jurisdiction in this context was accepted in *Auckland Area Health Board v A-G* [1993] 1 NZLR 235, and reaffirmed by the High Court in *Re W* [1994] 3 NZLR 600 and *Re G* [1997] 2 NZLR 201.

<sup>52</sup> *KR v MR* [2004] 2 NZLR 847 at [72]. Also reported as *X v Y (Mental Health: Sterilisation)* [2004] 23 FRNZ 475.

<sup>53</sup> *KR v MR*, above n 52 at [25].

<sup>54</sup> Protection of Personal and Property Rights Act 1988, ss 12(5)(b), 18(3), 97A(2) and 98A(2). See Chapter 4 Defining Capacity.

<sup>55</sup> The factors relevant to deciding capacity are the ability to: communicate choice; understand the relevant information; manipulate the information and appreciate the situation and its consequences (*KR v MR* at [51]).

<sup>56</sup> *In the Matter of A* [1996] 2 NZLR 354 at 356.

<sup>57</sup> See Chapter 5 Best Interests.

lawyer to represent them in court proceedings.<sup>58</sup> Where there is a conflict between the views of the subject person and others' views about their welfare and best interests, the lawyer is required to discuss the issues with them as far as possible, and attempt to resolve the conflict with that person, but also required to put before the court all relevant information from a "best interests point of view".<sup>59</sup> The court can make an interim personal order under urgency without the person being served but can only do so after a lawyer for the subject person is appointed and is in a position to be heard.<sup>60</sup> People subject to personal orders (including the appointment of a welfare guardian) have the right of review of the order and/or decisions by the welfare guardian at any time during the currency of the order. Other than appointing the lawyer at the time the order is made, these safeguards are not often used.<sup>61</sup>

- 1.27 Enforcing court orders against third parties to protect the person with diminished capacity, who may be vulnerable to undue influence from others, is a vexed issue.<sup>62</sup> There have been cases involving incapacitated persons where (unsuccessful) habeas corpus arguments have been considered, based on allegations that a person subject to care and welfare orders has been unlawfully deprived of their liberty by their appointed welfare guardian.<sup>63</sup> There are a number of decisions where the court has creatively used supplementary orders under s10(4) as a means of enforcing the main order but the extent to which this provision can be used as a method of enforcement is unclear and unsatisfactory.<sup>64</sup>
- 1.28 The court has limited ability to take contempt action against third parties who unduly influence the subject person and interfere with court orders designed to meet their needs. In *JMG (by her Litigation Guardian AMB) v CCS Disability Action Inc*,<sup>65</sup> JMG and her mother interfered with the provision of disability services to JCE and a tenancy order was made in the Family Court to facilitate access to these services. The Family Court Judge expressed concern that JCE was being manipulated and controlled by his partner JMG and her mother, contrary to his rights under the CRPD.<sup>66</sup> A report from the court-appointed psychologist "compellingly" confirmed JCE's need for supported decision-making from both the disability service and his

<sup>58</sup> Protection of Personal and Property Rights Act 1988, s 65. An application to the Court activates the appointment of a lawyer to represent the "subject person" under s 65 and to report to the Court, among other things, whether the medical evidence supports the Court having jurisdiction to intervene.

<sup>59</sup> Ministry of Justice "Guidelines for subject person appointed under PPPR Act, Principal Family Court Judge" (24 March 2011) at [www.justice.govt.nz](http://www.justice.govt.nz). Where there is a conflict between the wishes of the subject person and what might be considered in a person's best interests the Court may appoint a lawyer to assist the Court under s 65A.

<sup>60</sup> *Public Trust v MJD* [2013] NZFC 2706.

<sup>61</sup> Protection of Personal and Property Rights Act 1988, ss 86-89. The maximum term of personal orders is three and sometimes five years.

<sup>62</sup> See for example, *JMG (by her Litigation Guardian AMB) v CCS Disability Action Inc* [2012] NZFLR 369, Miller J.

<sup>63</sup> *E v E*, Wellington HC, CIV-2009-485-2335, 20 November 2009. Simon France J. See also *JDEB & ors v JAB & RHB and MAB* [2013] NZFC 4234, Judge O'Dwyer, following an unsuccessful writ of habeas corpus in the High Court.

<sup>64</sup> Examples include: setting in place a procedure on notice to a landlord to make the subject person a party to a tenancy agreement so that support services could be provided to him, *JMG v CCS Disability Action*, above n 62; facilitating attendance at a hospital so that the mental health patient who lacked capacity to consent to treatment could receive cancer treatment (*CD v JMT* [2012] NZFC 10147), and transporting a person with severe alcohol dependence to a residential facility to avoid "absconding" *Loli v MWY* FAM-2009-004-001877, 13 Jan 2011 NZFC Auckland 2011.

<sup>65</sup> Above n 62.

<sup>66</sup> Above n 62 at [8]. Counsel to assist was appointed by the High Court to consider its *parens patriae* jurisdiction with regard to JMG who lacked capacity to litigate, but was not subject to any orders under the PPPR Act and who was considered vulnerable.



parents.<sup>67</sup> In an unsuccessful appeal to the High Court, Ronald Young J warned JMG's mother, DH, of the risk of contempt action and that:<sup>68</sup>

... only for so long can a Court tolerate the flouting of its orders. Given that JMG admittedly is not able to play a full part in the litigation, and so is unlikely to be sanctioned for breach, attention must turn for enforcement purposes to those who act on her behalf and by their own admission possess the ability to influence her decisions. I find that DH is in that position.

## The PPPR Act – law reform

- 1.29 The PPPR Act may be regarded as progressive legislation and in some respects ahead of its time. It was enacted in 1988, the year of the report of the Cartwright Inquiry, and pre-dates significant developments of the law relating to patients' rights following the Cartwright Inquiry and leading passage of the Health and Disability Commissioner Act 1994 and the HDC Code. Despite these developments, there has been surprisingly little attention or review of the operation of the PPPR Act or the principles that underpin it.
- 1.30 In 2001, the Law Commission published a report following a discussion paper entitled, *Misuse of Enduring Powers of Attorney*.<sup>69</sup> The discussion paper was triggered by concerns expressed by Age Concern about the lack of protection and adequate safeguards for those whom the statute was designed to assist, and by increasing awareness of elder abuse in the community. The subsequent report of the Law Commission identified problems with the way in which the initial grants of enduring powers of attorney (EPOA) were made, such as the donor feeling under duress, failure to explain the implications of the powers given to the attorney, or a donor lacking the capacity to understand what they were signing.
- 1.31 Part 9 of the PPPR Act was subsequently amended by the PPPR Amendment Act 2007. Prior to this amendment, the issue of a donor's capacity was not addressed in the legislation; one of the most significant changes was the introduction of a presumption of donor competence.<sup>70</sup>
- 1.32 In the response to a 2013 request for "feedback" on the 2007 amendments from the Office for Senior Citizens of the Ministry of Social Development, the New Zealand Law Society reported that these changes have been problematic and difficult to implement. But the Law Society recommended that the changes to EPOAs made in 2007 should be considered in the context of a review of the PPPR Act as a whole.<sup>71</sup>
- 1.33 The Law Society advised that the increase in cost to meet the new legal requirements has had the effect of dissuading some clients from appointing attorneys; the new legal threshold for determining whether a person lacks capacity for the purpose of activating an EPOA is different from the threshold for the appointment of a welfare guardian by the court, adding to

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<sup>67</sup> *JMG (by her Litigation Guardian AMB) v CCS Disability Action Inc* (stay application) Wellington HC, (27 May 2011) Ronald Young J at [20].

<sup>68</sup> Above n 67 at [52].

<sup>69</sup> Law Commission *Misuse of Enduring Powers of Attorney* (NZLCR, Wellington, 2001).

<sup>70</sup> Protection of Personal and Property Rights Act 1988, s 93B. See also B Atkin "Schizophrenia and Protection Orders" (1990) NZLJ 204 and discussion on the Part 9 Amendments in S Bell *Protection of Personal and Property Rights Act & Analysis* (Thomson Reuters, Auckland, 2012) at 36.

<sup>71</sup> Letter from Chris Moore (President, New Zealand Law Society) to Claire Kibblewhite (Ministry of Social Development Office for Senior Citizens) regarding the 2007 Amendments to Enduring Powers of Attorney Provisions (5 July 2013) [https://www.lawsociety.org.nz/data/assets/pdf\\_file/0011/69194/MSD-EPAs-5-7-13.pdf](https://www.lawsociety.org.nz/data/assets/pdf_file/0011/69194/MSD-EPAs-5-7-13.pdf).

the complexity of using the Act; the different processes create confusion for people using them and complexities for health professionals making capacity assessments; and there is no independent oversight of the medical certification process required to certify a donor's mental incapacity when the power is activated, such as an appointed lawyer to represent a person where court orders are proposed.<sup>72</sup>

- 1.34 The Law Society also highlighted the lack of guidance for health practitioners concerning EPOAs. A similar gap exists regarding court proceedings under the Act, particularly about what the courts require of medical, psychiatric and psychological reports from clinicians and healthcare providers, to ensure there are consistent procedures for capacity assessment and a common approach to the essential question of whether the court has jurisdiction.
- 1.35 In June 2014, the Minister for Senior Citizens reported to Parliament on a review of the effectiveness of the 2007 amendments.<sup>73</sup> That report recommended an information campaign to improve legal and health professionals' knowledge about their responsibilities and sources of information and support, but rejected the Law Society's submission for a national register of EPOAs.
- 1.36 In 2015, an amendment to the PPPR Act was introduced to make minor and technical changes to the EPOA provisions and the witnessing requirements.<sup>74</sup> The 2015 amendments reflect the ongoing concern expressed by the New Zealand Law Society that the witnessing requirements in the 2007 amendments more than doubled the legal costs of making EPOAs and resulted in fewer EPOAs being made.<sup>75</sup> These changes will provide neither system-wide mechanisms to protect those vulnerable to abuse through incapacity, nor take account of New Zealand's human rights obligations under international treaties.<sup>76</sup>

## Family Court statistics

- 1.37 There is no comprehensive data published on Family Court proceedings concerning the PPPR Act. The Ministry of Justice published a general review of the Family Court in 2009. This showed a generally upward trend in numbers of applications for welfare guardians and property management orders and a relatively stable number of applications for personal orders. In 2011 the Family Court Public Consultation Paper looked at the total number of PPPR applications between 2004 and 2010. While there was some fluctuation, on average there were approximately 2500 applications annually.<sup>77</sup> During the 2006–2007 period, 40

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<sup>72</sup> Ibid.

<sup>73</sup> The report was required by s 108AAB of the PPPR Act 1988. *Report of the Minister for Senior Citizens on the Review of the Amendments to the Protection of Personal and Property Rights Act 1988 made by the Protection of Personal and Property Rights Amendment Act 2007*, Ministry of Social Development, June 2014.

<sup>74</sup> Statutes Amendment Bill 2015, Part 21, introduced into Parliament in November 2015.

<sup>75</sup> Submission by the New Zealand Law Society on the Statutes Amendment Bill: Part 21 (29/01/2016), [http://www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0008/98207/Statutes-Amendment-Bill,-Part-21-29-1-16.pdf](http://www.lawsociety.org.nz/_data/assets/pdf_file/0008/98207/Statutes-Amendment-Bill,-Part-21-29-1-16.pdf) at [2.7]. The Law Society submitted that the effect of the 2007 changes to the PPPR Act was "an increasing number of people who, for reasons of cost, have not made their own decision about who should be their substituted decision-maker if they lose their mental capacity".

<sup>76</sup> See Chapter 3 Supported Decision-making, and the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

<sup>77</sup> Ministry of Justice *Reviewing the Family Court: a public consultation paper* (Ministry of Justice, Wellington, 2011) at 81.

percent of cases involved people over the age of 60, showing the weighting of proceedings toward older people, as this group only represents 17 percent of the general population.<sup>78</sup>

- 1.38 Appendix A is a review of reported Family Court cases under the PPPR Act from 1988, and unreported cases from 2010 to 2015, where the decision expressly refers to the subject person's capacity in ascertaining whether the court had jurisdiction (that is, that the person lacks capacity and there is a basis for the court to intervene).<sup>79</sup> The review is not a comprehensive evaluation of the PPPR Act but a snapshot of how decisions on jurisdiction are made.<sup>80</sup> Nor do these judgments tell the full, or even partial, story behind the many applications before the court that may have been resolved – not by way of judicial hearing and formal decision – but either “on the papers”, by way of unreported interim decision, court minutes, or judicial or settlement conferences.<sup>81</sup>
- 1.39 There have been few cases where a person's capacity (and the jurisdiction of the court) have been contested by way of a defended hearing and even fewer where the person has given sworn or oral evidence. When judges are concerned that there is insufficient evidence to determine jurisdiction, they sometimes order further medical reports, and the outcome of these cases is often not known. The review identified 41 cases (30% of the total) where the subject person participated in a defended hearing, and another two cases where the decision records that the judge talked to the person on an unsworn basis. Of these, there were 19 cases where the person gave evidence contesting incapacity.<sup>82</sup> The requirement that the person subject to an application should be present, unless formally excused under s76, does not appear to be rigorously followed.

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<sup>78</sup> Ministry of Justice *Family Court Statistics in New Zealand in 2006 and 2007* (Ministry of Justice, Wellington, 2009) at 57.

<sup>79</sup> Unreported Family Court judgments were accessed from the Ministry of Justice but many of these judgments are not on any electronic database. While the process for deciding which judgments will be published aims to become more transparent, there is no “hard data” that can be statistically validated. Furthermore, even where capacity may have been contested, the case may have been resolved through the court-appointed lawyer's involvement or for reasons unknown.

<sup>80</sup> The review was limited by the small sample size and what information can be ascertained from the combined reported (41) and unreported (94) cases.

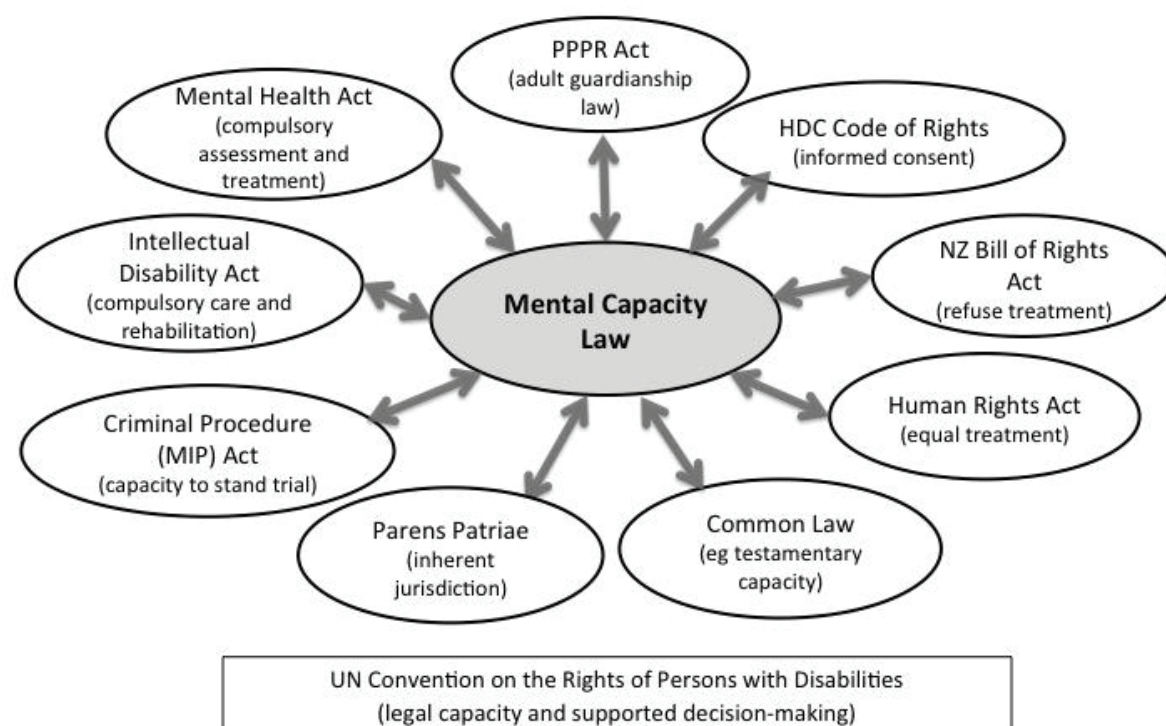
<sup>81</sup> Even where capacity may have been contested, the case may have been resolved through the involvement of the court-appointed lawyer.

<sup>82</sup> There are few reports of judges visiting the person in their care setting or on a hospital ward, an approach used for reviews and hearings under the MH(CAT) Act. It is common and appropriate for judges to engage in informal discussion with the subject person and to encourage them to participate, where possible.



## Mental capacity law in New Zealand

Figure 1: Mental Capacity Law in New Zealand



- 1.40 In addition to the adult guardianship law under the PPPR Act, there is also common law (case law), and other legislation that is relevant to people who lack capacity. The common law provides legal tests of capacity in respect to a range of situations and transactions, including: capacity to make a will (testamentary capacity); capacity to make a gift; capacity to enter into a contract; capacity to vote; and capacity to consent in the context of the criminal law, and particularly of sexual offences. The legal system recognises capacity to litigate and the role of a litigation guardian to represent those who lack capacity to instruct a lawyer.<sup>83</sup>
- 1.41 There is a wide range of legislation in New Zealand where a person's capacity for decision-making has an important bearing on the operation of the law and people's access to it. The Accident Compensation Act 2001, for example, provides cover for claimants who may have suffered a traumatic brain injury and who may be either incapable or in need of support to access and manage their entitlements to rehabilitation and compensation.<sup>84</sup> There is a clear gap in the law for young persons between the ages of 17 and 18 who lack capacity and who are in need of care and protection, as custody orders under the Children, Young Persons and

<sup>83</sup> Judicature Act 1908, Schedule 2 High Court Rules, Part 4 subpart 7; and District Court Rules 2014, Part 4 subpart 7.

<sup>84</sup> A recent report on claimants' experiences with the ACC appeal process does not address for example, problems ACC encounters in case management for claimants with diminished capacity for decision-making during the claims process: *Acclaim Otago Understanding the Problem: An analysis of ACC appeals process to identify barriers to access to justice for injured New Zealanders* (Acclaim Otago and University of Otago Legal Issues Centre, Dunedin, 2015).

their Families Act 1989 expire when the person attains the age of 17, and the PPPR Act generally does not apply until a person turns 18.<sup>85</sup> There are criminal offences that recognise sexual exploitation<sup>86</sup> or neglect or abuse of vulnerable adults who may lack capacity.<sup>87</sup> Protection orders have been made where there has been domestic violence towards people who lack capacity.<sup>88</sup> Some legislation that governs what can and cannot be done for people lacking capacity may be viewed as paternalistic and out-dated.<sup>89</sup>

- 1.42 There is legislation with compulsory powers under mental health law and the law for people with intellectual disabilities who commit criminal offences that affects people who lack capacity.<sup>90</sup>

### **Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH(CAT) Act)**

- 1.43 The MH(CAT) Act provides a civil commitment process under which people who are considered to be “mentally disordered” may be placed under compulsory assessment and treatment. The MH(CAT) Act’s criteria for compulsion are not based on capacity but on a special legal test of “mental disorder” (based on the presence of discrete mental phenomena) and a serious threat of harm to self or others, or seriously diminished capacity to care for self.
- 1.44 Mental health legislation and mental capacity legislation have very different aims. The MH(CAT) Act provides powers for the detention and treatment of a person with a mental disorder, if necessary without that person’s consent. It is primarily concerned with the reduction of risk, both to the patient and to others, using compulsion where necessary. By contrast, mental capacity legislation, such as the PPPR Act, is concerned with enabling and supporting people to make their own decisions where possible. Whilst there is a need to protect people, the legislation is not intended to provide coercive powers (which can also be a problem, as discussed above).
- 1.45 The interface between the compulsory powers under the MH(CAT) Act and the PPPR Act is not entirely clear and sometimes the court has a choice over which Act to use. In *Canterbury District Health Board v MH*,<sup>91</sup> the Family Court confirmed that the MH(CAT) Act cannot be used to keep a patient with dementia in hospital against her wishes for the purpose of providing for the patient’s physical, not mental, healthcare, despite such care not being available at her home.

<sup>85</sup> Children, Young Person and Their Families (CPYF) Act 1989, s 108; Protection of Personal and Property Rights Act 1988, s 6(2). See AJ Cooke “State Responsibility for Children in Care” (PhD Thesis, University of Otago, 2014) <http://hdl.handle.net/10523/4796>; Personal communication from L Harrison, (former Barrister) (Dunedin, 2015).

<sup>86</sup> Crimes Act 1961, s 138.

<sup>87</sup> Crimes Amendment Act (No 3) 2011, ss 151, 195 and 195A create criminal liability for failure to provide necessities of life, or protect from ill treatment or injury to a child or a vulnerable adult. Section 2 of the Crimes Act 1961 defines a “vulnerable adult” as a person who is unable, by reason of detention, age, sickness, mental impairment, or any other cause to withdraw himself or herself from the care and charge of another. The definition of “vulnerable adult” does not specify an age threshold, but it is presumed to refer to persons over 18.

<sup>88</sup> Domestic Violence Act 1995, s 11. See for example, *AR and Anor v RDH FC* Christchurch FAM-2008-009-002784.

<sup>89</sup> Contraception Sterilisation and Abortion Act 1977 and the Alcohol and Drug Addiction Act 1966. This latter legislation is due to be repealed: Substance Addiction (Compulsory Assessment and Treatment) Bill 2015.

<sup>90</sup> Mental Capacity (Compulsory Care and Treatment) Act 1992; Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003; Criminal Procedure (Mentally Impaired Persons) Act 2003.

<sup>91</sup> [2012] NZFC 4432, Judge C P Somerville.

- 1.46 Under the MH(CAT) Act, mental capacity is largely irrelevant, as the Act does not specifically require a compulsory patient's capacity to consent to their psychiatric treatment to be formally assessed at intervals, or to be taken into account in deciding on their detention. A study has shown that of those patients under compulsory treatment in New Zealand, many of whom are under community treatment orders, a significant proportion – perhaps as many as two-thirds of involuntary patients – might retain the capacity to agree with, or refuse, their proposed course of psychiatric treatment. Therefore, potentially only one-third of involuntary patients do not have capacity for decision-making affecting their care.<sup>92</sup>
- 1.47 The New Zealand mental health system has an emphasis on informal care. The safeguards available to patients subject to compulsory powers, such as the watchdog role of the District Inspector, do not apply to informal patients who are not subject to the MH(CAT) Act. To date, there has been no consideration by the New Zealand Government of the English law reforms concerning the position of compliant people who lack capacity and do not object to their detention in care facilities, who are effectively deprived of their liberty but are not under the MH(CAT) Act.<sup>93</sup>
- 1.48 There is a complex interface between these two legislative regimes, particularly where an individual lacks capacity to consent to or refuse treatment. Problems include: the extent to which the proper treatment is for a “mental disorder” and would therefore be authorised under the MH(CAT) Act, or treatment is for a general medical condition that is being provided on a “voluntary” basis; how the presumption of competence operates in these circumstances; and whether the provisions of the PPPR Act – rather than the MH(ACT) Act – should apply, since it is likely to be less restrictive of a person's human rights and freedom of action.

### **Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act)**

- 1.49 The IDCCR Act is unique to New Zealand.<sup>94</sup> It provides for compulsory care and rehabilitation within the health system of persons with an intellectual disability who commit criminal offences and who are no longer subject to the criminal justice system (referred to as “care recipients” or “special care recipients”). There are two principal pathways into the care regime under this Act. The most common route is a court order upon being found unfit to stand trial, found not guilty on the basis of insanity, or convicted of an imprisonable offence.<sup>95</sup> Rarely, a prison manager will activate the second route, by applying for the making of a care order under s 29 of the IDCCR Act.<sup>96</sup>
- 1.50 Eligibility is determined by application of a test based on assessed IQ and social functioning. The Act defines an intellectual disability as a permanent impairment that has manifested during the developmental period of the person and results in significantly sub-average general

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<sup>92</sup> J Skipworth “Should Involuntary Patients with Capacity Have the Right to Refuse Treatment” in J Dawson and K Gledhill *New Zealand's Mental Health Act in Practice* (VUP, Wellington, 2013) at 218. See also Lepping, Stanly and Turner, above n 29 and discussed in Chapter 1A of this report.

<sup>93</sup> See Chapter 3 – Liberty Safeguards, for discussion of the interface between MH(CAT) Act and the PPPR Act.

<sup>94</sup> See W Brookbanks “Further Reform of Unfitness to Stand Trial” in Dawson and Gledhill, above n 92 at 321.

<sup>95</sup> Criminal Procedure (Mentally Impaired Persons) Act 2003, s 24(2)(b) (detention in a secure facility of a defendant found unfit to stand trial or insane as a special care recipient) and s 25(1)(b) (orders declaring a defendant found unfit to stand trial or insane as a care recipient to receive care under a care programme).

<sup>96</sup> Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 29 allows a manager of a prison (in the case of a serving prisoner) or the Director of Area Mental Health Services (DAHMS) (in the case of a former special patient) to apply for an assessment if there are reasonable grounds for believing that the person has an intellectual disability.

intelligence (IQ less than 70) and significant deficits in adaptive functioning.<sup>97</sup> When a compulsory care order is made, the judge must specify the term of that order, with a maximum of three years.<sup>98</sup> The court reviews the care and rehabilitation plan at six months but only has the power to recommend changes. Care recipients are legally represented at some stages of the proceedings and there are six-monthly clinical reviews. However, there is no ongoing independent scrutiny of whether the care recipient continues to meet the criteria of intellectual disability.<sup>99</sup> Specialist assessors are designated by the Director-General of Health and are qualified health and disability professionals. Their role is to assess the level of risk posed by the individual and to try and predict the likelihood of future behaviour.<sup>100</sup>

- 1.51 Exiting the compulsory care regime can be difficult, particularly for care recipients who are not likely to rehabilitate. As intellectual disability is defined in the Act as a permanent status, the ongoing detention of people under the regime presents a conundrum: as there is no guarantee that rehabilitation will necessarily reduce risk factors, there is potential for an indefinite sentencing regime with disproportionately severe infringements on an individual's liberty. In *RIDCA Central v VM*,<sup>101</sup> the Court of Appeal held the principle of proportionality required there to be a balance between the need to protect the community and the liberty interests of the care recipient in extending a compulsory care order. The Court concluded that any "order must be the least coercive and restrictive option available".
- 1.52 While the expressed aim of the IDCCR Act is to limit the detention period to a maximum of three years, in reality the failure of the legislature to define criteria limiting the courts' ability to extend such orders has repeatedly resulted in a de facto position whereby compulsory care risks becoming indefinite preventive detention.<sup>102</sup> In a dissenting opinion in the application for leave to appeal in *VM*, Baragwanath J highlighted the "difficult balance" between protecting the community from low level offending by individuals, who because of intellectual disability are not legally responsible, and the human rights of such people.<sup>103</sup>

<sup>97</sup> Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 7(1); s 7(5) states that the developmental period of a person "generally finishes when the person turns 18 years". Evidence now shows that cognitive development takes place at least until the mid-20s, and is dependent on a person's developmental environment. Often care recipients who have been raised in a developmentally deprived circumstances will show significant improvement in cognitive functioning. This has already resulted in some care recipients no longer meeting the criteria of intellectual disability and under s 8(2), the IDCCR Act does not apply. Email from Anthony Duncan (National Advisor to the IDCCR Act, Ministry of Health) to A Douglass regarding the IDCCR Act (7 October 2015).

<sup>98</sup> Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003, s 46.

<sup>99</sup> For example, in a case where the writer represented the care recipient, the initial assessment undertaken in the criminal court was based on reports 12 years prior and there had not been a reassessment of the care recipient's adaptive functioning for the purpose of bringing the person under the IDCCR Act regime.

<sup>100</sup> Ministry of Health *Guidelines for the Role and Function of Specialist Assessors under the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003* (Ministry of Health, Wellington, 2004) at 5–6. These guidelines have not been reviewed since originally published and the measures for predictive risk have not been translated into the New Zealand context.

<sup>101</sup> *Regional Intellectual Disability Care Agency Central v VM* [2012] BCL 398; [2011] NZCA 659 at [92(a)]. The appeal upheld a High Court decision, *VM v RIDCA Central (Regional Intellectual Disability Care Agency)* HC Wellington CIV-2009-485-541 (Simon France J). In both *VM* and another High Court appeal, *L v Regional Intellectual Disability Care Agency Central* HC Wellington CIV-2010-485-1279 (Mallon J), the care recipients were women in their mid-forties who had assaulted and threatened violence against their caregivers. Prior to being under compulsory care orders they had largely lived in the community with supported care.

<sup>102</sup> W Brookbanks "Managing the challenges and protecting the rights of intellectually disabled offenders" in B McSherry and I Freckleton (eds) *Coercive Care: Rights, Law and Policy* (Routledge, Abington Oxon, 2013) at 219.

<sup>103</sup> *RIDCA Central (Regional Intellectual Disability Care Agency) v VM* [2010] NZCA 213 at [16].

- 1.53 The IDCCR Act has not been reviewed since it was passed. When it was first introduced, a significant funding pool was allocated from disability resources and there is more potential in disability services for the provision of individualised care packages than under the MH(CAT) Act.<sup>104</sup> In a recent study of people with intellectual disability, lawyers, among others, voiced concern that some of the procedural aspects of the IDCCR Act impacted on access to justice by care recipients.<sup>105</sup> The Act also does not cover the unknown number of prisoners who may lack capacity through intellectual disabilities or those who have suffered brain injuries and were convicted prior to the Act coming into force.<sup>106</sup>

### **The Code of Health and Disability Services Consumers' Rights (the HDC Code)**

- 1.54 The HDC Code is now a central part of New Zealand's health and disability regulatory framework. The interface between the PPPR Act and the HDC Code for people who lack capacity is not well understood. The PPPR Act is essentially about incapacity and the formal procedures for the appointment of substitute decision-makers for adults who lack capacity in a wide range of situations, some of which cross over into healthcare delivery. In contrast, the aim of the HDC Code is to place patients at the heart of healthcare decision-making and, where possible, without a substitute decision-maker. It is concerned with informal procedures for ensuring that a patient is capable of giving consent or refusal to a healthcare procedure and the standards to be adhered to by health professionals and providers of healthcare. Decisions are made every day by, or for, people in the health system who may have diminished capacity to give informed consent to healthcare procedures.
- 1.55 Capacity to make an informed choice and give informed consent to healthcare procedures is a key component to ensuring that the rights of patients are protected under Rights 5, 6 and 7 of the HDC Code.<sup>107</sup> Decision-making capacity may become an issue in the healthcare setting where a person's ability to give informed consent is in question because of their refusal, for example, to consent to a treatment decision or to undergo a needs assessment for the purpose of assessing the level of ongoing care they require.<sup>108</sup>
- 1.56 Unlike the PPPR Act, the HDC Code does not define the concept of capacity but it does recognise the common law presumption of competence (Right 7(2)) and that those with impaired capacity should participate as much as possible in decisions regarding their healthcare (Right 7(3)).<sup>109</sup> The presumption of competence may often be entirely appropriate in the context of legal proceedings but it does not provide an adequate framework for clinical

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<sup>104</sup> Email from Anthony Duncan, National Advisor in the IDCCR Act 2003 regarding the IDCCR Act (7 October 2015).

<sup>105</sup> Mirfin-Veitch, Gates, Diesfeld and others, above n 21 at viii. This study recommended that there needed to be mandatory training for individuals representing clients under the IDCCR Act.

<sup>106</sup> Justice S Glazebrook "Foreword" in Dawson and Gledhill, above n 92 at 9. It is estimated that some 64 percent of prisoners have experienced a head injury. The extent of prisoners having impaired decision-making capacity is unknown. For example, the writer represented a prisoner before the Parole Board with dual disabilities (mental health and intellectual disabilities) who was subject to an indefinite sentence of periodic detention but whose disabilities only became apparent when in prison.

<sup>107</sup> The HDC Code is set out in Appendix C. Right 5 is the right to effective communication; Right 6 is the right to be fully informed; and Right 7 is the right to make an informed choice and give informed consent. Section 11 of the New Zealand Bill of Rights Act 1990 provides that everyone has the right to refuse to undergo medical treatment. The word "everyone" has been interpreted to mean every person who has capacity to consent: *Re S* [1992] 1 NZLR 363, although this interpretation would now be called in question with the modern notion of legal capacity under the CRPD.

<sup>108</sup> In *Bedford* [2013] NZCorC Decision No. 43/2013, the Coroner commented that no capacity assessment was undertaken when the patient (under the MH(CAT) Act) with Korsakoff's dementia refused insertion of a nasogastric tube for a hernia repair operation and subsequently died.

<sup>109</sup> The terms "capacity" (PPPR Act) and "competence" (HDC Code) are used interchangeably in the relevant legislation.



practice. The discussion on the presumption has tended to proceed without consideration of a clinician's duty of care towards a patient, particularly the circumstances in which there is a duty to assess the patient's competence.<sup>110</sup>

- 1.57 There is no formal requirement or procedure for assessing a person's competence under the HDC Code for the purposes of giving or refusing informed consent under Right 7. Nevertheless, the Health and Disability Commissioner has found a GP to be in breach of the HDC Code for failing to assess the capacity of a woman with Huntington's disease who was living in isolation and squalor in her own home over a 10-year period. The doctor was found to be in breach of Right 4 in that she failed to provide adequate care and support for her patient.<sup>111</sup>
- 1.58 If a person is assessed as lacking capacity and there is no substitute decision-maker, Right 7(4) of the Code of Rights provides legal justification for providing health and disability services without consent. The right is based on the common law principle or doctrine of necessity and justifies healthcare providers acting in what they consider to be the person's best interests. It largely provides a defence for the health professional, rather than a safeguard for the patient, and does not provide a good basis for making important decisions with ongoing consequences for people who lack capacity.<sup>112</sup>
- 1.59 Providers of services for the elderly, including District Health Boards (DHBs) and rest home proprietors, often seem confused about the requirements under the PPPR Act. They often require prospective residents to appoint an attorney for personal care and welfare decisions (a HealthCERT audit requirement), whether or not the resident wishes to do so, resulting in a facility insisting on the appointment of an EPOA as a requirement for admission. There is also inconsistency on how Right 7(4) of the HDC Code is applied.<sup>113</sup>
- 1.60 Unlike in England, the prominence of capacity issues in health and disability law has not led to a comprehensive review of adult guardianship law in New Zealand. One of the consequences of the "no-fault" accident compensation scheme and its statutory bar against suing health professionals for medical negligence causing "personal injuries" is the absence in New Zealand of litigation, and associated case law, contesting and clarifying capacity to consent. Yet capacity to consent is increasingly recognised in the more informal "case law" of the Health and Disability Commissioner's opinions.<sup>114</sup>
- 1.61 Appendix B is a review of the Health and Disability Commissioner's opinions and of decisions of the Human Rights Review Tribunal. This review shows that over time, the issue whether a consumer/patient lacks capacity or has impaired capacity for decision-making is becoming more prevalent in complaints investigated. Even where there is a substitute decision-maker appointed (a welfare guardian or attorney under an EPOA) there have been breaches of Rights 6 and 7 of the HDC Code in circumstances where the person is unable to make an

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<sup>110</sup> PDG Skegg "Presuming Competence to Consent: could anything be sillier?" (2011) 30 U Queensland Law J 165.

<sup>111</sup> Health and Disability Commissioner: *General Practitioner Dr C*, 11 HDC00647.

<sup>112</sup> The doctrine of necessity and Right 7(4) is discussed below in Chapter 3 Liberty Safeguards and Chapter 6 Research on People who Lack Capacity.

<sup>113</sup> Letter from Chris Moore (President, New Zealand Law Society) to Claire Kibblewhite (Ministry of Social Development Office for Senior Citizens) regarding the 2007 Amendments to Enduring Powers of Attorney Provisions (5 July 2013) [https://www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0011/69194/l-MSD-EPAs-5-7-13.pdf](https://www.lawsociety.org.nz/_data/assets/pdf_file/0011/69194/l-MSD-EPAs-5-7-13.pdf).

<sup>114</sup> Negligent failure to obtain informed consent was previously a ground for medical misadventure but is no longer since the introduction of treatment injury provisions in the Accident Compensation Act 2001, as amended in 2005.

informed choice or give informed consent. These breaches have occurred when there has been a failure to properly activate an EPOA or to consult with the legally appointed substitute decision-maker. There is a greater emphasis on ensuring that providers adequately assess capacity, and are clear on the legal basis on which substitute decisions are made when a person cannot give informed consent.

- 1.62 The Commissioner is charged with investigating complaints under the HDC Code.<sup>115</sup> It is a reactive, not a proactive, process, and does not provide adequate protective mechanisms for those who lack capacity and are especially vulnerable in the health system. The Commissioner's opinions are limited to breaches of the HDC Code, and the requirement for the Commissioner to investigate a complaint initially has a gatekeeper effect, as few complaints are investigated in fact and even fewer result in further action through the tribunal or disciplinary processes.<sup>116</sup> There is a health and disability advocacy service under the Commissioner, but the role of the advocates is centred on providing assistance when a complaint is made, rather than at the front-end of the informed consent process.<sup>117</sup>

## New Zealand summary

- 1.63 The PPPR Act is in need of review.<sup>118</sup> The legal landscape of mental capacity law in New Zealand is fragmented. There is neither an overarching legal framework nor a cohesive social policy in New Zealand for dealing with issues arising for people who lack capacity. Mental capacity affects all aspects of people's lives and access to the legal system. There is a danger of a silo effect isolating different aspects of the legal system, compartmentalising the issues in elder, family, property, medical, mental health or disability law, and so on. Increasingly, there is greater recognition that regulatory frameworks in the health and social policy spheres need to avoid these gaps. As Professor Laurie says: <sup>119</sup>

These regulatory gaps are described as “liminal” (the spaces in between). They often exist outside existing formal legal and social structures, and are often in a state of flux. Citizens who also experience flux in their capacity can find themselves in liminal regulatory spaces where at times laws might, or might not, apply to them.

- 1.64 A review of the law therefore requires a coordinated government approach.

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<sup>115</sup> Health and Disability Commissioner Act 1994, s 14(e). The Commissioner can investigate potential breaches of the HDC Code on a complaint or on his own initiative.

<sup>116</sup> Email from Chris Moore (President, New Zealand Law Society) to the Health and Disability Commissioner regarding Review of the HDC Act and Code (17 February 2014) [https://www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0012/75999/HDC-Act-and-Code-Review-17-02-14.pdf](https://www.lawsociety.org.nz/_data/assets/pdf_file/0012/75999/HDC-Act-and-Code-Review-17-02-14.pdf).

<sup>117</sup> Health and Disability Commissioner Act 1994 s 30 sets out the functions of advocates, which includes ensuring that consumers are aware of their rights under the HDC Code and to provide assistance to ensure that healthcare procedures are performed with informed consent of the consumer: s 30(d). Health advocates can also receive complaints and assist persons who wish to pursue a complaint.

<sup>118</sup> B Atkin “The Protection of Personal and Property Rights Act 1988 – Update and Reflections” (2013) 44 VUWLR 439.

<sup>119</sup> These regulatory gaps are described as “liminal” (the spaces in between) in socio-political literature. Liminal spaces are realms of possibility and transition. Interview with Professor Graeme Laurie, Chair of Medical Jurisprudence and Director of the JK Mason Institute for Medicine, Life Sciences and Law, Edinburgh University (A Douglass, Edinburgh, 29 May 2015).



## 1C: OVERVIEW OF MENTAL CAPACITY LAW IN ENGLAND AND WALES

### Historical origins – Magna Carta 1215

- 1.65 The origins of the adult guardianship system in England and Wales are a poignant reminder of the enduring significance of the Magna Carta just after it marked the 800th anniversary in 2015. In about 1270, shortly after the end of the Second Barons' War, King Henry III, as head of the feudal system, assumed control over the estates of "lunatics" and "idiots". The powers and obligations held by the Crown became part of "the royal prerogative" and were reserved to the king in his role as *parens patriae* or father of the nation.<sup>120</sup> Subsequently the king delegated the exercise of these powers to the judges.
- 1.66 The area of law now known as mental capacity law was historically referred to as lunacy law and from 1846 to 1947 the judges were called the "Masters in Lunacy". Senior Judge Lush of the modern day Court of Protection describes this jurisdiction as "optimistic", because it was based on the premise that lunatics (sometimes of good and sound memory and understanding and sometimes not) might regain capacity and would expect their assets to be restored to them intact, whereas idiots (fools from birth) would not.<sup>121</sup>
- 1.67 Since the Reform Act 1832, generally regarded as the beginning of modern parliamentary democracy in Britain, there have been changes to mental health and mental capacity legislation about once in a generation to reflect current trends and best practice. The next revision of the English legislation will probably take into account recent developments including the United Nations Convention on the Rights of Persons with Disabilities (CRPD).<sup>122</sup>

### Law reform – United Kingdom and Ireland

- 1.68 In England and Wales, the Mental Capacity Act dates from 2005; it has, however, been described as a "1995 law", reflecting the policies, philosophy and practice of the 1990s.<sup>123</sup> The Mental Capacity Bill was already 10 years old when it was put before Parliament, having originally appeared in a Law Commission report published in 1995.<sup>124</sup> The 1995 report was the culmination of a series of four Law Commission consultation papers on decision-making and incapacity, which identified a number of deficiencies in the law, including there being no legislation authorising any other person or court to take a medical decision on behalf of an adult patient without capacity to make a decision. This meant heavy reliance had to be placed on the common law justification of necessity, under which clinicians made the decision to proceed.<sup>125</sup>
- 1.69 The Law Commission recommended there be a single coherent statutory scheme to which recourse could be had when any decision (whether personal, medical or financial) needed to

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<sup>120</sup> Ashton, above n 26 at 11.

<sup>121</sup> D Lush "The Evolution of the Statutory Will Jurisdiction" (2014) Eld LJ 173.

<sup>122</sup> D Lush, Paper presented to The Academy of European Law's Conference on the Rights of Persons with Disabilities (12 Dec 2014). Relevant statutes were passed in 1833, 1863, 1890, 1913, 1934, 1959, 1983 and 2005, some of which were more radical than others.

<sup>123</sup> Lush, above n 121.

<sup>124</sup> Ashton, above n 26 at 68–9. The Law Society provided the stimulus for the review by publishing a discussion document in 1989, "Decision-making and mental incapacity".

<sup>125</sup> *Re F (Mental patient: Sterilisation)* [1990] 2 AC 1. See also Law Commission *Mental Incapacity* (UKLC No 231, 1995) at 2.

be made for a person aged 16 or over who lacked capacity.<sup>126</sup> The Mental Capacity Act 2005 (England and Wales) eventually came into force on 1 October 2007.

- 1.70 Scotland achieved mental capacity legislation first. The Adults with Incapacity (Scotland) Act 2000 followed recommendations of the Scottish Law Commission<sup>127</sup> and was one of the earliest pieces of legislation to be passed by the newly formed Scottish Parliament.<sup>128</sup> The Scottish legislation was implemented in stages. There are three main agencies involved: the Public Guardian has a supervisory role and keeps registers of attorneys, people who can access funds, guardians and intervention orders; local authorities look after the welfare of adults who lack capacity; and the Mental Welfare Commission protects the interests of adults who lack capacity as a result of a mental disorder, under both the mental health and the mental capacity legislation.<sup>129</sup> The Commission's functions include: undertaking visits in a variety of settings; carrying out investigations relating to improper detention, abuse, neglect or deficiency of care and treatment; giving advice; promoting best practice; and challenging legislation and social policy where appropriate.<sup>130</sup> It has similar investigatory powers to the Health and Disability Commissioner in New Zealand but is not operating under a code of patients' rights.<sup>131</sup>
- 1.71 It is interesting to note that the Scottish legislation establishes a special procedure for approving medical treatment in certain cases for a person who lacks capacity. A second opinion can be obtained from a doctor through the Mental Welfare Commission, to review specified treatments given under that Act, and to adjudicate in cases where there is disagreement between a treating physician and a welfare guardian or attorney, although it is rare for a doctor to carry out treatment in the face of a refusal by a welfare guardian or attorney.<sup>132</sup>
- 1.72 In Northern Ireland, the Mental Capacity Bill recently passed by the Parliament is the newest and most ambitious piece of legislation.<sup>133</sup> It will put Northern Ireland ahead of any other jurisdiction in the world in terms of trying to combine mental health and mental capacity legislation that is strongly (if not exclusively) capacity based. It is a brave attempt to be compatible with the CRPD and to avoid discrimination on the grounds of disability as the sole basis for compulsory treatment. It retains the functional test and the "diagnostic threshold"

<sup>126</sup> In the early 1990s there were four Law Commission reports that formed the basis of the Mental Capacity Act 2005 <http://www.bailii.org/ew/other/EWLC/1991/c119.html>.

<sup>127</sup> Law Commission *Report on Incapable Adults* (Scot LC No 151, July 1995).

<sup>128</sup> A Ward *The Power to Act: The Development of Scots Law for Mentally Handicapped People* (Scottish Society for the Mentally Handicapped, Glasgow, 1990) at 121. Much of the impetus for the Scottish law reform and gaining the attention of the Scottish Law Commission was (and still is) driven by Adrian Ward, a solicitor based in Glasgow, who wrote several books in the 1990s on law reform that was occurring internationally, including the New Zealand model in the then newly passed PPPR Act 1988.

<sup>129</sup> Mental Health (Care and Treatment) (Scotland) Act 2003 and Adults with Incapacity Act 2000. See [www.mwscot.org.uk](http://www.mwscot.org.uk).

<sup>130</sup> Interview with Colin McKay, Chief Executive, Mental Welfare Commission for Scotland (A Douglass, Edinburgh, 21 May 2015). There has been a steep rise in welfare guardianship applications to the Commission – 58% in four years.

<sup>131</sup> A Ruck Keene and E Horne "Why a Mental Capacity Act Commission (and What Should It Look Like)?" (2014) 4 Eld LJ 217.

<sup>132</sup> Adults with Incapacity Act 2000, ss 48, 50. The Commission has a responsibility to nominate an independent medical practitioner. Interview with Colin McKay, Chief Executive, Mental Welfare Commission for Scotland (A Douglass, Edinburgh, 21 May 2015). Section 51 of this Act provides legislative safeguards where research is undertaken on people who lack capacity similar to ss 30–34 of the MCA. See Chapter 7 Research on People who Lack Capacity.

<sup>133</sup> Introduced into the Northern Ireland Parliament on 8 June 2015. The bill was completed on 15 March 2016 and was awaiting Royal Assent at the time of writing this report. [www.niassembly.gov.uk/assembly-business/legislation/primary-legislation-current-bills/mental-capacity-bill](http://www.niassembly.gov.uk/assembly-business/legislation/primary-legislation-current-bills/mental-capacity-bill).

(impairment of, or disturbance in the functioning of, the brain or mind)<sup>134</sup> of the English and Welsh MCA. However, the MCA test is qualified so that it “does not matter whether the impairment or disturbance is caused by a disorder or disability or otherwise than by a disability”.<sup>135</sup>

- 1.73 In the Republic of Ireland, the Assisted Decision-Making (Capacity) Bill was introduced in 2013. Following substantive amendments during 2015 it was passed into law at the end of the year.<sup>136</sup> Law reform is well overdue in Ireland: the new law will replace the Lunacy Regulations Act Ireland 1871, draconian legislation administered through the Wards of Court system in the High Court.
- 1.74 The new legislation in Ireland embraces supported decision-making under the CRPD with a three-stage approach to the assessment of capacity.<sup>137</sup> At the least formal end of the spectrum, people can appoint a decision-making assistant when they are concerned that they have or will shortly have difficulty in making decisions without assistance.<sup>138</sup> The next step is appointment of a co-decision-maker, which is a contractual arrangement that must be witnessed by two people (one completely independent of either party), but does not require court approval.<sup>139</sup> Finally, there is an application process for a decision-making representative appointed by the court, who is an individual with a “bona fide” interest in the welfare of the relevant person, when the person lacks capacity to make decisions.<sup>140</sup> The Irish law is progressive and aligns with human rights obligations by recognising legal capacity as a continuum and the role of supported decision-making. Co-decision-making represents an intermediate phase where a person falls somewhere between needing help to make decisions and being completely unable to make decisions for themselves.<sup>141</sup>

### **Mental Capacity Act 2005 (England and Wales) – an overview**

- 1.75 The Mental Capacity Act 2005 (MCA) is a comprehensive overhaul of this area of law in England and Wales. The legislation made significant changes to the legal rights afforded to those who lack capacity in England. The MCA establishes a single statutory framework for the making of personal welfare decisions, healthcare decisions and financial decisions on behalf of adults who may lack capacity to make specific decisions for themselves.<sup>142</sup> The framework provides a hierarchy of processes, extending from informal day-to-day care and treatment decisions, to decision-making requiring the exercise of formal powers, and ultimately to court decisions and judgments. It also clarifies the actions that can be taken by others involved with the care or medical treatment of people lacking capacity to consent.
- 1.76 The key provisions of the MCA, relating to the guiding legal principles (s 1), the definition of capacity and the legal test for intervention (ss 2 and 3), and the concept of the person’s best interests (s 4), are set out in Appendix C.

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<sup>134</sup> Mental Capacity Bill (NI), s 3(1).

<sup>135</sup> Mental Capacity Bill (NI), s 3(3).

<sup>136</sup> The Assisted Decision-making (Capacity) Act 2015 was passed into law on 30 December 2015. <http://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/pdf>.

<sup>137</sup> GR Ashton, “Has our Mental Capacity Jurisdiction Reached the Turning Point?” [2014] Eld LJ, 214.

<sup>138</sup> Assisted Decision-Making (Capacity) Act 2015 (Republic of Ireland), Part 3, s10.

<sup>139</sup> Assisted Decision-Making (Capacity) Act 2015 (Republic of Ireland), Part 4, s 17.

<sup>140</sup> Assisted Decision-Making (Capacity) Act 2015 (Republic of Ireland), Part 5, s 36.

<sup>141</sup> Interview with Dr Frances Matthews, GP/lawyer who has worked as a doctor in Ireland (A Douglass, Dunedin, 25 November 2015).

<sup>142</sup> In England and Wales, many people lacking capacity due to mental disorder (including learning disability and dementia) come under the Mental Health Act 1983, although the concept of capacity is not mentioned in the legislation.

- 1.77 The MCA's starting point is to confirm in legislation the presumption at common law that an adult (aged 16 or over) has full legal capacity, unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. It includes provisions to ensure that in any decision-making process people are given all appropriate help and support to enable them to make their own decisions and to maximise their participation in any decision-making process.
- 1.78 The statutory framework is based on two fundamental concepts: lack of capacity and best interests.<sup>143</sup> For those who lack capacity to make particular decisions, the MCA provides a range of processes extending from informal arrangements to court-based powers, to govern the circumstances in which necessary decisions can be made on their behalf and in their best interests.
- 1.79 The essential provisions of the MCA (and corresponding provisions of the PPPR Act, where they exist) include:<sup>144</sup>
- *Principles*: Five guiding statutory principles – the values that underpin the legal requirements of the Act (MCA s 1; PPPR Act s 8).
  - *Capacity definition*: A definition of people who lack capacity (MCA s 2; no equivalent in PPPR Act).
  - *Capacity test*: A single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time (MCA s 3; PPPR Act ss 6, 12, 25(1)(b), 94(1) and 94(2)).
  - *Best interests standard*: A single criterion (best interests) for carrying out acts or taking decisions on behalf of people who lack capacity to consent to such acts or take those specific decisions for themselves (MCA s 4; no express criterion in PPPR Act).
  - *Codified defence of necessity*: Clarifying the law when acts in connection with the care or treatment of people lacking capacity to consent are carried out in their best interests without formal procedures or judicial intervention, with clear restrictions placed on the use of restraint, in particular, on acts resulting in deprivation of liberty (MCA ss 5 and 6; no equivalent PPPR Act, common law defence of necessity).<sup>145</sup>
  - *Lasting powers of attorney*: Extending the provisions for making powers of attorney which outlast capacity (referred to as “lasting powers of attorney” (LPA) – equivalent to an enduring power of attorney (EPOA) in New Zealand), covering health and welfare decisions as well as financial affairs, with safeguards against abuse and exploitation (MCA ss 22 and 23; PPPR Act Part 9 EPOAs).<sup>146</sup>

<sup>143</sup> These are discussed in Chapter 4 Defining Capacity and Chapter 5 Best Interests.

<sup>144</sup> Sections 1–4 of the Mental Capacity Act 2005 are set out in full in Appendix C.

<sup>145</sup> The provisions of s 5 are based on the common law “doctrine of necessity” as set out in *Re F*, above n 125. The MCA 2005 was subsequently amended by the Mental Health Act 2007 to provide procedural safeguards in cases where someone lacking capacity may be deprived of their liberty and their best interests – discussed below.

<sup>146</sup> Ashton, above n 26 at 165. The existing enduring powers of attorney regime under the Enduring Powers of Attorney Act 1985 continues concurrently with the same legal principles as existed when they were made, although within the framework of the MCA 2005. The EPA jurisdiction had several drawbacks, including that EPA relates only to property and affairs of the donor and as they operated with little official

- *Deputies*: Providing for decisions to be made by a “deputy”, to be appointed by a specialist Court of Protection; (MCA ss 16; PPPR Act s 18 (welfare guardian) or s 25 (property manager)).
- *Advance decisions*: Provides statutory rules, with clear safeguards, for the making of advance decisions as to refusal of medical treatment (MCA ss 23–25; Code of Rights, Right 7(5) (advance directives)).
- *Research on people who lack capacity*: Sets out specific parameters for research involving, or in relation to, people lacking capacity to consent to their involvement (MCA ss 30–34; no provisions in New Zealand legislation, HDC Code Right 7(4) applies).
- *Independent advocates*: Providing for the appointment of independent mental capacity advocates (IMCAs) to support people with no-one to speak for them who lack capacity to make important decisions about serious medical treatment and changes of accommodation, deprivation of liberty safeguarding procedures and research; (MCA, ss35–41; no equivalent in the PPPR Act, health and disability advocates with focus on complaints under the HDC Code).<sup>147</sup>
- *Code of Practice*: Authorising statutory guidance to be issued, in the form of a code (or codes) of practice, setting good practice standards for people using the Act’s provisions (MCA ss 42 and 43; no equivalent in the PPPR Act).<sup>148</sup>

1.80 The Mental Capacity Act also created two public bodies: the new Court of Protection (COP) and the Office of the Public Guardian (OPG). Both of these bodies play a key role in supporting and implementing the statutory framework.

## Court of Protection

1.81 Central to the MCA 2005 is the expanded Court of Protection (COP), which enjoys a wide-ranging jurisdiction to oversee the care of adults lacking mental capacity.<sup>149</sup> It is a superior court of record with jurisdiction relating to the whole of the MCA 2005 and with its own procedures and nominated judges.<sup>150</sup> As a specialist court it can deal with decision-making for adults (and children in a few cases) who may lack capacity to make specific decisions for themselves. The court is able to establish precedent (set examples for future cases) and it can build up expertise in all issues related to incapacity.<sup>151</sup> The court has wide powers including making interim orders and directions and calling for expert reports from a public guardian or a Court of Protection visitor.<sup>152</sup> Appeals go directly from the COP to the Court of Appeal.

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intervention were not viewed as protecting the incapable person who is vulnerable and at risk from abuse.

<sup>147</sup> Currently referred to as the “Deprivation of Liberty Safeguards” (DoLS).

<sup>148</sup> Mental Capacity Act 2005, ss 35–41, Code of Practice 2007.

<sup>149</sup> The MCA extended the jurisdiction of the old Court of Protection from property alone to personal care and welfare.

<sup>150</sup> Mental Capacity Act 2005, s 45.

<sup>151</sup> R Jones *Mental Capacity Act Manual* (6<sup>th</sup> ed, Sweet & Maxwell, London, 2014) at 383. There are extensive Court of Protection Rules that can be made under s 51, currently revised in 2014 and again in 2015.

<sup>152</sup> Mental Capacity Act 2005, s 49.



- 1.82 The emphasis in the MCA is on case-specific decisions and, where possible, the participation of the person who lacks capacity (referred to as “P”). A judge can visit a person in their own home in reaching a decision about whether a person lacks capacity and the court will not shy away from reaching its own decision on that matter, even if it is contrary to the expert evidence before the court.<sup>153</sup>
- 1.83 The Official Solicitor is the “litigation friend of last resort” for P, especially in serious medical treatment cases.<sup>154</sup> To ensure legal representation where the official solicitor is not funded, the Court has issued directions for the person, P, to be a party to proceedings and is in the process of establishing a panel of “accredited legal representatives”.<sup>155</sup> In common with the Family Court, there is a move towards greater transparency of court hearings and decisions.<sup>156</sup>
- 1.84 The Court has power to appoint substitute decision-makers, known as deputies,<sup>157</sup> to make decisions for people who lack capacity, or to remove deputies or attorneys who act inappropriately. The thrust of the MCA is that decisions about complex and serious issues are taken by a court rather than any individual, subject to commonsense practicalities such as where a series of decisions need to be made (for example, medical procedures) or the management of substantial assets.
- 1.85 A deputy's powers must be as limited in scope and duration as is reasonably practicable in the circumstances.<sup>158</sup> By far the majority of the appointments of deputies, and of contested cases, relate to property and similar affairs, not personal welfare. In 2014, there was an increase of cases to 26,000, of which 90 per cent concern property and affairs, and of these, 90 per cent are uncontested.<sup>159</sup>
- 1.86 The living arrangements for people who lack capacity, and how healthcare packages are funded, are often central to the issues before the court under the MCA. In *In the matter of MN (Adult)*,<sup>160</sup> for instance, the Court of Appeal considered the scope of the COP's jurisdiction where a care provider was unwilling to provide or fund the care sought by the patient or, as here, by the patient's family. The case concerned where a young man should live (and receive education and care), and supervision of his contact with his parents and other family members where the relevant funding body had made it clear that it was not prepared to fund contact between him and his family at the parents' home. Sir James Munby P, giving the lead judgment, held that the COP was bound to choose between the options that were actually available.<sup>161</sup> It had no more power, just because it was acting on behalf of an adult who lacked

<sup>153</sup> Interview with Judge Elizabeth Batten, Court of Protection (A Douglass, London, 16 April 2015).

<sup>154</sup> Interview with Janet Illett, Deputy Official Solicitor, (A Douglass, London, 7 May 2015).

<sup>155</sup> The Court of Protection (Amendment) Rules 2015, r 3A.

<sup>156</sup> Sir J Munby “Practice Guidance (Transparency in the Court of Protection): Publication of Judgments” (16 January 2014) <https://www.judiciary.gov.uk/wpcontent/uploads/JCO/Documents/Guidance/transparency-in-the-cop.pdf>.

<sup>157</sup> Mental Capacity Act 2005, s 19(9)(a). There is a panel of professional deputies who are often solicitors. The court can request from a property and affairs deputy some form of security (such as a guarantee bond).

<sup>158</sup> Mental Capacity Act 2005, s 16(4) as discussed in *G v E* [2010] EWHC 2512 (COP) Baker J at [59].

<sup>159</sup> Sir William Charles, Vice-President of the Court of Protection of England and Wales (to the House of Lords MCA Committee, 26 November 2013) <http://www.parliamentlive.tv/Event/Index/0fe8cea8-89db-453c-afb2-7a97d8b20db1>.

<sup>160</sup> [2015] EWCA Civ 411, Sir James Munby P, upholding the decision of Eleanor King J in the Court of Protection.

<sup>161</sup> *In the matter of MN*, above n 160 at [34]. Leave has been granted to one of MN's parents to appeal the decision of the Court of Appeal on whether the COP is constrained solely to consider available options presented to it.

capacity, to obtain resources or facilities from a third party, whether a private individual or a public authority, than would the adult if they had capacity to obtain the resources personally.

- 1.87 While the MCA is considered sensible legislation, the statutory jurisdiction is limited to matters that fall under the MCA. This limitation can be problematic. For example, cases involving vulnerable adults (who have capacity) require separate proceedings under the inherent jurisdiction of the High Court, as do public law cases involving judicial review applications to the High Court's Administrative Division. Mr Justice Charles, Vice President of the COP, considers a better solution would be to create a "one-stop shop" designed to cover not only the law under the statute but those issues that can only be decided under the inherent jurisdiction or public law jurisdiction.<sup>162</sup>

### *Serious healthcare and treatment decisions*

- 1.88 As well as property and affairs, the COP now also deals with serious decisions affecting healthcare and personal welfare matters. These matters were previously dealt with by the High Court under its inherent jurisdiction, if they came before the courts at all. The COP can make a declaration as to the lawfulness of a specific act relating to a person's care or treatment (where somebody has either carried out the action or is proposing to).<sup>163</sup>
- 1.89 This power to decide on the lawfulness of an act is particularly relevant for major medical treatment cases where there is doubt or disagreement over whether the treatment would be in the person's best interests.<sup>164</sup> In addition, the Code of Practice refers to the kind of cases that should be brought before the Court. These include:
- decisions about proposed withholding or withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state;<sup>165</sup>
  - cases involving organ or bone marrow donation by a person who lacks capacity to consent;<sup>166</sup>
  - cases involving the proposed non-therapeutic sterilisation (e.g. for contraceptive purposes) of a person who lacks capacity to consent.<sup>167</sup>

<sup>162</sup> Interview with Mr Justice Charles, Vice-President, The Court of Protection (A Douglass, Royal Courts of Justice London, 9 June 2015).

<sup>163</sup> Mental Capacity Act 2005, s 15.

<sup>164</sup> Department of Constitutional Affairs *Mental Capacity Act 2005, Code of Practice* "Serious Healthcare and Treatment Decisions" (TSO, Norwich, 2007) at 143–145. Although this power is based on the declaration of lawfulness (which doctors might want), the decision of the Court as recorded in the order under s 16(2)(a), which in effect represents the giving of the necessary consent on the person's behalf. Email from A Ruck Keene (barrister) to A Douglass (17 January 2016). See for example, *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 and *In the Matter of MN*, above n 160.

<sup>165</sup> *Airedale NHS Trust v Bland* [1993] AC 789. The COP recently expanded the declaratory jurisdiction to withdrawing life-sustaining treatment from someone who was only in a minimally conscious state, not just a permanent vegetative state: *M v Mrs N* (by her litigation friend, the Official Solicitor) [2015] EWCOP 76(Fam).

<sup>166</sup> *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1996] 2 FLR 787. It was in Y's best interest for her to donate bone marrow to her sister. The Court decided that it was in Y's best interest to continue to receive strong emotional support from her mother, which might be diminished if her sister's health were to deteriorate further, or she were to die.

<sup>167</sup> *Re A (Medical Treatment: Male Sterilisation)* (1999) 53 BMLR 66. A mother applied for a declaration that a vasectomy was in the best interests of A, her son (who had Down Syndrome and was borderline between significant and severe impairment of intelligence) in the absence of his consent. After balancing



- 1.90 There is a specific process for dealing with “serious medical treatment” cases which must be referred to the Court,<sup>168</sup> including cases involving a “novel ethical dilemma”. Practice directions define “serious medical treatment” as treatment that involves providing, withdrawing or withholding treatment in circumstances where there may be a fine balance between the benefits and burdens to the patient, or situations in which there is a choice of treatment and what is proposed would likely involve serious consequences for the patient.<sup>169</sup>
- 1.91 There are many reported cases where life-saving treatment has been ordered in the face of trenchant opposition from the person who lacks capacity. For example, in *Re E (Medical Treatment: Anorexia)*<sup>170</sup> all of the parties supported with different degrees of strength the view that it would not be in the best interests of a 32-year-old woman with severe anorexia nervosa to be force-fed. Nonetheless Jackson J held that, as the woman did not have capacity to make the decision about treatment by forcible feeding, the court must take the decision that was in her best interests.
- 1.92 By comparison, in a more recent case, *Wye Valley NHS Trust v Mr B*,<sup>171</sup> the COP affirmed the right of an individual, deemed to lack capacity as a result of mental illness marked by religious delusions, to refuse life-saving medical treatment. Even though Mr B was found to lack capacity to refuse amputation of his gangrenous leg, Jackson J came to the clear conclusion that enforced amputation would not be in his best interests.<sup>172</sup>
- 1.93 While these serious medical treatment cases are considered in a different medico-legal context than New Zealand, they demonstrate the ability of the Court to be an independent decision-maker and take the burden of decision-making from clinicians and healthcare providers in circumstances that are complex and ethically challenging for all of the parties involved.

## The Public Guardian and the Register of Powers of Attorney

- 1.94 The MCA established a new statutory office, known as the Public Guardian. The Office of the Public Guardian (OPG) is an executive agency of the Ministry of Justice, set up to support the Public Guardian. These agencies exist to help make sure that adults who lack capacity to make decisions for themselves are protected from abuse. The functions of the Public Guardian fall into three categories: establishing and maintaining a register of LPAs; supervising deputies (welfare guardian or property manager) appointed by the court; and investigations – referred to as “safeguarding referrals”.<sup>173</sup>

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the burdens and benefits of the proposed vasectomy to A, the Court of Appeal held that the vasectomy would not be in A’s best interests.

<sup>168</sup> *Airedale NHS v Bland*, above n 165. The case law requirement to seek a declaration in cases involving the withholding or withdrawing of artificial nutrition and hydration to people in a permanent vegetative state is unaffected by the Act.

<sup>169</sup> Court of Protection: Practice Direction 2015, r 9E, authorised under Mental Capacity Act 2005, s 52. See for example, *NHS Trust v FG* [2014] EWCOP 30, where Mr Justice Keehan annexed guidance to the judgment in cases where a pregnant woman who lacks, or may lack, the capacity to make decisions about her obstetric care resulting from a diagnosed psychiatric illness.

<sup>170</sup> [2012] EWHC 1639 (COP).

<sup>171</sup> [2015] EWCOP 60 Peter Jackson J.

<sup>172</sup> *Wye Valley NHS Trust v Mr B*, above n 171 at [38]: “A conclusion that a person lacks decision-making capacity is not an ‘off-switch’ for his rights and freedoms” per Jackson J. See discussion of this case in Chapter 2E Supported Decision-making.

<sup>173</sup> Mental Capacity Act 2005 s 59; Office of the Public Guardian *Annual Report and Accounts 2013–14*, (William Lea Group, London, 2014).

- 1.95 Since the commencement of the MCA in October 2007, the OPG has registered a total of 1,436,731 LPAs.<sup>174</sup>
- 1.96 The key objective of the OPG is to develop an approach to resolving issues with deputies and attorneys that does not require recourse to the COP, by building an in-house capacity to use mediation to resolve cases where parties are in dispute.<sup>175</sup>
- 1.97 Safeguarding referrals are received from a number of sources, including relatives, local authorities, care homes and financial institutions.<sup>176</sup> The Code of Practice widely defines the types of abuse that the MCA protections are designed to prevent, including financial, physical, sexual, psychological abuse, and neglect and acts of omission.<sup>177</sup>
- 1.98 Court of Protection visitors have an important part to play in investigating possible abuse.<sup>178</sup> They advise on how anyone given power under the Act should be, and is, carrying out their duties and responsibilities. There are two types of visitor: general visitors and special visitors. Special visitors are registered medical practitioners with relevant expertise. The COP or Public Guardian can send whichever type of visitor is most appropriate to visit and interview a person who may lack capacity, or an attorney or deputy, and to inspect any relevant healthcare or social care records.
- 1.99 The Public Guardian investigation process can ultimately result in an application to the court to remove a deputy or an attorney. Denzil Lush, Senior Judge of the COP, credits the OPG's supervisory role over deputies, and its effectiveness in identifying wayward deputies, for the increasing incidence of applications to the court – an increase from 185 in 2013 to 345 in 2014.<sup>179</sup>
- 1.100 In Judge Lush's experience, financial abuse in England is almost exclusively perpetrated by close relatives.<sup>180</sup> Of a sample of 250 cases in which the power of attorney was revoked by the court because of financial abuse of the donor of the power, the victims of abuse were generally four or five years older than the average donor. Of the abused donors, 174 (70 percent) were women and 76 (30 percent) were men, compared with 61.25 percent and 38.75 percent respectively in the overall sample of 3,958 donors as a whole.<sup>181</sup> Further conclusions can be drawn from the relationship of the abusive attorney to the donor. In 68 percent of cases, the abuser was the donor's child; 35 percent of the donors were abused by their son, 22 percent by their daughter, and 11% by more than one child.
- 1.101 The typical scenario is not of an unscrupulous individual downloading a power of attorney form from the internet and getting a vulnerable elderly person to sign it, but quite the opposite.

<sup>174</sup> This includes cases that are no longer on the Register, due to withdrawal or cancellation. Interview with Marion Bowgen, Supervision Project, Office of the Public Guardian (A Douglass, London, 4 June 2015).  
<sup>175</sup> P Hartley-Jones "The Role of the Office of the Public Guardian Investigations of Abuse" (2011) 13 J Adult Protect 160 at 161.

<sup>176</sup> Office of the Public Guardian, *Annual Report and Accounts 2014-2015* (William Lea Group, London, 2015) at 15. [www.gov.uk/government/publications](http://www.gov.uk/government/publications). The OPG investigated 743 cases of the 1970 safeguarding referrals during the 2014/15 business year, and 695 investigations were concluded.

<sup>177</sup> Mental Capacity Act 2005, Code of Practice, above n 164 at 245.

<sup>178</sup> Mental Capacity Act 2005, Code of Practice, above n 164 at 248.

<sup>179</sup> D Lush "Financial Crime Committed Against the Elderly and Infirm: A Review of its Increasing Prevalence and how Effective Practitioners, Public Bodies and the Courts are Tackling It" (paper presented at joint seminar STEP London Central Branch and ACTAPS, London, 10 December 2014).

<sup>180</sup> For example, the following three cases all involve members of the person's family: *Re Harcourt* [2013] COPLR 69, Mrs Harcourt's daughter; *Re Buckley* [2013] COPLR 39, Miss Buckley's niece; and *Re GM* [2013] COPLR 290, GM's late husband's niece and great niece.

<sup>181</sup> Lush, above n 179 at 10.

In three-quarters of these abuse cases there was input from the legal or medical professions at the time of the creation of the power; there are individuals who are required to assess the donor's capacity to create an enduring power of attorney.<sup>182</sup>

- 1.102 The granting of a power of attorney is an important expression of autonomy: it allows a prior exercise of the individual's autonomy, when the person has capacity, to direct or make provision for when they may subsequently lack capacity.<sup>183</sup> The combination of having a register of powers of attorney plus a public agency to oversee its use has been a cornerstone of the new COP's ability to tackle financial crimes and abuse of mainly older adults who lack capacity.
- 1.103 In New Zealand, the 2007 amendments to the PPPR Act have not resolved the ongoing problems of misuse and abuse of EPOAs, first raised by the Law Commission in 2000 and 2001,<sup>184</sup> and still apparent in the minor changes currently being made to Part 9 of the PPPR Act.<sup>185</sup> A key factor promoting the success of the English model is the fact that the national register of LPAs is supported by a public agency, to ensure effective supervision of such powers of attorneys.. This would therefore be an essential reform to be adopted in New Zealand.<sup>186</sup>

### **Mental Health Act 1983 (MHA)**

- 1.104 In addition to the MCA, England and Wales have the Mental Health Act 1983 (MHA) and its accompanying Code of Practice<sup>187</sup> which allow for the detention, hospitalisation, and/or treatment of people with a "mental disorder". Mental disorder is broadly defined as "any disorder or disability of the mind",<sup>188</sup> and can include learning disability and personality disorder. English mental health law provides for a system of guardianship for some patients under the MHA, although "capacity" is not a concept referred to in the legislation.<sup>189</sup> Guardians appointed under the MHA have the exclusive right to decide where a patient should live, taking precedence over an attorney or deputy appointed under the MCA.<sup>190</sup>
- 1.105 The dividing line between the need to use the compulsory powers of the MHA and the need - to respect a person's prior exercise of autonomy in an advance decision is not always clear cut. The powers under the MHA to detain and treat people for a mental disorder apply even if a patient has capacity under the MCA. In *Nottinghamshire Healthcare NHS Trust v RC*<sup>191</sup> a young man with capacity had a severe personality disorder and was detained under the MHA. RC required a blood transfusion, but was a practicing (unbaptised) Jehovah's Witness. The Court held that RC had capacity to refuse a blood transfusion as it was not a medical treatment

<sup>182</sup> Ibid. Of a sample of 100 cases, 51 were legal professionals; solicitor, barrister or legal executive.

<sup>183</sup> Mental Capacity Act 2005, ss 24–26. The provision for advance directions (known as advanced directives in New Zealand) are also an expression of a person's prior autonomy.

<sup>184</sup> Refer above: PPPR Act – law reform at 17.

<sup>185</sup> The current amendment proposes to reverse the independent witnessing requirements for EPOAs under the 2007 Amendments. The Law Society submitted that the 2007 amendments increased the cost and complexity of establishing EPOAs and as a result the number of people completing EPOAs has decreased not increased: New Zealand Law Society submission on Part 21 (Enduring Powers of Attorney) Statutes Amendment Bill 2015, dated 29 January 2016.

<sup>186</sup> See Chapter 8 Conclusion - Checklist for Reform.

<sup>187</sup> Department of Health *Mental Health Act 1983: Code of Practice* (TSO, Norwich 2015) at 22. The Code sets out the overarching principles of the Act, which are not included in the statute itself.

<sup>188</sup> Mental Health Act 1983, s 1(2).

<sup>189</sup> Mental Health Act 1983, s 8(1)(a).

<sup>190</sup> *MHA Code of Practice*, above n 187 at 342.

<sup>191</sup> *Nottinghamshire Healthcare NHS Trust v RC* [2014] EWHC 1317 (COP). In this case, Mostyn J sat as a COP judge to consider RC's capacity and the advance direction to refuse treatment under the MCA, but as a High Court judge considering the lawfulness of the actions of the treating psychiatrist.

for the mental disorder.<sup>192</sup> It upheld the validity of his advance decision, despite self-harming behaviours and the fact that RC was pursuing a “self-destructive course” leading to inevitable death. Justice Mostyn recognised the ethical dilemma that confronted the treating psychiatrist who had the power under the MHA to override RC’s advance decision and impose treatment against his will but instead used the court process to confirm the validity of the advance direction.

- 1.106 In 1999, an expert committee, chaired by Professor Geneva Richardson, reviewed the mental health legislation in England and Wales, recommending specific legislation for people with long-term incapacity.<sup>193</sup> The report foreshadowed the problems with how to respond to informal patients not subject to compulsory powers under the MHA and the interface with the subsequent mental capacity legislation.

## Ongoing law reform in England and Wales

- 1.107 The comfortable assumption of the English Mental Health Act (of 1959 and 1983), that people could be admitted to hospital and detained there for psychiatric treatment, without formality, provided they did not object, was dealt a “serious blow”<sup>194</sup> by the European Court of Human Rights in Strasbourg (ECtHR)<sup>195</sup> following a decision in the House of Lords.<sup>196</sup> It exposed a gap in the interface between mental health and mental capacity law, known as the “Bournewood gap”: this is the inability of compliant people who lacked capacity to object to their detention, identified in a case involving Bournewood Hospital. Further changes were made to the Mental Capacity Act in an attempt to protect this vulnerable group of informal compliant patients who lacked capacity and did not have the benefit of the safeguards provided by the mental health legislation.

- 1.108 As Lady Hale explains in her textbook on mental health law: <sup>197</sup>

If the reality was that a person was being deprived of his liberty within the meaning of Article 5 [of the European Convention on Human Rights], there had to be some safeguards to protect him against arbitrary action, even if this was meant for his own good. Indeed safeguards against unjustified deprivation of liberty were needed, whether the reason for it was mental or physical disorder or simply to keep him safe.

- 1.109 The result was the Deprivation of Liberty Safeguards regime (universally known as the DoLS), inserted into the Mental Capacity Act 2005 by the Mental Health Act 2007.
- 1.110 This regime was enacted to “plug” the Bournewood gap. First, there was an amendment to the Mental Capacity Act in 2007 to insert certain procedural safeguards for detained incapacitated persons, called the “DoLS”. Second, a post-legislation scrutiny report was prepared by the House of Lords in 2014 that described the DoLS as not fit for purpose. Third, around the same time, a decision of the Supreme Court, *Cheshire West*, expanded the range of circumstances in which a person must be regarded as deprived of their liberty. So many

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<sup>192</sup> Mental Health Act 1983, s 58.

<sup>193</sup> Report of Expert Committee, *Review of the Mental Health Act 1983* (Department of Health, London, 1999).

<sup>194</sup> B Hale *Mental Health Law* (5th ed, Sweet & Maxwell, London, 2010) at 4.

<sup>195</sup> *HL v United Kingdom*, above n 4. The European Court of Human Rights held that the use of the common law power of necessity to detain people in this context, rather than using the Mental health Act 1983, was not adequate protect against the risk of arbitrary detention and was in breach of art 5 (1)(e) of the European Convention on Human Rights 1950 (ECHR) and also art 5(4) because of the lack of any adequate court review of the lawfulness.

<sup>196</sup> *Bournewood*, above n 5.

<sup>197</sup> Hale, above n 194 at 4.

more people in care homes and hospitals, as well as in community settings such as foster care placements, were deprived of liberty than had previously been understood. Some lawful justification for this was therefore required.

- 1.111 Under the MCA, the DoLS set out a set of procedures that must be followed to render the person's deprivation of liberty lawful: namely, when they are detained pursuant to a decision made by the court or under an urgent or standard authorisation given under the DoLS regime.<sup>198</sup> In *Cheshire West*, the majority in the Supreme Court held that, in cases involving the placement of mentally incapacitated persons, the test to be applied in determining whether they are being deprived of their liberty is whether they are under the continuous supervision and control of those caring for them and are not free to leave. But the DoLS regime does not authorise such deprivation of liberty outside a care home or hospital. So, the consequence was that, where it occurred in other settings, such as in a foster home, an application to the COP would be required to obtain the necessary authority, as DoLS does not extend to such settings.
- 1.112 The DoLS were originally designed to provide a comprehensive set of safeguards for what was thought would be a relatively small number of people who would be made subject to them (less than 6,000 people in England and Wales).<sup>199</sup> However, since the *Cheshire West* judgment there has been a significant increase in DoLS applications and in the associated resource implications for funding the scheme.<sup>200</sup> As an indication of the potential impact of the *Cheshire West* judgment, the Alzheimer's Society predicts that there will be one million people with dementia in the United Kingdom by 2025. The potential increase of people who may lack capacity poses a tremendous challenge for everyone: sufferers, carers and medical and social care professionals.<sup>201</sup>
- 1.113 The scale of the problem following *Cheshire West* is graphically summarised by Allen:<sup>202</sup>

We are presently witnessing something very unique, something historical. And that is the mass authorisation of deprivation of liberty of a significant proportion of the disabled population. Tens of millions of pounds are being diverted from health and social care budgets to enable such authorisations on an industrial scale. Up and down the country – as Art 5 ECHR takes hold – an additional layer of legal procedures are now required to oversee health and social care. We are in the throes of what might be called a great confinement.

<sup>198</sup> In addition, deprivation of liberty may be necessary for life-sustaining treatment or doing any "vital act": Mental Capacity Act 2005, ss 4A and 4B.

<sup>199</sup> Interview with Tim Spencer-Lane, Nicholas Paines QC, Commissioner responsible for the DoLS and the Rt Hon Sir David Lloyd-Jones, Chairman of the Law Commission of England and Wales (Law Commission) (Alison Douglass, London, 28 April 2015). In a 12 month period in 2013-14 the total number of applications in England was 11,300. In the subsequent 12 month period in 2014-15 there were 113,300 DoLS applications, of which 36 percent were granted (40,000). These figures are considered to be the "tip of the iceberg" as some local authorities are not prioritising cases of alleged deprivation of liberty in supported living and community settings, such is the burden that has been placed upon them: Law Commission *Mental Capacity and Deprivation of Liberty: A Consultation Paper No.222* (TSO, London, 2015) at 17.

<sup>200</sup> There has also been resistance among some members of the judiciary who have stated their dissatisfaction with the *Cheshire West* judgment arguing that the law is "In a state of serious confusion": Mostyn J. This criticism was rejected by the Court of Appeal: "Even if *Cheshire West* is wrong, there is nothing confusing about it. In our view, the judge's passionate view that the legal analysis of the majority in *Cheshire West* is wrong is in danger of distorting his approach to these cases." *KW & Ors v Rochdale Metropolitan BC* [2015] EWCA Civ 1054 at [33], Lady Justice Black, MR.

<sup>201</sup> A Ruck Keene, V Butler-Cole, N Allen and others, 39 Essex Street "Mental Capacity Law Guidance Note" (London, 2014): [www.39essex.com/mental-capacity-law-guidance-note-brief-guide-carrying-capacity-assessments](http://www.39essex.com/mental-capacity-law-guidance-note-brief-guide-carrying-capacity-assessments).

<sup>202</sup> N Allen "The (not so?) great confinement" (2015) Eld LJ 45.



- 1.114 England is now reviewing the labyrinth of reforms at a time when there is a heavy burden on the National Health System to implement the DoLS, and in the wake of the Winterbourne View scandal affecting the rights of people with learning disabilities.<sup>203</sup> The Law Commission has consulted on a proposal to replace the DoLS that would cover both institutional and “community” settings, and is required to provide draft legislation to the Government by the end of 2016.<sup>204</sup>

### Problems with implementation of the MCA

- 1.115 In addition to the DoLS scheme, the second problem highlighted by the House of Lords’ report in 2014 was with the implementation of the MCA. There is a lack of awareness and understanding of the MCA which has led, in some instances, to perverse outcomes for people who lack capacity. As poignantly stated by Baroness Baker, the House of Lords Select Committee was “trying to get to the bottom of why this legislation, which everybody tells us is so good, is so patchily observed or widely ignored”.<sup>205</sup>
- 1.116 The report found that prevailing cultures of paternalism (in health) and risk aversion (in social care) had prevented the Act from becoming widely known or embedded. It called for the establishment of an independent oversight body, as the Act (and its core principles) had failed to become embedded in everyday practice.<sup>206</sup>
- 1.117 Too often, the empowering ethos of the MCA 2005 gave way to concerns of paternalism, risk and safeguarding, with decisions taken to overrule the wishes and feelings of the person lacking capacity rather than to support them. At the same time, the presumption of capacity had sometimes become an excuse for the provision of substandard care, or indeed denial of care entirely, on the basis of a highly suspect view that the person was agreeing and had capacity to agree to such inappropriate care. This was particularly evident when the choice of the person lacking capacity worked to the financial advantage of a service provider. There was little evidence of supported decision-making, notwithstanding its express requirements in the Act.<sup>207</sup>

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<sup>203</sup> The Winterbourne View hospital inquiry occurred at Winterbourne View, a private hospital in South Gloucestershire, England. A Panorama investigation, broadcast on television in 2011, exposed the physical and psychological abuse suffered by people with learning disabilities and challenging behaviour at the hospital, despite the fact that local services and the English national regulator (Care Quality Commission) had received various warnings. There have been subsequent reports for a new national framework: Transforming Care and Commissioning Steering Group *Winterbourne View – Time for Change: Transforming the commissioning of services for people with learning disabilities and/or autism* (NHS, London, 2014).

<sup>204</sup> These developments and how New Zealand might address the Bournemouth gap are discussed in Chapter 3 Liberty Safeguards.

<sup>205</sup> Select Committee on the Mental Capacity Act 2005, Volume 1 (2013) 771 cited in P Skowron “Evidence and Causation in Mental Capacity Assessments *PC v City of York Council* [2013] EWCA Civ 478” Med L Rev fwu014.

<sup>206</sup> HM Government *Valuing every voice, respecting every right: Making the case for the Mental Capacity Act – The Government’s response to the House of Lords Select Committee Report on the Mental Capacity Act 2005* (Williams Lea Group, London, 2014) <http://www.gov.uk/government>. The independent oversight body was a recommendation of the Government’s response, but has not yet eventuated.

<sup>207</sup> Mental Capacity Act 2005, ss 1(3), 3(2), 4(4). See also P Bartlett “Good Act, Poor Implementation: A Report of the House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005” (2014) 4 Eld LJ 123 at 157.

- 1.118 The English experience to date has demonstrated that even the most up-to-date law that has a clear explanation of its core principles, is difficult to embed. It requires participation from the professionals and the appointed decision-makers who must implement the law.

### Vulnerable adults and the inherent jurisdiction

- 1.119 Traditionally, the law's protective function was engaged by a person's lack of capacity. More recently, the English courts have developed the notion of "vulnerable adults", adults who are capacitous<sup>208</sup> (and therefore are not subject, now, to the MCA) but who are nevertheless thought to need protection.

- 1.120 Until 1959, the English High Court and its predecessors had jurisdiction over the lives of adults who lacked capacity. However, according to Munby LJ (now President of the CoP), although the court's inherent jurisdiction in relation to incapacitated adults' *financial* affairs was transferred to the (old) Court of Protection, the corresponding jurisdiction in relation to personal care and welfare was "inadvertently abolished".<sup>209</sup> As a result, the court's inherent jurisdiction has been rediscovered to fill this gap.<sup>210</sup>

- 1.121 In the leading judicial statement in this respect, Munby P identified the "vulnerable adult" as:<sup>211</sup>

(S)omeone who whether or not mentally incapacitated, and whether or not suffering from any mental illness or mental disorder, is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.

- 1.122 In the same judgment, Munby P described the inherent jurisdiction as follows:<sup>212</sup>

... the inherent jurisdiction can be exercised in relation to a vulnerable adult who, even if not incapacitated by mental disorder or mental illness, is, or is reasonably believed to be, either (i) under constraint or (ii) subject to coercion or undue influence or (iii) for some other reason deprived of the capacity to make the relevant decision, or disabled from making a free choice, or incapacitated or disabled from giving or expressing a real and genuine consent.

- 1.123 The Court of Appeal subsequently made clear that this jurisdiction had survived the coming into force of the MCA, in *DL v A Local Authority*<sup>213</sup> where elderly parents with capacity were abused and unduly influenced by their son to the extent that DL was seeking to coerce his father into transferring the ownership of the house into DL's name and the mother was forced to move into a rest home. The Court found the parents' capacity to make balanced and considered decisions about their relationship with their son was compromised and invoked the inherent jurisdiction to make orders to control DL's behaviour.<sup>214</sup>

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<sup>208</sup> The Latin term for capacity/incapacity is "capax" and "incapax".

<sup>209</sup> Munby LJ "Taking Stock: The Mental Health and Mental Capacity Reforms" Keynote address to the Cardiff Law School Conference at Manchester (15 October 2010) (emphasis in the original) in A Szerletics *Best interests decision-making under the Mental Capacity Act: Green Paper Technical Report* (Essex Autonomy Project, University of Essex, 2011) at 7.

<sup>210</sup> The *parens patriae* power ceased to exist for adults who lacked capacity and was put on a statutory footing under the Mental Health Act 1959 and limited powers of guardianship under the Mental Health Act 1983.

<sup>211</sup> *Re SA (Vulnerable Adult with Capacity: Marriage)* [2005] EWHC 2942 (Fam) [82].

<sup>212</sup> *Re SA*, at [77].

<sup>213</sup> [2012] EWCA Civ 253.

<sup>214</sup> Subsequent case law has used the inherent jurisdiction to authorise deprivation of liberty of a deluded man who lacked capacity but was under the MHA to receive force feeding: *A NHS Trust v Dr A* [2013] EWHC 2442 (COP) Baker J. In *NCC v PB and TB* [2014] EWCOP 14 [2015] COPLR 118, Parker J



- 1.124 The wide-ranging jurisdiction and the basis upon which it might intervene in an individual's decisions has, however, been criticised as leading to a confused and outmoded concept of the vulnerable older adult, as it conflates what is considered as in a person's best interests under the MCA, with the goal of facilitating an individual's autonomous decision-making capability.<sup>215</sup> The use of the inherent jurisdiction has none of the accompanying safeguards for assessing what is in a person's best interests under the MCA. It blurs the dividing line between those people on whose behalf decisions can be taken by a court and those people who need protection but in respect of whom decisions cannot be taken. As Ruck Keene says:<sup>216</sup>

[The inherent jurisdiction] risks leading to a situation where decisions are taken on behalf of the capacitous but vulnerable, rather than steps being taken to create a safe space for them to take their own decisions, at which point the entire point of the MCA disappears.

- 1.125 A justification for the expanded jurisdiction is the difference between having capacity and being autonomous: a person may have capacity but be unable to exercise it because they are in an abusive relationship. Protection of autonomy requires the courts to protect people who are robbed of their autonomy and who are pressurised or forced by others (or by delusion) into acting against their genuine wishes.<sup>217</sup>
- 1.126 The real dividing line between the MCA and the inherent jurisdiction remains uncertain, as does the extent to which undue influence, exerted by others, has a bearing on a person's capacity for decision-making, whether in respect of property or personal care and welfare decisions. In *Re BKR*, a recent case decided by the Singapore Court of Appeal (where the Singapore MCA is almost identical to the English MCA), the Court took into account an elderly woman's susceptibility to undue influence in finding she lacked capacity. The Court observed that there was a "confluence of mental impairment and undue influence", and that the proven or potential presence of undue influence is relevant to an account of the person's circumstances and a finding of incapacity.<sup>218</sup>
- 1.127 The problem that has emerged under English law is that there are some individuals who retain capacity but who are in need of protection. Incapacity as defined under the MCA requires the inability to make a decision to be linked to a person's impairment ("impairment of, or a disturbance of the functioning of, the mind or brain").<sup>219</sup> Not only is this approach viewed as discriminatory under human rights law (CRPD), it has created a problem because the court

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observed that in determining whether the causative nexus between an individual's mental impairment and the inability to make a decision under the MCA, the question was whether the impairment was an "effective, material or operative cause of the incapacity, even if other factors come into play."

<sup>215</sup> L Pritchard-Jones "The good, the bad, and the "vulnerable older adult"" (2016) J Soc Welf Fam Law DOI: 10.1080/09649069.2016.1145838 1 at 13. This article examines the Care Act 2014 and recent judgments involving the court's inherent jurisdiction to protect vulnerable adults. See also M Dunn, I Clare and A Holland, "To Empower or to Protect? Constructing the Vulnerable Adult in English Law and Policy" (2008) 28 Leg Stud 234.

<sup>216</sup> Email communication from A Ruck Keene (Barrister, London) to A Douglass (20 May 2015).

<sup>217</sup> Herring, above n 25, at 58.

<sup>218</sup> *Re BKR* [2015] SGCA 26 (Singapore Court of Appeal) at 88ff. The question before the court was whether BKR, an extremely wealthy elderly woman, had capacity to make decisions regarding her property and affairs in the face of competing interests among her adult children. A line of English cases were cited, emphasising that susceptibility to undue influence is only relevant where it is caused by mental impairment. For example, *London Borough of Redbridge v G* [2014] EWHC 485 (COP), where the court took account of both the person's impairment in the functioning of G's mind and also the influence C and F had over her in coming to the conclusion that G lacked capacity to take material decisions.

<sup>219</sup> Mental Capacity Act 2005, s 2(1).

can only intervene under the MCA when the inability to make a decision is due to the impairment.<sup>220</sup> The inherent jurisdiction has been used to fill this lacuna in the English law.

## **MCA – a summary**

- 1.128 There are some very positive features of the Mental Capacity Act, notably much greater transparency (of both the standards and the process) concerning decision-making regarding people who lack capacity, under a single piece of legislation that has codified much of the common law. The Act provides for the specialised jurisdiction of the Court of Protection with corresponding expertise; a Code of Practice to accompany it; a streamlined procedure for dealing with serious medical treatment cases; and a register of powers of attorney, with oversight by the Office of the Public Guardian which can investigate potential abuse and initiate reviews by the Court of Protection.<sup>221</sup>
- 1.129 Despite the distraction of the ongoing reform of the DoLS, the mental capacity legislation in England has provided a real focus and visibility for mental capacity law and practice. There is corresponding recognition that issues of capacity permeate many fields of law and practice, not just those within the scope of the Court of Protection. Better training of lawyers and judges has been regarded as essential to develop a new legal culture that takes into account the needs of vulnerable individuals who as members of society encounter the legal system.<sup>222</sup>
- 1.130 The changing legal landscape and the impetus for ongoing reform of capacity law in the United Kingdom and elsewhere is due, in part, to contemporary thinking about the adequacy of the law's approach to autonomy and about the growing role to be played by human rights instruments in the construction of capacity as a legal concept.

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<sup>220</sup> See Chapter 4 Defining Capacity.

<sup>221</sup> These features as well as some of the legal provisions are set out in the checklist for reform of New Zealand's law.

<sup>222</sup> Ashton, above n 26 at x (Introduction). See S Miles "Time to accredit mental capacity work" (2015) 5 Eld L J 3.

# Chapter 2

## **Supported Decision-making**

## Chapter 2 – Supported Decision-making

Chapter 2 is in five sections:

- A. The human rights concepts in the United Nations Convention on the Rights of Persons with Disabilities (CRPD).
- B. The common legal principles in both the Mental Capacity Act (England and Wales) and the Protection of Personal and Property Rights Act 1988.
- C. The notion of autonomy as understood in ethics and in the law.
- D. New Zealand's cultural dimension and tikanga Māori.
- E. Supported decision-making in practice and in English case law.

### Introduction

- 2.1 This chapter considers the impact of human rights instruments and the paradigm shift promoted in the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>223</sup> from *substituted* decision-making to *supported* decision-making.<sup>224</sup> It considers the role of the law and argues that substituted and supported decision-making regimes are not mutually exclusive: there is a place for both of them in law and they can coexist.
- 2.2 Supported decision-making refers to a process of providing support to people whose decision-making ability is impaired, to enable them to make their own decisions whenever possible.<sup>225</sup> Originally developed in Canada as an alternative conceptual framework for decision-making, the idea of supported decision-making challenged the belief that personal autonomy could only be expressed independently.<sup>226</sup> It was seen as a way to overcome barriers for people with intellectual disabilities. The concept now has far greater reach, applying to people with a wide range of impairments that affect decision-making. While the concept has gained international traction, it poses significant challenges for the development of law and policy. This is due in part to multiple and sometimes confused understandings of what legal capacity and supported decision-making actually entail and how to translate those concepts into workable laws. Therefore, it is essential to have a clear understanding of these human rights

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<sup>223</sup> Convention on the Rights of Persons with Disabilities (opened for signature 30 March 2007, entered into force 3 May 2008), (CRPD).

<sup>224</sup> As discussed below, neither “substituted decision-making” nor “supported decision-making” are defined in the CRPD. A “substitute decision-maker” generally refers to a person or body who can make decisions for someone else who lacks capacity in law, such as an attorney or welfare guardian under adult guardianship law, a healthcare provider under Right 7(4) of the HDC Code, or the Court itself under statute or by way of the inherent jurisdiction.

<sup>225</sup> Law Commission, T Spencer-Lane “Mental Capacity and Deprivation of Liberty” consultation document <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty> at 154.

<sup>226</sup> M Browning, C Bigby and J Douglas “Supported Decision-making: Understanding How its Conceptual Link to Legal Capacity is Influencing the Development of Practice” (2014) 1 Res Pract Int Devel Disab 34. Since the 1990s supported decision-making has been incorporated in legislation in several Canadian Provinces. Bach and Kerzner, above n 33. *A New Paradigm For Protecting Autonomy And The Right To Legal Capacity* is a commissioned report that has been influential in interpreting approaches to legal capacity.

concepts when undertaking a review of the law and to place them in a social and cultural context.

- 2.3 Contemporary thinking in ethics reflects a shift in focus from individual notions of autonomy to accounts of autonomy that affirm the importance of relationships in exercising legal capacity. The positive obligation to recognise support relationships in the CRPD also has synergies with tikanga Māori, where the values of individual autonomy and collective decision-making processes can work alongside each other. This chapter makes connections between supported decision-making as understood in human rights law, legal principles, ethics and Aotearoa/New Zealand's own cultural dimension.

## 2A: HUMAN RIGHTS

### International human rights instruments

- 2.4 The impetus for change in mental capacity law internationally is derived from the growing role played by human rights instruments. These instruments affirm that an absence of capacity does not mean an absence of rights. The focus is on the individual's current position rather than past preferences.<sup>227</sup> A central theme is the universality of human rights and of equal recognition before the law.
- 2.5 New Zealand is a party to the main international human rights instruments relevant to both mental capacity and mental health law. These are: the International Covenant on Civil and Political Rights 1966 (ICCPR), the International Covenant on Economic, Social and Cultural Rights 1966 (ICESCR), and the United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD). As a matter of international law, New Zealand is required to ensure that the standards set out in these instruments are implemented, although as a general principle a treaty will not have the force of law unless explicitly incorporated into domestic law.<sup>228</sup>
- 2.6 In domestic law, the New Zealand Bill of Rights Act 1990 (NZBORA) and the Human Rights Act 1993 recognise these international obligations. The NZBORA expressly affirms New Zealand's commitment to the ICCPR and requires all statutes to be construed consistently with these rights if possible.<sup>229</sup>
- 2.7 In England, the Human Rights Act 1998 has adopted the European Convention on Human Rights 1950 (ECHR) into domestic law.<sup>230</sup> As a result, those rights under the ECHR, which have long been closely scrutinised by the European Court of Human Rights in Strasbourg (ECtHR), are now also enforced by domestic courts in the United Kingdom. New Zealand is not a party to the ECHR but, like the United Kingdom, is a party to both the ICCPR and the CRPD. Substantially the same rights are protected by all three of these human rights

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<sup>227</sup> Donnelly, above n 24 at 274.

<sup>228</sup> K Gledhill, "A Rights Audit of the Mental Health Act" in Dawson and Gledhill, above n 92 at 285–286. See also S Bell, J McGregor "Human Rights Law and Older People" in K Diesfeld, I McIntosh (eds) *Elder Law in New Zealand* (Thomson Reuters, Wellington, 2015) at 180. New Zealand is said to have a dualist approach, which distinguishes between international and national law. There is a trend towards monism internationally, whereby domestic courts can enforce both international and domestic law.

<sup>229</sup> New Zealand Bill of Rights Act 1990, s 6. See also MA Waters "Creeping Monism: The Judicial Trend Toward Interpretive Incorporation of Human Rights Treaties" (2007) Columbia Law Rev, Washington & Lee Legal Studies Paper No. 2006-12.

<sup>230</sup> The Convention on the International Protection of Adults signed at The Hague on 13 January 2000 is also expressly given effect in England and Wales in the MCA, s 63 and Schedule 3.

conventions. Strasbourg jurisprudence from the ECtHR is therefore directly relevant and likely to be influential in New Zealand courts, especially when its interpretations are authoritative in the English legal system, upon which the New Zealand legal system has traditionally drawn.<sup>231</sup>

- 2.8 The Supreme Court of the United Kingdom referred to the CRPD for the first time on 19 March 2014 in its judgment in *P v Cheshire West and Chester Council*. Lady Hale said:<sup>232</sup>

The whole point about human rights is their universal character. The rights set out in the European Convention are to be guaranteed to ‘everyone’ (Article 1). They are premised on the inherent dignity of all human beings whatever their frailty or flaws. The same philosophy underpins the United Nations Convention on the Rights of Persons with Disabilities (CRPD), ratified by the United Kingdom in 2009. Although not directly incorporated into our domestic law, the CRPD is recognised by the Strasbourg court as part of the international law context within which the guarantees of the European Convention are to be interpreted.

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

- 2.9 The CRPD was the first binding international human rights instrument to expressly address disability. It has been heralded as signalling a “paradigm shift” in thinking about disability rights.
- 2.10 New Zealand signed the CRPD in March 2007, ratified it in 2008, and has played a significant role in its evolution, particularly involving representatives of disabled people’s organisations (DPOs).<sup>233</sup> Prior to ratification of the CRPD, the New Zealand Public Health and Disability Act 2000 foreshadowed the New Zealand Disability Strategy and the development of the Disability Action Plan 2014–2018, led by the Office for Disability Issues within the Ministry of Social Development.<sup>234</sup>
- 2.11 An Optional Protocol operates alongside the CRPD and would allow individuals who consider that they have been victims of a violation by a State Party of the provisions of the CRPD to directly petition the United Nations Committee on the CRPD.<sup>235</sup> Despite a large number of member states having ratified the Optional Protocol, New Zealand’s move to ratify it is still “in progress”.<sup>236</sup>
- 2.12 The CRPD does not create new rights but consolidates existing international obligations and clarifies their application to persons with disabilities. The principles underpinning the CRPD include respect for inherent dignity and individual autonomy – including the freedom to make choices – of persons with disabilities (art 3). Important rights include the right to liberty and security of the person (art 14); the right to freedom from exploitation, violence and abuse (art

<sup>231</sup> Gledhill, above n 228 at 286.

<sup>232</sup> Above n 7 at [36].

<sup>233</sup> J McGregor, S Bell and M Wilson *Fault Lines: Human Rights in New Zealand* (Law Foundation, Wellington, 2015). Chapter 7 describes the background to New Zealand’s involvement with the development of the CRPD and New Zealand’s responses including the independent monitoring mechanism set up under art 33.

<sup>234</sup> Minister for Disability Issues *The New Zealand Disability Strategy: Making a World of Difference Whakanui–Oranga* (Ministry of Health, Wellington, 2001).

<sup>235</sup> Article 34 of the CRPD is the key enforcement mechanism and State Parties that have ratified the CRPD must report to the Committee.

<sup>236</sup> Office for Disability Issues, Ministry of Social Development *Government Response to the United Nations Committee on the Rights of Persons with Disabilities’ Concluding Observations on New Zealand* (June 2015, <http://www.odi.govt.nz>) paragraph 1. As at November 2015, 160 countries have ratified the CRPD and 88 countries have ratified the Optional Protocol. United Nations Enable “Convention and Optional Protocol Signatories and Ratification” [www.un.org/disabilities/countries.asp?id=166](http://www.un.org/disabilities/countries.asp?id=166).

15); the right to respect for physical and mental integrity (art 17); and the right to live independently and be included in the community (art 19).

## Article 12 of the CRPD

2.13 In addition to the general principles and obligations contained in the CRPD, art 12 and the right to equal recognition before the law are of central importance in understanding how the CRPD applies to mental capacity law and practice. The emphasis is on equal *legal* capacity. Legal capacity comprises both *legal standing* – being recognised as a person before the law, and *legal agency* – the ability to act within the framework of the legal system.<sup>237</sup> There is an obligation on states to provide support to achieve equal capacity, for persons with disabilities who broadly include those who have “long-term physical, mental, intellectual or sensory impairments”.<sup>238</sup> In summary, art 12 recognises the following rights and obligations on state parties:

- the right to enjoy *legal capacity on an equal basis* with others;<sup>239</sup>
- the obligation of governments to implement *measures that provide access to support* by those who need it to exercise their legal capacity;<sup>240</sup> and
- the obligation of governments to ensure *safeguards are in place to prevent abuse* in relation to measures for the exercise of legal capacity.<sup>241</sup>

## The support paradigm

2.14 In 2014, the United Nations Committee on the Rights of Persons with Disabilities (the UN Committee) released a General Comment (the General Comment) to aid interpretation of art 12. The UN Committee perceived: <sup>242</sup>

... a failure by state parties to understand the human rights-based model of disability implies a shift from the substitute decision-making paradigm to one that is based on supported decision-making.

2.15 This paradigm shift represents a change in attitudes to disability that have moved away from the medical model of disability, which concentrates on the individual's limitations, to a social model, which identifies barriers created in society.<sup>243</sup> Under the UN Committee's interpretation of the CRPD, perceived or actual deficits in mental capacity must not be used as a justification for denying legal capacity.<sup>244</sup>

2.16 The scope of the obligations imposed by art 12, as interpreted in the General Comment, are controversial, particularly whether the concept of incapacity can still be used as a relevant

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<sup>237</sup> Bach and Kerzner, above n 33. See also B McSherry “Legal issues: legal capacity under the convention on the rights of persons with disabilities” (2012) 20 J Law Med 22.

<sup>238</sup> United Nations Convention on the Rights of Persons with Disabilities, art 1.

<sup>239</sup> United Nations Convention on the Rights of Persons with Disabilities, art 12(1) and (2).

<sup>240</sup> United Nations Convention on the Rights of Persons with Disabilities, art 12(3).

<sup>241</sup> United Nations Convention on the Rights of Persons with Disabilities, art 12(4).

<sup>242</sup> United Nations Committee on the Rights of Persons with Disabilities *General Comment Number 1 Article 12: Equal recognition before the law*, CRPD/C/GC/1 (2014) at [3]. The Convention itself does not actually mention “supported decision-making” or “substitute decision-making” or define these terms.

<sup>243</sup> Bach and Kerzner, above n 33 at 18.

<sup>244</sup> General Comment No 1, above n 242 at [12]. As discussed above, a distinction is made between legal capacity – a legal status or standing, and mental capacity – the ability of individuals to make decisions for themselves, either on their own or with support.



concept in law without breaching the CRPD.<sup>245</sup> Although legal capacity is a central concept within the CRPD, the Convention itself provides no definition of it. The General Comment also claims that art 12 prohibits the imposition of “substitute decisions” on people with disabilities in all cases, requiring instead that they be given access to the support they need to exercise their legal capacity in accordance with their will and preferences.<sup>246</sup>

- 2.17 In England, a report commissioned by the Ministry of Justice found that the MCA was not fully compliant with the CRPD in terms of its definition of “mental incapacity”, and in safeguarding the “rights, will and preferences” of the person, as required by art 12(4), in the MCA’s best-interests decision-making framework.<sup>247</sup> The authors rejected, however, the UN Committee’s claim that compliance with the CRPD requires the abolition of substitute decision-making and the best-interests decision-making framework. As a matter of international law, the status of the General Comment is that of an authoritative statement rather than a binding instrument such as the Convention itself, but it is considered to be a powerful influence on domestic policy debates.<sup>248</sup>
- 2.18 The UN Committee’s view that all persons have legal capacity at all times irrespective of mental status has attracted criticism, particularly if it requires the immediate abolition of mental health laws involving involuntary admission and treatment.<sup>249</sup> Even proponents of the “fusion” of mental health and mental capacity law into a single statutory regime governing state intervention in the lives of people with disabilities that would be based squarely on incapacity criteria, regard the UN Committee’s interpretation of art 12 as being unrealistic.<sup>250</sup> It fails to recognise potential difficulties in determining a person’s genuine “will and preferences”, and there is a lack of clarity as to when “supported” decision-making becomes “substitute” decision-making, and when and why the safeguards listed in art 12(4) are required around this process.

## Safeguards to prevent abuse

- 2.19 The notion that supported decision-making should be “free of conflict of interest and undue influence” under art 12(4) of the CRPD is one of the most important provisions of the CRPD. The safeguards must ensure that:<sup>251</sup>

... measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.

- 2.20 A common criticism of the support paradigm is that it offers few tools under art 12(4) to mitigate harmful decisions and does not deal with the “hard cases”, where there is the potential for

<sup>245</sup> P Bartlett “The UN Convention of the Rights of Persons with Disabilities and Mental Health” (2012) 75 *Mod Law Rev* 752; S Callaghan and C Ryan “An Evolving Revolution: Evaluating Australia’s compliance with International Human Rights in Mental Health Law” (2016) draft article.

<sup>246</sup> General Comment No.1, above n 240 at [26].

<sup>247</sup> Szerletics, above n 209.

<sup>248</sup> Szerletics, above n 209 at 12, fn 18 where the legal status of General Comments is discussed further. See also T Carney “Supported decision-Making for People with Cognitive Impairments: An Australian Perspective?” (2015) 4 *Laws* 37 at 41.

<sup>249</sup> MC Freeman, K Kolappa, JM de Almeida and others “Reversing hard won victories in the name of human rights: a critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities” (2015) 2(9) *Lancet Psychiatry* 844.

<sup>250</sup> J Dawson “A realistic approach to assessing mental health laws’ compliance with the UNCRPD” (2015) *Intl J Law Psych* 1; Callaghan and Ryan, above n 245.

<sup>251</sup> United Nations Convention on the Rights of Persons with Disabilities, art 12(4).

undue influence, exploitation and abuse by supporters of the person with impaired capacity. The hard cases can occur within both substitute decision-making (guardianship) and supported decision-making regimes.<sup>252</sup> While the latter is less paternalistic, it runs the risk of offering little protection against harm.

- 2.21 Protecting people from harmful influences raises the whole notion of how autonomy is viewed in the law, when a facet of autonomy concerns an individual's ability to make an informed, uncoerced decision. In this respect, capacity and the notion of undue influence are inextricably linked.<sup>253</sup>

## Negative and positive rights

- 2.22 The CRPD is also significant because it attempts to break down traditional distinctions between civil and political rights, which are usually negative – such as non-interference by the state – and social and economic rights, which are usually positive, such as guaranteeing social inclusion and participation and the right to healthcare.<sup>254</sup> Positive obligations in respect of autonomy do not mean that “what I want should be delivered”, but that a fair balance should be struck between individual rights and societal interests.<sup>255</sup>
- 2.23 Under the CRPD, the problem that emerges is how to deliver support mechanisms required under art 12(3) (a positive right), while at the same time ensuring protection from abuse under art 12(4) (a negative right).<sup>256</sup> Protection from harm, and the recognition of the vulnerability of people with impaired capacity to abuse and exploitation, form the rationale for the appointment of substitute decision-makers in adult guardianship law, and for the existence of the inherent “protective” jurisdiction of the court.<sup>257</sup> For example, the purpose of the PPPR Act is to “protect and promote” the rights of people who lack capacity.<sup>258</sup> The law recognises that protecting people from harm can be a source of empowerment and can correspondingly promote autonomy.

## The CRPD and the PPPR Act

- 2.24 After signing the CRPD, New Zealand's PPPR Act was initially considered consistent with the CRPD, although the analysis undertaken was relatively superficial as there was a push at the time for New Zealand to ratify the Convention as soon as possible given New Zealand's role in promoting the Convention.<sup>259</sup> While the primary objectives of the PPPR Act and its

<sup>252</sup> L Series “Relationships, autonomy and legal capacity: Mental capacity and support paradigms” (2015) 40 Int J Law Psych 80 at [4.5].

<sup>253</sup> D Lush, Senior Judge of the Court of Protection “Question and Answer session” (Academy of European Law's Conference on the Rights of Persons with Disabilities, Trier, Germany, 11 and 12 December 2014).

<sup>254</sup> M Donnelly *Healthcare Decision-making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, Cambridge, 2010) at 5. This divide between positive and negative rights is not always clear. Participation and inclusion are equally evident in some of the ICCPR.

<sup>255</sup> M Brazier cited by Donnelly, above n 254 at 79.

<sup>256</sup> Bach and Kerzner, above n 33 at 37.

<sup>257</sup> The protection of vulnerable adults outside of statutory law under the MCA has led to the re-emergence of the inherent jurisdiction in England: *DL v A Local Authority*, above n 213. See discussion of Vulnerable Adults and the Inherent Jurisdiction in Chapter 1A Setting the Context. In New Zealand, the inherent jurisdiction of the High Court still survives in the Protection of Personal and Property Rights Act, s 114 and Judicature Act 1908, s 17.

<sup>258</sup> Protection of Personal and Property Rights Act 1988, Preamble.

<sup>259</sup> McGregor, Bell and Wilson, above n 233 at 107-134.

participatory model may be aligned with the CRPD in some respects, supported decision-making (or a legal mechanism to implement it) is not expressly recognised in the legislation.<sup>260</sup>

- 2.25 The General Comment released in 2014 casts doubt on New Zealand's compliance with the CRPD as does the subsequent report on New Zealand's position from the UN Committee. New Zealand, along with many other countries that ratified the convention, has an adult guardianship law (the PPPR Act), the scheme of which provides for adult guardianship and substituted decision-making. Yet the concluding observations recommended "that the State party take immediate steps to revise the relevant laws and replace substituted decision-making with supported decision-making. This should provide a wide range of measures that respect the person's autonomy, will and preferences, and is in full conformity with Article 12 of the Convention."<sup>261</sup>
- 2.26 The Government's response to the UN Committee's criticisms of New Zealand law (based on its interpretations of art 12, as part of the independent monitoring process), has been muted. That response does not directly address the UN Committee's recommendation to take "immediate steps" to revise relevant laws and replace substituted decision-making with supported decision-making.<sup>262</sup> Paul Gibson, the Disability Commissioner, says, "We are getting so far behind and we were once a leader".<sup>263</sup>

## Australian law reform

- 2.27 In 2014, the Australian Law Reform Commission's report (the Australian report) examined the legal framework within Australia and the changes required having regard to the CRPD.<sup>264</sup> The main recommendation of the Australian report is for the Commonwealth states to establish national decision-making principles to ensure that supported decision-making is encouraged.<sup>265</sup> In fact, much of the relevant legislation would have to be enacted in Australia at the state – rather than federal (or Commonwealth) – level of government.
- 2.28 Prior to the Australian report in 2012, the Victorian Law Reform Commission (VLRC) advised that the existing laws in Victoria were complex and inaccessible, with provision for six different types of substitute decision-makers to be appointed, under three separate Acts.<sup>266</sup> The key VLRC recommendation was to create a single statute to provide for substitute decision-making for people with impaired capacity that allowed for a continuum of decision-making

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<sup>260</sup> The primary objectives of the PPPR Act are to make the least restrictive intervention and maximise a person's participation to the greatest extent possible: Protection of Personal and Property Rights Act 1988, s 8, discussed below.

<sup>261</sup> Office for Disability Issues *Government response to the United Nations Committee on the Rights of Persons with Disabilities Concluding Observations on New Zealand* (Ministry of Social Development, Wellington, 2015) at [22].

<sup>262</sup> Instead the Government's response refers to the existing Disability Action Plan 2014-2018 and that this work may recommend changes to legislation. ODI above n 261 at [19]. The UN Committee directed its recommendations more towards compliance with the Mental Health (Compulsory Assessment and Treatment) Act 1992. It is also important to note that the CRPD is concerned to remove discrimination across a range of laws that affect people with disabilities.

<sup>263</sup> Interview with Paul Gibson, Disability Commissioner, Human Rights Commission. (A Douglass, Wellington, 2015).

<sup>264</sup> Australian Law Reform Commission *Equality, Capacity and Disability in Commonwealth Laws* (ALRC Report 124, Canberra, August 2014).

<sup>265</sup> Other key principles are that representative decision-makers are appointed only as a last resort; and a person's will, preferences and rights are to direct decisions that affect their lives. However, the Australian report says very little about *how* to implement measures to safeguard against abuse under art 12(4) of the CRPD. See Guidelines at 86 - 87 of Australian report.

<sup>266</sup> Victorian Law Reform Commission *Guardianship: Final Report 24* (VLRC, Melbourne, 2012) at 37 at [3.30].

arrangements and mechanisms. In addition to more traditional substitute decision-making arrangements, the VLRC recommended the creation of “supporters” and “co-decision-makers” who could be appointed by the person or by the Victorian Civil and Administrative Tribunal (VCAT).<sup>267</sup>

- 2.29 In 2014, a Bill was introduced to the Victorian Parliament which would have established Australia’s first supported decision-making model. However, it has not yet passed into law.<sup>268</sup> Two of the reform initiatives were roundly criticised and were described as “botched”.<sup>269</sup> There was conflation of the concepts of supported and substituted decision-making by creating “supportive guardians” and “supportive attorneys”, as well as a proposal for expedited appointment of parents as guardians or administrators of children lacking decision-making capacity on turning 18.<sup>270</sup>

## 2B: LEGAL PRINCIPLES

### Supported decision-making – in law

- 2.30 Supported decision-making is a central concept in art 12 of the CRPD. It is based on the idea that all adults, except in limited circumstances, have some level of ability and should be entitled to make decisions expressing their will and preferences, but may require varying levels of support to do so. Rather than question whether a person has capacity to make decisions – reflecting a “binary view” of capacity and decision-making – the preferable approach is to ask what level of support, or what mechanisms, are necessary to support people to express their will or preferences.<sup>271</sup> Supported decision-making can be referred to as a process, a mechanism, a system, or a framework.<sup>272</sup> The concept encompasses a range of support mechanisms from informal to formal. Carney summarises a number of these:<sup>273</sup>

1. effective communication, especially in providing information and advice to a person and ensuring they are able to communicate their decisions to others;
2. spending time to determine a person’s preferences and wishes;
3. informal relationships of support between a person and members of their social networks;
4. agreements or appointments to indicate that a relationship of support exists; and

<sup>267</sup> Victorian Law Reform Commission, above n 266, at xxvii and xli. A similar continuum concept was developed (and subsequently revised) in the Irish Assisted Decision-Making Bill, see Chapter 1C.

<sup>268</sup> Guardianship and Administration (G&A) Bill 2014. This was a partner Bill to the Powers of Attorney Bill 2014, which was passed and the Act commenced on 1 September 2015. The G&A Bill did not pass before the 2014 elections, which the governing conservative coalition lost. The Bill is no longer listed on the Victorian Legislation and Parliamentary Documents website ([www.legislation.vic.gov.au](http://www.legislation.vic.gov.au)).

<sup>269</sup> T Carney “What does the UN CRPD and Supported Decision-making Mean in the Real World?” Presentation to Capacity Australia conference, Sydney, 13 November 2015.

<sup>270</sup> T Carney “Supporting People with Cognitive Disabilities with Decision-Making: Any Australian Law Reform Contributions?” (2015) 15/23 Sydney Law School Legal Studies Research Paper at 2. Carney, above n 269.

<sup>271</sup> Australian report, above n 264 at 93.

<sup>272</sup> Browning, Bigby and Douglas, above n 226 at 36.

<sup>273</sup> T Carney “Participation and Service Access Rights for People with Intellectual Disability: A Role for the Law?” (2013) 38 J Intell Devel Disab 59 at 66.

5. statutory relationships of support – whether through private or court/tribunal appointment.

- 2.31 Unlike traditional guardianship law, supported decision-making focuses on people retaining their *legal* powers of decision, but a third party is authorised by law to do such things as provide assistance, or access and share their personal information.<sup>274</sup> As understood in human rights law, supported decision-making involves more than support *with* decision-making: it is about providing an alternative legal mechanism that give people legal standing where possible and to recognise their needs within the framework of the law.<sup>275</sup>
- 2.32 Legal capacity can be understood as a continuum in which supported decision-making occurs throughout. There is a point along the continuum in which a person may be found unable to make a legally binding decision, even with support (here the person loses legal agency but retains legal standing).<sup>276</sup> Where this point is to be found depends on the complexity of the decision. But the likely will and preferences of the person still remain central to the decision-making process.
- 2.33 There are some challenges in establishing legal frameworks in line with the CRPD. The lack of a clear definition of supported decision-making has led to conceptual confusion about what it means in law. Its connection to the concept of legal capacity is not entirely clear. Nor is it clear how substitute decision-making and the modern notion of supported decision-making are to co-exist. There will be some situations when a person is completely unable to participate in decisions, such as when in a coma. There will also be circumstances where a person with impaired capacity is given support but they may still lack the ability to make a decision for themselves. In these situations a substitute decision-maker will need to make a decision for them.

### Supported decision-making – a legal principle

- 2.34 Existing legal principles in both the MCA and PPPR Act implicitly assume that there is a role for supported decision-making, more expressly so in the MCA. These legal principles and concepts govern all decisions made and actions taken under both mental capacity laws. They are the aids to interpreting the law. Both the MCA and the PPPR Act have principles that are remarkably similar except for the MCA's overriding decision-making principle of the person's best interests.<sup>277</sup> By comparison, best interests is not an express principle of the PPPR Act; instead its primary objectives are to make the least restrictive intervention and to maximise the person's capacity to participate in decision-making.<sup>278</sup>

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<sup>274</sup> T Carney, above n 273 at 60.

<sup>275</sup> Browning, above n 226 at 40.

<sup>276</sup> Browning, above n 226 at 39.

<sup>277</sup> Mental Capacity Act 2005, ss 1(5) and 4.

<sup>278</sup> Protection of Personal and Property Rights Act 1988, s 8(1) and (2). Under the HDC Code, where a person has diminished competence for decision-making they still retain the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence: Right 7(3).

**Figure 2: Legal principles**

| Mental Capacity Act   | PPPR Act   |
|---|--|
| <ul style="list-style-type: none"> <li>• Assumption of capacity</li> <li>• All practicable steps to help make a decision</li> <li>• Unwise decisions</li> <li>• <b>Best interests</b></li> <li>• Less restrictive of the rights and freedoms</li> </ul> | <ul style="list-style-type: none"> <li>• Presumption of capacity</li> <li>• <b>Maximising a person's capacity to the greatest extent possible</b></li> <li>• Imprudent decisions</li> <li>• <b>Least restrictive intervention</b></li> </ul> |

**KEY : Red shows primary principles of the respective legislation**

- 2.35 All legal principles in the MCA and the PPPR Act are underpinned by the ethical notion of autonomy to a lesser or greater degree, even though the value of autonomy in some situations is contested. The presumption of capacity,<sup>279</sup> maximising a person's capacity, and maintaining their freedom to make unwise decisions (if capable or "capax"),<sup>280</sup> reflect the legal "right" to non-interference and to make decisions for one's self.
- 2.36 The "unwise decisions" principle asserts that people are entitled to make imprudent decisions so long as they have the capacity to do so.<sup>281</sup> Thus, a person cannot be deemed to lack capacity just because health professionals, or even the court, disagree with their decisions. But making unwise choices may be sufficient to raise doubts as to the person's capacity, for example, if this is out of character.<sup>282</sup> It is an assessment of a person's decision-making ability and not the substance of the decision they make, that is relevant to the court exercising jurisdiction. Despite this "imprudence limitation", under the PPPR Act the court may still consider that the appointment of a welfare guardian is the only way to achieve "appropriate" decisions, one of the criteria for appointing a welfare guardian.<sup>283</sup>
- 2.37 Both English and New Zealand statutes have principles akin to the notion of supported decision-making but there are few mechanisms to prioritise or enforce them. In the MCA, a person is "not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success."<sup>284</sup> The accompanying Code of Practice under the MCA provides guidance to professionals and decision-makers on how to support people

<sup>279</sup> The PPPR Act affirms the common law presumption of competence. The presumption is rebuttable and the legal burden of establishing lack of competence falls on the person alleging it. The presumption of competence appears in s 5 Part 1, Personal Rights, s 24, Part 5 Property Rights and s 93B Enduring Powers of Attorney, the Protection of Personal and Property Rights Act 1988. Under the HDC Code the presumption of competence is recognised in Right 7(2).

<sup>280</sup> "Capax/incapax" is Latin for capable/incapable, latin-dictionary.net.

<sup>281</sup> Mental Capacity Act 2005, s 1(5); Protection of Personal and Property Rights Act 1988, s 6(3).

<sup>282</sup> P Letts (ed), *Assessment of Mental Capacity, A Practical Guide for Doctors and Lawyers* (3<sup>rd</sup> ed, The British Medical Association and the Law Society, 2010) at 27.

<sup>283</sup> Protection of Personal and Property Rights Act 1988, s 12(2).

<sup>284</sup> Mental Capacity Act 2005, s 1(3).



to understand relevant information during assessment of their capacity and to enhance their capabilities for decision-making.<sup>285</sup>

- 2.38 In the PPPR Act, one of the primary objectives is to maximise a person's capacity to the greatest extent possible. This is sometimes referred to as the "empowerment principle". This description overstates the weight attached to it in practice, as it tends to be overshadowed by the other primary objective of making the least restrictive intervention.<sup>286</sup> Both these principles generally come into play only *after* a person has been found to lack capacity and an intervention is considered necessary. For example, only after a welfare guardian has been appointed are they placed under a duty to consult the person subject to the order and to maximise their participation in decisions.<sup>287</sup>
- 2.39 The weakness of this legal framework is that there is no positive obligation to support the person to exercise their capacity at the beginning of the decision-making process; or, put another way, there is no *presumption* of supported decision-making. Furthermore, if a person lacks capacity and intervention is considered necessary, the framework does not emphasise that their will and preferences are still to be taken into account when decisions are made by others.

## 2C: ETHICS, AUTONOMY AND THE LAW

### Autonomy and capacity

- 2.40 The law's approach to capacity is consistent with a traditional liberal account of autonomy based on individual rights and non-interference. The liberal account still places limits on autonomy to avoid harm. In John Stuart Mill's words:<sup>288</sup>

The only purpose for which power can be rightfully exercised over any member of a civilised community against his will, is to prevent harm to others...Over himself, over his own body and mind, the individual is sovereign.

- 2.41 There are occasions when the State, through the law, might legitimately override the autonomy of individuals for their own good; for example, the mandatory use of bike helmets for road safety, or mental health laws that override an individual's autonomy to protect the individual from doing harm to self or others.
- 2.42 Although autonomy is not without limits, once the right to autonomy does arise, it is accorded primary status in a hierarchy of values.<sup>289</sup> If there is a conflict between autonomy and other

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<sup>285</sup> Office of the Public Guardian *Mental Capacity Act Code of Practice* (TSO, London, 2013) at 29.

<sup>286</sup> The objective of maximising a person's participation to the greatest extent possible is rarely referred to in Family Court judgments.

<sup>287</sup> Protection of Personal and Property Rights Act 1988, s 12.

<sup>288</sup> JS Mill *On Liberty* (John Parker & Son, London, 1859). JS Mill is often cited by Judges in refusal of treatment cases. For example, *Nottinghamshire Healthcare NHS Trust v RC*, above n 191, at [1.105].

<sup>289</sup> One of the most influential texts in medical ethics where the principle of autonomy has been accorded status above other principles such as beneficence is TL Beauchamp and JF Childress, *Principles of Biomedical Ethics* (7<sup>th</sup> ed, Oxford University Press, New York, 2013).

values, respect for autonomy dictates that decision-making power must be fully situated in the individual regardless of consequences for the person's welfare and even for their life.<sup>290</sup>

- 2.43 Capacity is said to be the gatekeeper for autonomy,<sup>291</sup> as embodied in the legal principles of the presumption of competence and that a person is entitled to make imprudent decisions (in English law, “unwise decisions”) so long as they are considered to have the capacity to do so.<sup>292</sup> This “brightline” division between capacity and incapacity, however, avoids broader questions of decision-making agency (and to be recognised as “an actor in law”), preferring instead to shoehorn questions of agency into the test of capacity.<sup>293</sup> The problem with this brightline approach is the failure to recognise the extent to which people with impaired capacity can truly exercise their autonomy. As Donnelly explains,<sup>294</sup>

A person with dementia forced to choose between continuing to live at home with an abusive child or life in a nursing home, can hardly be described as an autonomous agent, notwithstanding whether or not he or she meets a legal standard for capacity.

- 2.44 In setting boundaries of mental capacity, if the person's decision fits with societal norms, there is a tendency to regard the decision as demonstrating the person's capacity. If however, the decision differs from societal norms, it is more likely that the person's capacity is questioned.<sup>295</sup> Intervention on the basis of incapacity is an important component of the law's approach to healthcare decision-making, where there is a need to balance the values of autonomy (self-determination) and beneficence (well-being).<sup>296</sup>

## Autonomy and the importance of relationships

- 2.45 There is a substantial body of literature in bioethics that is critical of the liberal notion of autonomy because it is viewed as too individualistic and inconsistent with other important values, such as dignity<sup>297</sup> or trust.<sup>298</sup> There has been increased recognition of autonomy as a relational concept. In essence, relational autonomy treats a person's agency as shaped or even constituted by their environment and supporting relationships with others,<sup>299</sup> even though relationships can also be oppressive and a threat to a person's autonomy. Beyond agreement that autonomy is valuable and cannot be separated from relational and social conditions, there are diverse approaches to relational autonomy.<sup>300</sup>
- 2.46 While respect for autonomy is central to the human rights framework, other values, including respect for dignity are also important.<sup>301</sup> The CRPD's approach to legal capacity has largely

<sup>290</sup> Donnelly, above n 254 at 21.

<sup>291</sup> Donnelly, above n 254 at Chapter 3.

<sup>292</sup> Protection of Personal and Property Rights Act 1988, s 6(3).

<sup>293</sup> Donnelly, above n 254 at 59 - 65.

<sup>294</sup> Donnelly, above n 24 at 278. This example is in reference to the development of the vulnerability-based inherent jurisdiction in England.

<sup>295</sup> M Brazier and E Cave *Medicine, Patients and the Law* (5<sup>th</sup> ed Penguin Books, London, 2011) at 65.

<sup>296</sup> Buchanan and Brock, above n 35.

<sup>297</sup> C Foster *Choosing Life and Choosing Death: The tyranny of autonomy in medical ethics and law* (Hart Publishing, Portland & Oxford, 2009).

<sup>298</sup> O'Neill *Autonomy and Trust in Bioethics* (Cambridge University Press, Cambridge, 2002).

<sup>299</sup> Relational models of autonomy have been influential among feminist theorists with some approaches more controversial than others. See C MacKenzie and N Stoljar (eds) *Relational Autonomy: Feminist Perspectives on Autonomy, Agency and the Social Self* (Oxford University Press, New York, 2000). See also J Herring *Relational Autonomy and Family Law* (Springer, New York, 2014).

<sup>300</sup> Series, above n 252.

<sup>301</sup> The stated purpose of the CRPD in art 1 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”. See also art 15, freedom from torture and inhuman and degrading treatment; art 17, respect for physical and mental integrity; and art 22, respect for privacy.

drawn on the notion of relational autonomy.<sup>302</sup> A relational approach to capacity assessments for example, requires a shift in focus away from testing the internal workings of the individual's mind and instead requires that account be taken of the wider context, both structural and personal, which influences the person's capacity. As Donnelly says:<sup>303</sup>

The capacity assessor may no longer be viewed as an objective outsider who tests the patient and decides whether she is capable or not but as an essential part of the process of developing her capacity.

- 2.47 Whether the rights enshrined in the CRPD are viewed through an individualistic or a relational lens on autonomy, there is agreement about the importance of relationships in exercising legal capacity. Decision-making ability cannot be viewed in isolation and may be dependent on the quality of a person's relationships with others. Valuing autonomy is viewed as a positive obligation, even an achievement,<sup>304</sup> which places the individual at the centre of the decision-making.

### Best interests and supported decision-making

- 2.48 Despite its paternalistic origins, the "best interests" standard for decision-making in the MCA has the potential to provide meaningful protection for a person's autonomy where a person lacks capacity in law.<sup>305</sup> In the past, best interests at common law (and as understood in earlier case law) has traditionally been associated with imperatives of doing good, and avoidance of harm. In its highest form it is regarded as an expression of paternalism – what is best for that person decided by someone else.
- 2.49 Properly understood, assessing best interests recognises the importance of relationships.<sup>306</sup> As a standard for decision-making it adds considerable transparency to the decision-making process and to the reality that there will be situations where a person is unable to make and/or participate in making a decision and the decision will need to be made for them by others.
- 2.50 Section 4 of the MCA provides a checklist of factors to be applied in making an assessment of best interests that takes into account "a wide range of ethical, social, moral, emotional and welfare considerations".<sup>307</sup> It is a hybrid standard: the overall question of a person's best interests is an objective one, but is informed by the person's past and present wishes and the opinion of others as to what would be in their best interests.<sup>308</sup>

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<sup>302</sup> Series, above n 252. The Essex Autonomy project argued that the functional test for decision-making ability is consistent with the CRPD in part because of the intrinsic connection between decision-making ability and autonomy. They accepted a moderate relational position but rejected the idea that the CRPD requires recognition of *active* legal capacity, accepting that legal agency (being "an actor under the law") is a fundamental component of legal capacity.

<sup>303</sup> Donnelly, above n 254 at 113.

<sup>304</sup> An account of autonomy as an "achievement" draws on the work of J Raz *The Morality of Freedom* (Oxford University Press, London, 1986) at 204, cited in M Donnelly, above n 254 at 41.

<sup>305</sup> See Chapter 5 Best Interests: a standard for decision-making.

<sup>306</sup> J Herring and C Foster "Welfare Means Relationality, Virtue and Altruism" (2010) 32(3) *Legal Studies* 480. The authors refer to the welfare principle in the Children Act and the best interests test in the MCA as synonymous.

<sup>307</sup> *Re MM (An Adult)* [2007] EWHC 2003 (Fam) at [99] Munby J.

<sup>308</sup> Best interests decisions can also result in a decision that is contrary to a person's wishes. For example, *The Mental Health Trust and others v DD by her litigation friend, the Official Solicitor*: BC [2015] EWCOP 4 (Fam), a series of decisions where a 36-year-old woman with learning disabilities was ordered against her wishes to be taken to hospital for laparoscopic sterilisation. DD had six children previously who were looked after by substitute carers and with all of whom she had no ongoing contact.

- 2.51 As understood in the MCA, best interests is also based on notions of autonomy. It makes it clear that, even though the person may lack capacity (in law), "so far as reasonably practicable" they should be permitted and encouraged to participate "as fully as possible in any act done and any decision affecting them"<sup>309</sup> and that their "wishes and feelings must be taken into account".<sup>310</sup> This approach recognises that even where a person does not have capacity to make an effective decision, they may play an important part in the decision-making process.<sup>311</sup>
- 2.52 As Herring observes:<sup>312</sup>
- ... that does not mean their views and feelings count for nothing. Indeed there is recognition in section 4 that even if it is not possible for P (the person) to make a decision, they should still be involved to a reasonable extent in the decision-making process and their views should be listened to.
- 2.53 The best interests framework has been rejected by those who strongly emphasise the value of supported decision-making that is given priority in the CRPD; however, the inclusion in the process of the person with impaired capacity for decision-making can be viewed as an "appropriate measure" under art 12(3) of the CRPD to ascertain the person's will and preferences under art 12(4).<sup>313</sup> The English Law Commission has recommended that there should be a presumption of the person's wishes and feelings to make the best interests standard more compliant with the CRPD.<sup>314</sup> The Australian report has effectively rephrased the best interests standard in the language of the CRPD as "Will, Preferences and Rights Guidelines," and there is no appreciable difference in the standard to be adhered to by the substitute decision-maker.<sup>315</sup>
- 2.54 The "best interests" standard, by whatever name, recognises that where supported decision-making options have been exhausted, decisions by others need to be made. It can provide a transparent basis for decision-making when a person is unable to fully exercise their legal capacity and is an essential complement to a supported decision-making framework.

## 2D: THE CULTURAL DIMENSION

### Tikanga Māori

- 2.55 The centrality and importance of Māori beliefs and values, as expressed through tikanga Māori, has received growing recognition in modern New Zealand law. Tikanga, as an expression of Māori customary values and practice, brings recognition of Te Ao Māori, a Māori world view, and depth to the understanding of cultural values that underpin the law. Te Tiriti

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<sup>309</sup> Mental Capacity Act 2005, s 4(4).

<sup>310</sup> Mental Capacity Act 2005, s 4(6).

<sup>311</sup> Law Commission *Mental Incapacity: Item 9 of the Fourth Programme of Law Reform: Mentally Incapacitated Adults*, Commission paper No 231 (HMSO, London, 1995) at 46.

<sup>312</sup> Herring, "Best Interests and Dementia" in Foster, Herring and Doron, above n 24 at 303.

<sup>313</sup> Donnelly, above n 24 at 192.

<sup>314</sup> Law Commission, above n 199 at 166 [12.47].

<sup>315</sup> ALRC Report, above n 264. Recommendation 3-3 Will, Preferences and Rights Guidelines at 77. In cases where it is not possible to determine the will and preferences of the person, the default position must be to consider the human rights relevant to the situation. The duties of the "representative" to "uphold the person's human rights" is vague and in the writer's opinion, less helpful than the English standard of best interests in the MCA.

o Waitangi<sup>316</sup> (the Treaty) recognises the obligations and the relationship between the Crown and Māori as tangata whenua. It values indigeneity and upholds a set of rights that the indigenous people ought reasonably to expect to exercise in modern times.<sup>317</sup>

2.56 The Treaty also represents the bringing together of different world views: that is, English law, based on individual rights of self-determination and non-interference, with traditional Māori values (tikanga) such as self-determination – tino rangatiratanga – concerned with collective, not individual, interests.<sup>318</sup> The Treaty processes have given Aotearoa/New Zealand the ability and experience to respect these differences in a pluralistic society, by providing “a plumb line for values and respect for tikanga Māori,” as a basis for new legal frameworks.<sup>319</sup>

2.57 Justice Joseph Williams describes tikanga in this way: <sup>320</sup>

The system of law that emerged from the baggage Kupe’s people brought and the changes demanded by his descendants by the land itself have come to be known as tikanga Māori: “tika” meaning correct, right or just; and the suffix “nga” transforming “tika” into a noun, thus denoting the system by which correctness, rightness or justice is maintained. That said, tikanga and law are not co-extensive ideas. *Tikanga includes customs or behaviours that might not be called law but rather culturally sponsored habits.* (Emphasis added)

2.58 In *Takamore v Clarke*,<sup>321</sup> a case involving a burial dispute between Mr Takamore’s iwi and his partner who was executor of his will, the Supreme Court held that “Māori custom according to tikanga is ... part of the values of the New Zealand common law”.<sup>322</sup> However, when considering the “executor rule”, the personal representative had the power not to acquiesce to tikanga.<sup>323</sup> One difference between the common law and tikanga in burial disputes concerns the decision-making process itself. Under common law, the burial decision is made by a single person, the executor. In contrast, tikanga facilitates and encourages discussion and debate over the place of burial. The emphasis is on collective discussion in deciding

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<sup>316</sup> Treaty of Waitangi 1840.

<sup>317</sup> M Durie “Universal provision, indigeneity and the Treaty of Waitangi”  
[www.victoria.ac.nz/law/research/publications/vuwlr/...3.../durie.pdf](http://www.victoria.ac.nz/law/research/publications/vuwlr/...3.../durie.pdf).

<sup>318</sup> 2015 is the 800th anniversary of the Great Charter: the Magna Carta. It is also the 175th anniversary of the signing of Te Tiriti o Waitangi, described, both in the 1840s and recently, by the Chief Justice, as the “Māori Magna Carta” in S Elias “The meaning and purpose of the Treaty of Waitangi” Hui-a-Tau Conference (Waitangi, NZ 4 September 2015).

<sup>319</sup> Submission to the Law Commission from the Public Issues Network of the Methodist Church of New Zealand, among many other submitters on tikanga Māori and the proposed new legal framework in *Death, Burial and Cremation, A New Law for Contemporary New Zealand* (NZLRC, R134, October 2015) at 206.

<sup>320</sup> J Williams “Lex Aotearoa: An Heroic Attempt to Map the Māori Dimension in Modern New Zealand Law” (2013) Waik L Rev at 1.

<sup>321</sup> [2012] NZSC 116, [2013] 2 NZLR 733.

<sup>322</sup> *Takamore v Clarke*, at [94], Elias CJ.

<sup>323</sup> *Takamore v Clarke*, at [152] and [164]-[165]. The common law provides that personal representatives have a right and duty to dispose of the deceased’s body, taking into account cultural considerations, including tikanga where relevant. However, the executor rule was confirmed by a majority of only three out of five members of the Supreme Court, with two members concluding it did not form part of New Zealand’s common law. This indicates that there may be different views about the continued appropriateness of this rule in burial disputes in modern circumstances. See Law Commission, *The Legal Framework for Burial and Cremation in New Zealand, A First Principles Review*, Issues Paper 34, 2013 at 17. It has been recommended that the current Burial and Cremations Act should be repealed and replaced by new statutes that reflect the basic principles of dignity of the deceased, recognition of tikanga Māori, freedom of religion and belief, and legislative certainty and accessibility. Law Commission, above n 319.



where the deceased will lie. The force and length of discussions often reflects the mana of the deceased.<sup>324</sup>

- 2.59 Not only is tikanga recognised in the evolving common law but also in legislation. Tikanga is routinely defined in statute as “Māori customary values and practices”.<sup>325</sup> In some instances, tikanga has acquired the status of a legal principle; for example, in the Resource Management Act 1991, decision-makers must have regard to the concept of kaitiakitanga (guardianship, as understood in accordance with tikanga).<sup>326</sup> The reasoning processes applied by the Environment Court takes into account these values and traditions in reaching a decision, by way of cultural relativism, respecting that each culture has its own value-laden system of traditions and beliefs.<sup>327</sup>
- 2.60 There is ongoing debate and discussion as to the precise status of tikanga at common law and within the legal system.<sup>328</sup> Creating a “space” for tikanga alongside legal certainty and individual autonomy is a challenge for policy and law-makers.<sup>329</sup> As Justice Christian Whata, speaking extra-judicially, says, “The real challenge is how tikanga, like the Treaty, might permeate the law”.<sup>330</sup>

### Whakawhanaungatanga – a platform for supported decision-making

- 2.61 One of the core values embedded within tikanga that aligns with supported decision-making is the relational notion of kinship, “whanaungatanga”. In traditional Māori society, the individual was important as a member of a collective.<sup>331</sup> The individual identity was defined through that individual’s relationships with others. The kinship relationship is based on whakapapa, which can be translated as a person’s genealogy. As Justice Joseph Williams explains:<sup>332</sup>

Of all the values of tikanga, whanaungatanga denotes the fact that in traditional Māori thinking relationships are everything – between people; between people and the physical world; and between people and the atua (spiritual entities). The glue that holds the Māori world together is whakapapa or genealogy identifying the nature of relationships between all things.

Whanaungatanga is ... the idea that makes the whole system make sense – including legal sense.<sup>333</sup>

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<sup>324</sup> Law Commission, above n 319 at 18.

<sup>325</sup> A Somerville “Tikanga in the Family Court – The Gorilla in the Room” (2016) NZFLJ (in print). Currently, there are statutory definitions in 43 Acts of Parliament and 79 Acts include the word “tikanga”, Appendix 1.

<sup>326</sup> Resource Management Act, s 7. Kaitiakitanga as understood in tikanga denotes guardianship and is distinct from the narrower pākehā concept of “stewardship” which is separately defined in s 7(aa). Māori values appear in ss 6, 7 and 8 of the Resource Management Act 1991 and are matters of national importance.

<sup>327</sup> See for example, *Ngati Hokopu Ki Hokowhitu v Whakatane District Council* 9 ELRNZ 111, Judge JR Jackson, where the “rule of reason” approach was applied with respect to the relationship (whanaungatanga) of Māori with Māori waahi tapu (sacred places) at 123, and discussion of cultural relativism in this context at 125.

<sup>328</sup> N Coates “The Recognition of Tikanga in the Common Law of New Zealand” (2015) 1 NZ L Rev 1.

<sup>329</sup> Law Commission, above n 319 at 19.

<sup>330</sup> CN Whata, High Court Justice “Evolution of Legal Issues Facing Māori” (Māori Legal Issues Conference, Pullman Hotel Auckland, 29 November 2013) at 25.

<sup>331</sup> This notion is not unique to Māori. Email communication with Dr Barry Smith (Chair of Health Research Ethics Committee, Te Rarawa and Ngāti Kahu) regarding kinship and supported decision-making to A Douglass (21 December 2015).

<sup>332</sup> J Williams “He Aha Te Tikanga Māori” (unpublished paper for the Law Commission, 1998) cited in Law Commission Māori Custom and Values in New Zealand Law, March 2001, Wellington. Study Paper 9 at 30.

<sup>333</sup> Williams, above n 320.



- 2.62 A second important concept of tikanga in this context is “mana”. In the decision-making context, mana ensures that individuals, especially elders, are accorded dignity and respect.<sup>334</sup> Mana is a very powerful concept because respect for an individual may be at the cost of collective advantage. It is not so easy in a tikanga decision to take away the mana of decision-making even if the whānau want to; for example, where an elder has stated a preference to stay living in her home when the whānau believes the support of hospital care is needed.<sup>335</sup>
- 2.63 “Whakawhanaungatanga”<sup>336</sup> refers to the process of bringing people together and fostering connections between people. The concept recognises the importance of the process of engaging with people through establishing relationships and relating well to others, by:
- *whanaungatanga*: making a connection and understanding relatedness to others; and
  - *mana*: upholding dignity for both personal and whānau integrity.
- 2.64 Whakawhanaungatanga describes this process of providing support and help in a broad sense by allowing the “blood links” beyond family to become an expression of the range of responsibilities and rights. Smith says: “As Māori, we do this (whakawhanaungatanga) well”.<sup>337</sup>
- 2.65 Supported decision-making processes that recognise whanaungatanga and mana have an obvious place in the Family Court. As observed by Judge Annis Somerville:<sup>338</sup>
- Whanaungatanga is an integral part of tikanga in the Family Court, incorporating concepts of societal relationships and the rights and obligations that are inherent in them. These concepts are fundamental to the working of the Family Court.
- 2.66 The involvement of families and support for whānau, hapū and iwi in Family Group Conferences (FGCs) under the Children, Young Persons and their Families Act 1989 (CYPF Act) is recognised as one of the more innovative aspects of the Family Court.<sup>339</sup> In this decision-making model, families have a collective imperative to find solutions for the care and protection of children. Yet surprisingly, neither tikanga nor whanaungatanga is defined or referred to in any statutes used in family law.<sup>340</sup> There are specific Māori cultural

<sup>334</sup> Interview with Justice Joseph Williams (Wellington, 10 December 2015). Mana is the source of rights and obligations of leadership. Mana is defined broadly as “a key philosophical concept, combining notions of psychic and spiritual force and vitality, recognised authority, influence and prestige and thus power and ability to control people and events” in R Benton (ed) *Te Matapunenga: A Compendium of references to the concepts and institutions of Māori customary law* (Victoria University Press, Wellington, 2013) at 154.

<sup>335</sup> Ibid.

<sup>336</sup> The derived causative with the prefix *whaka* denotes the application of, to make/do.

<sup>337</sup> Interview with Barry Smith, QSM: PhD, Chair of the Health Research Council Ethics Committee, Te Rarawa and Ngāti Kahu (A Douglass, December 2015). Bishop defines *whakawhanaungatanga* as a process by which relationships are generated and maintained through the identification (via culturally appropriate means) of linkages, engagement and connectedness and, on this basis, a commitment to other people and their welfare and well-being: R Bishop *Collaborative Research Stories* (Dunmore Press Ltd, Palmerston North, 1996).

<sup>338</sup> A Somerville, above n 325.

<sup>339</sup> Children Young Persons and Their Families Act 1989, s 5. The Care of Children Act 2004 has been criticised for taking a too individualistic approach to issues of care and protection. It makes only passing reference to Māori values and leaves potentially a more confused understanding of tikanga for the guardianship of children. See B Atkin “Harmonising family law” (2006) 5 NZFLJ 140 at 141.

<sup>340</sup> A Somerville, above n 325. For an example in child case law cited by Judge Somerville *WH v Chief Executive of the Ministry of Social Development* HC Auckland CIV-2007-404-007415, 11 September 2008, Courtney J. Another example of tikanga, and the inclusion of collective imperatives alongside

considerations recognised under mental health law, is also under the jurisdiction of the Family Court.<sup>341</sup> However, the extent that the cultural considerations in the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH(CAT) Act) are operationalised is unclear and there is no commonly accepted standard of practice.<sup>342</sup>

## Tikanga and diversity

- 2.67 Respecting the needs, values and beliefs of Māori does not mean that a pan-Māori perspective exists, as expressed in the question, “*whose tikanga?*” There is rarely one single viewpoint representative of Māori concerns, any more than there is a single ethical or religious viewpoint in any community. Moreover, there are examples in the development of law and policy in New Zealand where tikanga has shaped non-Māori views.<sup>343</sup> Any legal framework must accommodate cultural diversity in New Zealand’s pluralistic society, as well as the need to recognise the rights and needs of Māori as tangata whenua.
- 2.68 The positive obligation to recognise relationships of support in the CRPD sits comfortably with tikanga, and the process of engagement with Māori through whakawhanaungatanga. New Zealand has a unique opportunity to enrich the discussion in a review of the law by ensuring these cultural influences are taken into account and given status in law as an approach to supported decision-making.

## 2E: SUPPORTED DECISION-MAKING IN PRACTICE AND IN CASE LAW

### Supported decision-making in practice

- 2.69 Adult guardianship laws tend to be focused on the big decisions where there may be significant consequences or risks to the person concerned, for example life-threatening decisions about medical treatment or living arrangements in residential care. It is important to recognise that the vast majority of care and welfare decisions that occur on a daily basis are far more mundane and involve informal and practical methods of support. For example, it is well recognised that opportunities for people to participate in decision-making improve their ability to communicate.<sup>344</sup> The challenge is to include supported decision-making in everyday practice.
- 2.70 The needs, life experiences and family context of people with disabilities can be diverse between and within population groups. Support needs for people with intellectual disabilities or acquired brain injuries may be very different, for example, to the needs of older adults.

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valuing individual autonomy, are the Ngā Kooti Rangatahi, the Youth Courts held on marae (meeting places).

<sup>341</sup> The Mental Health (Compulsory Assessment and Treatment) Act 1992 makes special provision for “proper recognition” of whānau, hapū and iwi under ss 5 and 65.

<sup>342</sup> H Elder and R Tapsell “Māori and the Mental Health Act” in Dawson and Gledhill (eds), above n 92 at 249. See also J Baxter, T Kani Kingi, R Tapsell and others “The prevalence of mental disorder among Māori in Te Rau Hinengaro: The New Zealand Mental Health Survey” (2006) 39 Aust NZ Psych 401.

<sup>343</sup> For example, the recognition of the importance of whakapapa and the right to know your genetic origins in assisted reproductive technology has arguably led to a more open attitude to knowledge of genetic parentage in New Zealand than exists in other countries: K Daniels and A Douglass “Access to Genetic Information by Donor Offspring and Donors: Medicine, Policy and Law in New Zealand” (2008) 27 J Med Law 131.

<sup>344</sup> J Rosen, speech pathologist “Communication: the Keystone of Supported Decision-making” (Capacity Australia conference, Sydney, 13 November 2015).

Older adults may be more isolated and tend not to have the support systems that those with psycho-social disabilities may have. There may be less support for their decision-making and more dependency, by, for example, a parent on their adult children who hold an enduring power of attorney (EPOA). A younger adult with Down syndrome may seek more independence to live away from their family. Conversely, an older adult with Down syndrome and early onset of dementia may have only lived in the family home with little outside interaction but be lovingly cared for by their siblings: here the family relationship is built around dependency.<sup>345</sup>

- 2.71 Some people have no family to support them and, as is common in the Family Court, there are families that cannot agree or are incapable as a family group of providing appropriate support.<sup>346</sup> Failing to recognise these differences could result in an over-simplified legal framework for respecting the rights of people with impaired capacity.

### Patient-centred care and whakawhanaungatanga

- 2.72 Supporting people in making decisions for themselves, where this is possible, and, if it is not possible, providing mechanisms to maximise their participation, has some real advantages. In the healthcare context, the inclusion of the person subject to the decision not only improves the quality of the decision reached but also reflects best practice, referred to as “patient-centred care”.<sup>347</sup> Participative decision-making can have therapeutic benefits in terms of enhancing individual well-being and self-esteem. It can also reduce the possibilities of conflict between the person and healthcare professionals.<sup>348</sup>
- 2.73 In New Zealand, health disparities between Māori and non-Māori are well documented. Māori are significantly over-represented in populations treated under the MH(CAT) Act and the approach used to assess “mental disorder” has potential for bias in assessing Māori.<sup>349</sup> Similar biases may be present when assessing capacity under the PPPR Act or other areas of capacity law, such as fitness to plead under the criminal justice legislation. Elder and Tapsell highlight the current individual focus of capacity-based assessments and warn that this approach disregards the collective rights within whanau and the wider community.<sup>350</sup>
- 2.74 Health practitioners are required to demonstrate appropriate levels of cultural safety<sup>351</sup> and competency to be fit for practice.<sup>352</sup> “Cultural competence” is broadly defined – extending beyond ethnicity and recognising that patients identify with multiple cultural groupings,

<sup>345</sup> These are common examples experienced in practice by the writer and reflect the importance of not making assumptions about diverse family relationships.

<sup>346</sup> In New Zealand there is no public agency that fulfils this role and there is a shortage of people available to be an independent welfare guardian to assist families. An example is the Otago Welfare Guardian Trust. In Wellington a community trust has recently been established. For many years in Wellington the Catholic nuns, Sisters of Mercy, fulfilled this role for the Wellington Family Court.

<sup>347</sup> AE Bauman, HJ Fardy and PG Harris “Getting it right: why bother with patient-centred care?” (2003) 179 Med J Aust 253.

<sup>348</sup> Donnelly, above n 254 at 205 - 206.

<sup>349</sup> Measures for Māori wellbeing in mental health can be assessed from a holistic viewpoint and take into account the dimensions of spiritual, mental and physical health, as well as relationships with family and community; M Durie “Measuring Māori Wellbeing” (New Zealand Treasury Guest Lecture Series (Hau Oranga), Wellington, 2006).

<sup>350</sup> Elder and Tapsell, above n 342. The authors warn against using capacity to consent as a criterion for any revision of the MHA.

<sup>351</sup> “Cultural safety” (whakaruruhau) was a concept developed by the late Irihapeti Ramsden and adopted by the nursing profession. See also B Gray “Managing the cross-cultural consultation. The importance of cultural safety” (2008) 35(2) NZFP.

<sup>352</sup> Health Practitioners Competence Assurance Act 2003, s 118 (i).

including groupings with different belief systems and ideas about disability.<sup>353</sup> An understanding of cultural competence provides a basis for applying supported decision-making in practice. There is current recognition that the “Western” model of patient-centred care is at odds with a traditional Māori way of viewing the world<sup>354</sup> and that, if a broad view of culture is taken, then the majority of patients are culturally different from most health practitioners and from the dominant Western medical view of the world.<sup>355</sup>

2.75 Medical students are now trained in applying a Māori-centred consultation approach for engaging with Māori patients, known as the “Hui Process” and the “Meihana Model,” two Māori-centred clinical interviewing tools.<sup>356</sup> The Hui Process recognises whakawhanaungatanga in a clinical context (including where a capacity assessment might be undertaken), and the importance of the doctor establishing a cultural connection with the patient, thus distinguishing it from basic rapport.<sup>357</sup>

2.76 Dr Greg Young, a non-Māori doctor, explains experience of whakawhanaungatanga when undertaking a capacity assessment with a Māori patient:<sup>358</sup>

[Each] person at the meeting explained his ancestry in a brief but structured way, and Māori in the room were able to identify connections between their respective families. At the end, the Māori cultural advisor, rather kindly, explained to the patient and his support people that I, a European with English ancestry, was related historically through the wider Young family, to Nick Young, the cabin boy on the Endeavour who first spotted land when Cook came to New Zealand. Nick Young is remembered locally because his name is given to a cape – “Young Nick’s Head”. This process of identifying connections and relationships is vital to engaging Māori in the assessment, and in my experience it is very helpful to go through that process to some degree before getting into the technicalities of the assessment.

2.77 Whakawhanaungatanga can therefore be viewed as providing a platform for supported decision-making, and for Māori is a baseline for culturally responsive practice.<sup>359</sup> All of these factors suggest that any revised mental capacity law should recognise tikanga Māori decision-making processes, both at the level of legal principle and for implementation within a Code of Practice.<sup>360</sup>

<sup>353</sup> These include (but are not limited to) gender, spiritual and other belief systems, sexual orientation, disability, lifestyle, age or socioeconomic status. The definition of cultural competence in the New Zealand Medical Council’s statement is: “*Cultural competence requires an awareness of cultural diversity and the ability to function effectively, and respectfully, when working with and treating people of different cultural backgrounds.*” There is no similar professional standard of cultural competence for lawyers.

<sup>354</sup> R Parry, B Jones, B Gray and others “Applying a Māori-centred consultation approach for engaging with Māori patients: an undergraduate medical student case study” (2014) 6(3) J Prim Healthc 254.

<sup>355</sup> Parry, Jones, Gray and others, above n 354 at 254.

<sup>356</sup> C Lacey, T Huria, L Beckert and others “The Hui Process; a framework to enhance the doctor-patient relationship with Māori” (2011) 124 NZMJ at <http://www.nzma.org.nz/journal/read-the-journal/all-issues/2010-2019/2011/vol-124-no-1347/view-lacey>; S Pitama, T Huria and C Lacey “Improving Māori Health outcomes through clinical assessment: Waikare o te Waka o Meihana” (2014) 127 NZMJ 107.

<sup>357</sup> Parry, Jones, Gray and others, above 354 at 255.

<sup>358</sup> Email communication with Dr Greg Young, (Consultant Psychiatrist, Capital and Coast DHB) regarding whakawhanaungatanga (11 March 2016).

<sup>359</sup> Interview with Dr Jo Baxter, Associate Dean of Māori, University of Otago (A Douglass, Dunedin January 2016). There are calls for more training in cultural competency in psychiatry where Māori and non-Māori are working with whānau to develop understandings meaningful to Māori. See Elder and Tapsell, above n 342.

<sup>360</sup> A first step towards providing a culturally responsive approach to supported decision-making is the Toolkit for Assessing Capacity as discussed in Chapter 7 and annexed to this report in Appendix D.

- 2.78 Balanced against these expectations is the practical reality of time and resource constraints in clinical practice of all professionals involved with health and social care. Effective “front-end” supported decision-making therefore requires a systems response to put best practice standards into effect.

### Supported decision-making in English case law

- 2.79 Principle 1(3) of the MCA provides:

A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

- 2.80 There are few cases in the Court of Protection (COP) where this principle has been satisfied or clearly expressed in a judgment of the Court.<sup>361</sup> Nonetheless, English case law demonstrates how supported decision-making can be applied within the existing legal framework of the MCA.

### Supported decision-making at the beginning of the decision-making process

- 2.81 In *CC v KK*,<sup>362</sup> a local authority failed to prove that an elderly woman in its care did not have capacity to make decisions about her residence and care as they had not provided her with detailed options, including what support might be available at home, to allow a fair assessment of her capacity to weigh up those options.<sup>363</sup>
- 2.82 KK, who was aged 82, suffered from Parkinson's disease, vascular dementia and had a physical disability that meant she required a wheelchair or hoist to be mobilised. She was admitted to a nursing home but later wished to return home. KK gave evidence and was “clear and articulate” and “demonstrated an understanding of, and insight into, her care needs and the reality of life if she returned home, she was in need of total support and required carers 4 times a day”.<sup>364</sup> Although KK did not currently understand the issues about her residence, she would be able to do so if given more information. So it was argued she should be enabled to make the decision, rather than the best interests test being used.
- 2.83 Baker J held that when evaluating capacity there was a danger that professionals, including judges, might objectively conflate a capacity assessment with the best interests analysis and conclude that the person under review, KK, should attach greater weight to the physical security and comfort of a residential home and less importance to the emotional security and comfort derived from being in her own home. Baker J said:<sup>365</sup>

The choice which KK should be asked to weigh up is not between the nursing home and a return to the bungalow with no or limited support, but rather between staying in the nursing home and a return home with all practicable support.

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<sup>361</sup> A Ruck Keene “Mental Capacity Newsletter” March, 2016, <http://www.mentalcapacitylawandpolicy.org.uk/march-mental-capacity-law-newsletters>.

<sup>362</sup> *CC v KK and STCC* [2012] EWHC 2136 (COP).

<sup>363</sup> See also the importance of providing information in the context of a patient's capacity to refuse amputation of her leg, when there was “shifting medical opinion”: *Heart of England NHS Foundation Trust v JB* [2014] EWHC 342 Peter Jackson J at [24] and [25]. Discussed in Chapter 4 Defining Capacity. The Code of Practice requires that each person whose capacity is under scrutiny must be given “relevant information” including “what the likely consequences of a decision would be (the possible effects of deciding one way or another).”

<sup>365</sup> *Ibid.*



- 2.84 This case demonstrates the need to place the person who is being supported at the front of the decision-making process. Capacity assessments should not start with a “blank canvas”.<sup>366</sup> It requires all the information relevant to the decision to be made available to enhance the person’s capabilities to make the decision themselves.

### **Supported decision-making and substituted decision-making can coexist**

- 2.85 In *Re M (best interests deprivation of liberty)*<sup>367</sup> the Court held that M lacked capacity to decide where to live but that it was in her best interests, despite very significant care needs that were being successfully cared for in a care home, to return to her home with a care package.

- 2.86 M was aged 67 with chronic Type 1 diabetes and life-threatening complications. A central component in the decision was an appreciation of the risks arising from the lower level of supervision of her diabetes from a home placement compared with 24-hour professional oversight. Although finding that M lacked capacity, the court also carefully considered M’s wishes (and her partner’s views), plus the risks to her health of a return home compared to the risks of staying at the care home given her threats to kill herself (“*I want to be out of here quick or dead*”). Emphasis was placed on M’s own assessment of her quality of life.<sup>368</sup> Mr Justice Jackson said:<sup>369</sup>

In the end, if M remains confined in a home she is entitled to ask ‘what for?’ The only answer that could be provided at the moment is ‘to keep you alive as long as possible’. In my view that is not a sufficient answer. *The right to life and the state’s obligation to protect it is not absolute and the court must surely have regard to the person’s own assessment of her quality of life.* In M’s case there is little to be said for a solution that attempts without any guarantees of success to preserve for her a daily life without meaning or happiness which she, with some justification, regards as insupportable. (Emphasis added)

- 2.87 Substitute and supported decision-making can coexist. Even where a person lacks capacity in law, they do not lose their right to participate in decision-making that affects them. To this end, the standard by which the appointee, or substitute decision-maker is to act, requires them to support the person and take into account their will and preferences in reaching a decision.

### **Capacity is not an “off-switch” to rights and freedoms**

- 2.88 In *Wye Valley NHS Trust v Mr B*,<sup>370</sup> the COP affirmed the right of an individual to refuse life-saving treatment, even though he lacked capacity as a result of mental illness marked by religious delusions. Mr B suffered from Type 2 diabetes but resisted medication for a chronic foot ulcer and developed gangrene in his leg. Without an amputation, the medical evidence suggested he would succumb to an overwhelming infection and die within days. When it came to an assessment of Mr B’s best interests, the judge met with Mr B. Mr Justice Jackson came to the clear conclusion that an enforced amputation would not be in Mr B’s best interests:<sup>371</sup>

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<sup>366</sup> CC v KK, above n 362 at [68].

<sup>367</sup> *Re M (Best Interests: Deprivation of Liberty)* [2013] EWHC 3456 (COP) Peter Jackson J.

<sup>368</sup> *Re M*, above n 367 at [41]. Peter Jackson J noted that there was no criticism of the care received by M or the local authority and that, “it was perfectly appropriate that the responsibility for the outcome should fall on the shoulders of the court and not the shoulders of the parties”.

<sup>369</sup> *Re M*, above n 367 at [38].

<sup>370</sup> *Wye Valley NHS Trust v Mr B*, above n 171.

<sup>371</sup> *Wye Valley*, above n 171 at [38].



This is not an academic issue, but a necessary protection for the rights of people with disabilities. As the Act and European Convention make clear, *a conclusion that a person lacks decision-making capacity is not an ‘off-switch’ for his rights and freedoms*. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important. (Emphasis added)

- 2.89 Human rights considerations therefore make it clear that “best interests”, as a standard for decision-making, is broader than a paternalistic assessment of what a third party thinks would be best for the person. A finding that a person lacks capacity does not negate their legal agency and the right to have their will and preferences respected.

### Supported decision-making – summary

- 2.90 The CRPD requires State parties to rethink domestic laws and engage with its key concepts. To this end, the countries of the United Kingdom, Ireland, Canada and Australia have actively commissioned reports and/or have Bills before Parliament in order to meet their compliance obligations with the CRPD.<sup>372</sup> By ratifying the CRPD, New Zealand undertook to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in it. These obligations necessitate a critical review of the mental capacity laws in New Zealand and a careful assessment of the applicability of international law in this context.
- 2.91 The CRPD offers new ways of thinking about capacity, particularly in its emphasis on supported decision-making as a more integrated approach to decision-making, and recognition of universal legal capacity. Supported decision-making recognises the importance of relationships in understanding autonomy.
- 2.92 Challenges for establishing legal frameworks in line with the CRPD include: the lack of a clear definition of what supported decision-making means in law, which has led to conceptual confusion; uncertainty as to its connection to the concept of legal capacity; and doubts about the extent to which legal frameworks for substitute decision-making and the modern notion of supported decision-making can coexist. There are many forms of support for decision-making: family, friends and civil society networks which exist outside and quite independently of the law.<sup>373</sup> As a consequence, there is a risk of “net widening” (expanding, not reducing paternalism) by over-legalising informal mechanisms of support.

<sup>372</sup> See for example: a review of Canadian supported decision-making legislation by Bach and Kerzner, above n 33; England’s review of the Mental Capacity Act, above n 314; Australia’s Law Reform Commission report, above n 264; and the website of Inclusion Ireland [http://www.inclusionireland.ie/capacity\\_on\\_the\\_passage\\_of\\_the\\_Assisted\\_Decision-Making\\_Act\\_2015](http://www.inclusionireland.ie/capacity_on_the_passage_of_the_Assisted_Decision-Making_Act_2015). Canadian examples include: the British Columbia’s Representation Agreement Act – personal planning tools that enable adults to appoint someone to help the adult make decisions [http://www.bclaws.ca/civix/document/id/complete/statreg/96405\\_01](http://www.bclaws.ca/civix/document/id/complete/statreg/96405_01) Manitoba, Yukon Territories and Alberta legislation all specifically recognise supported decision-making. Ontario’s Substitute Decisions Act does not specifically recognise supported decision-making, but does provide for consideration of the role of supports <http://www.ontario.ca/laws/statute/92s30>.

<sup>373</sup> Carney, above n 248 at 39.

- 2.93 A number of comparable common law jurisdictions have decided to make specific provision for supported decision-making.<sup>374</sup> More research is urgently needed to determine the extent to which supported decision-making processes achieve their goals, and the conditions in which they are likely to do so.<sup>375</sup> In New Zealand, policymakers should consider how supported decision-making could reduce the role of guardianship, how mental capacity could be assessed in this framework, and how supported decision-making approaches could be integrated into the law.
- 2.94 The CRPD might simply be viewed as aspirational. Nonetheless, it has promoted discussion and debate about how to deliver support mechanisms under art 12, while at the same time ensuring protections from abuse.<sup>376</sup> Fundamentally, it raises the issue of the role of the law, and the extent to which the law can contribute to this shift in thinking by translating supported decision-making principles into workable laws.<sup>377</sup>

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<sup>374</sup> A number of these jurisdictions have been considered in the context of supported decision-making and best interests in the current English Law Commission report, above n 199.

<sup>375</sup> NA Kohn, J Blumenthal, A Campbell “Supported decision-making: A Viable Alternative to Guardianship?” (2012) 117 Penn State Law Rev 1111.

<sup>376</sup> Bach and Kerzner, above n 33 at 37.

<sup>377</sup> Carney, above n 273.

## RECOMMENDATIONS FOR SUPPORTED DECISION-MAKING

1. Supported decision-making should be clearly recognised as a legal principle, incorporating tikanga Māori, to provide support to people whose decision-making ability is impaired, to enable them to make their own decisions whenever possible.
2. There is a need for a legal mechanism to ensure that supported decision-making is given priority at the beginning of the decision-making process and as part of a continuum so that substitute decision-making is an option of last resort.
3. A person is not to be regarded as lacking capacity unless all practical help and support has been given to enable him or her to make a decision themselves; and steps are taken to support the person, including enlisting the help of support persons upon whom they rely for support.<sup>378</sup>
4. Reasonable steps are taken to ensure that those persons identified as available for support are present where a person's legal capacity is in doubt and an assessment of capacity is required
5. Consideration should be given to a supported decision-making framework that is sufficiently flexible and would allow for a person being able to appoint a "supporter" in order to assist them in circumstances where they retain capacity to understand the nature of the support offered, including:
  - a) possible models of appointment;
  - b) the nature of the relationship with the supporter and whether this could include a professional one;
  - c) how such a framework of support would interface with the appointment of substitute decision-makers under existing adult guardianship law, and the ability for ongoing support to be offered by the supporter;
  - d) the basis upon which the role of supporter could be displaced; and
  - e) the monitoring and oversight of this framework by a public agency.
6. A Code of Practice is developed to provide guidance on the implementation of supported decision-making as a culturally responsive practice that recognises diverse cultural contexts, and, for Māori, recognises the importance of whakawhanaungatanga.
7. More research is needed to examine how supported decision-making, as understood in human rights law and implemented in comparable jurisdictions, could be applied in practice within New Zealand's socio-cultural context.<sup>379</sup>

<sup>378</sup>

See for example, Northern Ireland Mental Capacity Bill (NI) Pt 1, s 5.

<sup>379</sup>

See for example, Assisted Decision-Making (Capacity) Act 2015 (Rep Ireland), Pt 3 s 10.

# Chapter 3

## **Liberty Safeguards**

## Chapter 3 – Liberty Safeguards

Chapter 3 is in four sections:

- A. The human rights framework for assessing whether a person who lacks capacity is deprived of their liberty.
- B. The case law in England and under the European Convention on Human Rights (ECHR) that exposed the “Bournewood gap” and led to the development of the Deprivation of Liberty Safeguards (DoLS).
- C. Identifying the Bournewood gap in New Zealand.
- D. Options for law reform to “plug the gap” with legal safeguards for deprivations of liberty – referred to in the recommendations in this report as “liberty safeguards”.

### Introduction

- 3.1 The major legal issue that emerged from reform of the English mental capacity law has been the need to provide legal protections for people who both lack capacity to consent or object to their healthcare and living arrangements, and are effectively detained. Detention that affects the liberty of people who lack capacity (referred to as “deprivations of liberty” in human rights conventions) is concerned with the fundamental human right not to be arbitrarily detained. Such liberty rights are guaranteed by the International Covenant on Civil and Political Rights 1966 (ICCPR),<sup>380</sup> the United Nations Convention on the Rights of Persons with Disabilities (CRPD),<sup>381</sup> the European Convention on Human Rights (ECHR),<sup>382</sup> and the New Zealand Bill of Rights Act 1990 (NZBORA), as well as having long been protected by the common law.
- 3.2 People who lack capacity may face substantial restrictions on their liberty and freedom of movement, not only when they receive treatment in a secure hospital unit, but also when they live in a residential care facility or in supported living arrangements in the community. Liberty and freedom of movement are values of fundamental importance in our society, yet currently in New Zealand there is no guaranteed legal process governing this loss of liberty for people who lack capacity. There is a process for people detained in psychiatric facilities under the Mental Health (Compulsory Assessment and Treatment) Act 1992 (MH(CAT) Act), some of whom may lack capacity. However, there is no guaranteed process for reviewing the need for detention of other people who may be detained in a range of healthcare and living environments, who are not subject to involuntary treatment under the mental health legislation.

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<sup>380</sup> ICCPR, art 9. The NZBORA expressly affirms New Zealand’s commitment to the ICCPR and requires all statutes to be construed consistently with these rights if possible.

<sup>381</sup> CRPD, art 14. The main international human rights instruments to which New Zealand is a party that are relevant to mental capacity law are referred to in Chapter 2A. The key provisions of the CRPD, ICCPR and the ECHR are set out in Appendix C.

<sup>382</sup> European Convention on Human Rights (opened for signature 4 November 1950, entered into force 3 September 1953) (“European Convention” or “ECHR”), art 5.

- 3.3 The House of Lords' decision in the *Bournewood* case in 1999,<sup>383</sup> and the decision of the European Court of Human Rights (ECtHR) in *HL v United Kingdom* in 2004,<sup>384</sup> exposed a gap in the legal protections that cover the detention of compliant people who lack the capacity to object, which became known as the "Bournewood gap". In *HL v United Kingdom*, the ECtHR found that a man who had been informally admitted to a psychiatric hospital in England had been deprived of his liberty when the staff exercised complete control over his freedom of movement. This deprivation of liberty was not "lawful" and breached art 5(1) of the ECHR as there was inadequate protection against the arbitrariness of his informal admission. Article 5(4) of the ECHR therefore required that he have guaranteed access to an independent review process concerning the lawfulness of his detention.
- 3.4 In 2007, the UK Parliament responded to this decision – so closing the Bournewood gap – by amending the Mental Capacity Act 2005 to create the Deprivation of Liberty Safeguards (DoLS) regime.<sup>385</sup> This was intended to create a suitable process governing such deprivations of liberty. It would only be mandatory to follow this process, however, when a person was deprived of their liberty in terms of art 5(1) of the ECHR.<sup>386</sup> Then the decision of the United Kingdom Supreme Court, in *Cheshire West*<sup>387</sup> in March 2014, gave a broad interpretation to the range of situations in which people were to be viewed as deprived of liberty under the MCA. This meant that the process required by DoLS would have to be applied to many more people in care homes and hospitals, as well as in community settings such as foster care placements.<sup>388</sup>
- 3.5 In view of these significant developments, which almost paralysed the operation of these safeguards under the mental capacity law in England, it is surprising how little attention has been given to this issue in New Zealand – in regards to detention of people who lack capacity but are not under the MH(CAT) Act.<sup>389</sup> The Bournewood gap and the ongoing developments in England raise important questions for New Zealand about the positive obligations on the State to provide oversight and legal protections for those who lack capacity and are effectively detained, independent of the standard of care or quality of living arrangements provided to them. Or, to put it another way: in the absence of legal safeguards, is there a significant gap in our law to protect detained people who lack capacity, where the State is involved with the provision of their health and social care? If so, how should New Zealand fill this gap in a review of its law?
- 3.6 Many people who lack capacity to make decisions about their accommodation arrangements – either those in residential care or those who are about to be discharged from hospital and admitted into care – have made no legal provision anticipating their loss of capacity. So they do not have a legally authorised person appointed under an enduring power of attorney

<sup>383</sup> *Bournewood*, above n 5.

<sup>384</sup> *HL v United Kingdom*, above n 4.

<sup>385</sup> MCA, ss 4A and 4B, Schedules 1A and A1. The new legislative scheme was inserted into the Mental Capacity Act 2005 (England and Wales) by the Mental Health Act 2007, which came into effect in 2009. See Chapter IC summary of ongoing law reform.

<sup>386</sup> Section 65(4) of the Mental Capacity Act provides: "In this Act, references to deprivation of a person's liberty have the same meaning as in Article 5(1) of the Human Rights Convention".

<sup>387</sup> Above n 7.

<sup>388</sup> The *Bournewood* case, *Cheshire West* and the Deprivation of Liberty Safeguards are discussed in more detail below.

<sup>389</sup> J Dawson "The Law of Emergency Psychiatric Detention" (1999) 2 New Zealand Law Review 275-303; A Douglass "Implications of the Treatment of Incompetent and Vulnerable Patients" (presentation to the Medical Law Conference, Wellington, 18 April 2011); A Martin "Who Decides in Hard Cases? The Boundaries of Competency and Consent" (presentation to HDC Medico-Legal Conference, Wellington, 18 October 2012); S Nightingale and I Reuvecamp "Regulating the Detention of Mentally Incapacitated Adults Not Subject to the Mental Health Act" in Dawson and Gledhill, above n 92 at 163.



(EPOA), or an appointed welfare guardian, who has the power to consent or object to decisions authorising their detention in relation to their living arrangements. Even if they do, or if court orders are obtained, the PPPR Act is not designed to provide ongoing oversight of their detention or restrictions on their liberty.

- 3.7 Where, in such situations, there is no-one to act on behalf of a person who lacks capacity, healthcare providers in New Zealand are often reliant upon the common law doctrine of necessity, expressed through Right 7(4) of the HDC Code, to provide a legal justification for their confinement. This justification is based on the assumption that decisions about the effective detention of a person who lacks capacity can simply be made in their best interests by healthcare professionals, without any independent oversight of those decisions being required – an assumption that has been rejected by the ECtHR.
- 3.8 The rights restricted by deprivation of liberty highlight the vulnerability of people who lack capacity and who are at risk of abuse, neglect and exploitation.<sup>390</sup> There are also legal risks for those working in the health and disability sector. These concern the extent to which providers of health and disability services might breach their duty of care to people by detaining them without legal authority or, indeed, for not detaining them when it is required to provide them with adequate care (including potentially breach of statutory objectives or duties),<sup>391</sup> the prospect of criminal liability for insufficient care,<sup>392</sup> and the potential for breach of professional standards.<sup>393</sup> Importantly, the lack of safeguards against deprivation of liberty poses practical and ethical challenges for people who work with this vulnerable group and recognise that the current legal framework is inadequate to best promote and protect the autonomy of those for whom they care.<sup>394</sup>
- 3.9 This chapter sets out the human rights framework for assessing when a person who lacks capacity has been deprived of their liberty, and for giving effect to the central guarantee that any detention should not be arbitrary. It outlines the meaning of the Bournwood gap, the effect of the DoLS regime, and subsequent case law in England under the MCA and the ECHR. Then it identifies the existence of a similar gap within New Zealand's legal framework and the problems encountered in practice due to the lack of adequate protections for people in these circumstances. It identifies the reasons why New Zealand should "plug the gap" and recommends the development of appropriate legal safeguards.

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<sup>390</sup> See for example, T Baker "Legal Protections and Remedies for Elder Abuse, Neglect and Exploitation" in Diesfeld and McIntosh, above n 228 at 477.

<sup>391</sup> See for example, ss 22 and 23 of the New Zealand Public Health and Disability Act 2000. The objectives and functions of DHBs include: "to promote effective care or support for those in need of personal health or disability support services" and "to promote the inclusion and participation in society and independence of people with disabilities", and "to monitor the delivery and performance of services."

<sup>392</sup> See for example, Crimes Act offences: s 151 - a duty in respect of vulnerable adults to provide necessities and protect from injury; s 195 - ill-treatment or neglect of child or vulnerable adult; and s 195A - a failure to protect a child or vulnerable adult.

<sup>393</sup> This chapter highlights some of these legal risks however its focus is on the legal protection needed for people who lack capacity and is not an analysis of the civil and criminal liability of public (DHBs) and private providers (residential care facilities, for example). Chapter 1B provides an overview of the relevant laws in New Zealand.

<sup>394</sup> More than any other aspect of this legal research project, the inadequacies of Right 7(4) of the HDC Code as a safeguard and the difficulties with the using the court process under the PPPR Act for the placement and living arrangements of people who lack capacity, have been raised with the writer.

### 3A: THE HUMAN RIGHTS FRAMEWORK

#### Liberty and the right not to be arbitrarily detained

- 3.10 Liberty and the right to be free from arbitrary detention is guaranteed in both New Zealand law (under legislation and the common law), as well as in the main international human rights instruments to which New Zealand is a party.<sup>395</sup> Sections 21–23 of the NZBORA, art 9 of the ICCPR, and art 14 of the CRPD express the right to liberty or the right to not be arbitrarily detained (sometimes referred to as habeas corpus rights) in a very similar fashion.<sup>396</sup>
- 3.11 Section 22 of the NZBORA plainly says that “Everyone has the right not to be arbitrarily arrested or detained”. The purpose of this right is to ensure that no person is subject to the constraints and ill effects that are associated with detention other than in accordance with the law.<sup>397</sup> There are several accompanying rights in the NZBORA,<sup>398</sup> including the right to have the validity of one’s detention determined without delay by way of habeas corpus, and the right to immediate release if one’s detention is unlawful.<sup>399</sup> These rights under section 3 of the NZBORA must be respected by anyone exercising a “public function”, and would include District Health Boards (DHBs) as well as private rest homes and mental health facilities that receive public funding.<sup>400</sup>
- 3.12 Article 5(1) of the ECHR is similar to the rights expressed in the NZBORA. It is also similar to art 14 of the CRPD,<sup>401</sup> which both New Zealand and the UK have ratified.<sup>402</sup> Therefore, the case law from the ECtHR will be influential in New Zealand. Article 14 of the CRPD provides:

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<sup>395</sup> The main international human rights instruments to which New Zealand is a party that are relevant to mental capacity law are set out in Chapter 2. These include the ICCPR, the ICESCR and the CRPD.

<sup>396</sup> The New Zealand Bill of Rights Act 1990 (NZBORA) expressly affirms New Zealand’s commitment to the ICCPR.

<sup>397</sup> A Butler, P Butler *New Zealand Bill of Rights Act: A Commentary* (LexisNexis, Wellington, 2015) at 1088.

<sup>398</sup> The following rights in the NZBORA are also relevant to placement of people into care or detention and their deprivation of liberty: s 11 the right to refuse to undergo medical treatment; s 17 freedom of association; s 18 freedom of movement and residence; s 19 - freedom from discrimination; s 23 associated procedural rights. For a review of applicable rights under the MH(CAT) Act, see K Gledhill, “A “Rights” Audit of the Mental Health Act”, in Dawson and Gledhill, above n 92 at 285.

<sup>399</sup> NZBORA, s 23(1)(c). The NZBORA rights are subject to reasonable and justifiable limitations, including those prescribed by law: NZBORA, s 5. Whenever legislation can be given a meaning that is consistent with the rights and freedoms contained in the NZBORA, that meaning is to be preferred: NZBORA, s 6.

<sup>400</sup> NZBORA s 3(a) confirms the Rights in the Act apply only to acts done by the State, or 3(b) “by any person or body in the performance of any public function, power, or duty conferred or imposed on that person or body”. The Crown Entities Act 2004, s 7 includes DHBs in its schedule of public entities. Added to this, Right 4 of the HDC Code requires health and disability services to be of an “appropriate standard of care”, in a manner appropriate to a person’s needs, that optimises their quality of life and with cooperation between providers.

<sup>401</sup> Article 5(1)(e) of the European Convention specifically allows detention for those of “unsound mind”, provided it is lawful and there is a necessity test based on adequate evidence of mental disorder: *Winterwerp v The Netherlands* (1979) 2 EHRR 387. These same criteria are not present in Article 14(1)(b) of the CRPD so to this extent art 5(1)(e) is inconsistent with art 14 of the CRPD: Gledhill, above n 398 at 292. See also P Fennel and U Khaliq, “Conflicting or complementary obligations? The UN Disability Rights Convention on Human Rights and English law” (2011) *Eur Hum Rights Rev*.

<sup>402</sup> New Zealand also has in common with the UK that it is a party to both the ICCPR, as expressly recognised in the New Zealand Bill of Rights Act 1990 (NZBORA), and the CRPD. See discussion on applicable international human rights treaties in Chapter 2 Supported Decision-making.

## Article 14 – Liberty and security of the person

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
  - (a) Enjoy the right to liberty and security of person;
  - (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.<sup>403</sup>

3.13 Article 14 of the CRPD is specifically concerned with liberty rights. In addition, art 19 provides the right to live independently and be included in the community. The UN Committee has identified the detention of people with disabilities without their consent (or with the consent of a substitute decision-maker) as a form of “arbitrary deprivation of liberty” that violates articles 12 and 14 of the CRPD, requiring State parties to refrain from such practices and to establish a mechanism to review existing cases.<sup>404</sup>

3.14 A prevailing theme in all of these human rights instruments is that any limit on liberty should be the least restrictive to achieve its purpose.<sup>405</sup> Statutes and common law rights that protect liberty should therefore be read with these rights in mind.

3.15 Statutes can also authorise deprivations of liberty of people with impaired capacity in the health and disability setting in situations where the detention is “prescribed by law”. The MH(CAT) Act for example, provides for involuntary treatment and detention of some people with a mental disorder, and the Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 (IDCCR Act) also authorises detention of people with intellectual disability who commit criminal offences.<sup>406</sup> The significance of these laws is that they have accompanying procedural safeguards to protect the interests of people subject to them. However, there are many people with impaired capacity who may be detained in similar health and disability settings – for example, “informal” patients on psychiatric wards – who are not subject to those laws and therefore do not have the benefit of those procedural safeguards.

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<sup>403</sup> The concept of “reasonable accommodation” means that modifications are to be made to achieve equal protection unless they impose a disproportionate burden. K Gledhill “The Filling of the Bournemouth gap” in McSherry and Freckleton, above n 102 at 115.

<sup>404</sup> UN Committee, above n 242 at [40]. In this respect, the UN Committee is particularly concerned with involuntary detention in psychiatric institutions and does not appear to contemplate detention of people with impaired capacity living in supported living arrangements in the community.

<sup>405</sup> The least restrictive intervention is also one of the primary objectives of the PPPR Act, s 8(a).

<sup>406</sup> See Chapter 1B for an overview of the MH(CAT) Act and the IDCCR Act. A summary of the MH(CAT) Act safeguards are set out below.

## Common law – habeas corpus and false imprisonment

- 3.16 The right to review the lawfulness of any deprivation of liberty has long been recognised under the common law.<sup>407</sup> Both an application for a writ of habeas corpus and the action for false imprisonment allow people to test the lawfulness of their confinement and they provide remedies when a person is unlawfully deprived of their liberty.
- 3.17 Habeas corpus has traditionally been available to secure the release of a person confined by any person or statutory body. Recently, habeas corpus applications in the High Court have been based on allegations that people subject to care and welfare orders under the PPPR Act have been unlawfully deprived of their liberty by their appointed welfare guardian.<sup>408</sup> While the Family Court, not the High Court, is the proper forum for these cases, they may indicate that there is not an adequate process under the PPPR Act itself to identify and monitor such deprivations of liberty.<sup>409</sup>
- 3.18 The habeas corpus procedure is designed for clear cases of unlawful detention and is less suitable for cases requiring detailed legal or factual analysis due to the swiftness of its procedure.<sup>410</sup> In these cases, proceedings in false imprisonment, or an application for judicial review (where those involved are performing a public function) would be more suitable.<sup>411</sup> Habeas corpus is also not available where the detained person has appeal rights that have not been exhausted.<sup>412</sup>
- 3.19 The tort of false imprisonment, a civil wrong, is committed when one person is detained or imprisoned by another person acting without lawful justification.<sup>413</sup> There must be total and intentional restraint by physical means, or by other means (such as coercion, threats, or claims of authority) that cause the person to submit to deprivation of their liberty.<sup>414</sup>
- 3.20 A person falsely imprisoned can seek a declaration that their detention is unlawful, or seek damages from the person or body responsible, and such proceedings can be brought against private individuals, not only against public bodies.<sup>415</sup> In *ZH v Commissioner of Police for the Metropolis*,<sup>416</sup> the English Court of Appeal upheld a decision to award damages for psychological trauma where the police – without lawful authority – forcibly removed a young man with severe autism and learning disabilities from a swimming pool and subsequently

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<sup>407</sup> *Chief Executive of the Department of Labour v Yadegary* [2001] 2 NZLR 495 (CA) at [44]. New Zealand Courts have recognised the presumption in law in favour of liberty - *in favorem libertatis*. In the Supreme Court decision: *Zaoui v Attorney General* [2005] 1 NZLR 577 at 650 [52] “And it is of prime importance that any powers of detention be approached in light of the fundamental right, long recognised under the common law, of liberty for all persons subject only to such limits as are imposed by law.”

<sup>408</sup> *E v E*, above n 63. See also *JDEB & ors v JAB & RHB and MAB*, above n 63, following an unsuccessful writ of habeas corpus in the High Court.

<sup>409</sup> There has been a successful habeas corpus case in Victoria, Australia. In *Antunovic v Dawson* [2010] VSC 377, it was held that Mrs Antunovic had been unlawfully restrained and the Court ordered her release, even though she had not been subject to any physical restraint. The Court accepted her evidence that she felt that she was unable to leave the premises at which she was residing without the permission of her psychiatrist.

<sup>410</sup> *N and N v CEO of CMDHB* [2016] NZHC 277, Thomas J at [18].

<sup>411</sup> Habeas Corpus Act 2001, s 14(1A)(b). *Manuel v Superintendent Hawkes Bay Prison* [2005] 1 NZLR 16 (CA).

<sup>412</sup> *E v E*, above n 63 at [48] and *T v Regional Intellectual Care Agency* [2007] NZCA 208.

<sup>413</sup> S Todd and J Hughes *The Law of Torts in New Zealand* (5<sup>th</sup> ed, Brookers/Thomson Reuters, Wellington, 2009) Chapter 4 Trespass to person.

<sup>414</sup> JG Fleming *The Law of Torts* (9<sup>th</sup> ed, LBC Information Services North Ryde NSW, 1998) at 33–37.

<sup>415</sup> Law Society *Identifying a Deprivation of Liberty: a practical guide* (2015) <http://www.lawsociety.org.uk> at 23.

<sup>416</sup> [2012] EWHC 604 (Admin), upheld in the English Court of Appeal, [2013] EWCA Civ 69.

physically restrained him and detained him in a police van. The police did so without consulting his carers, informing themselves of the nature of his disabilities, or considering less restrictive options.<sup>417</sup>

- 3.21 However, in the *Bournemouth* case, discussed below, the ECtHR rejected the idea that the common law actions of habeas corpus and false imprisonment – that have to be initiated by or on behalf of a disabled person – provided adequate remedies (or an adequate review process) for deprivations of liberty under the ECHR. A more accessible review process was required.

### Arbitrary detention – legal principles

- 3.22 A common set of legal principles concerning the meaning of “arbitrary detention” can be drawn from cases interpreting these liberty rights in both domestic and international courts and tribunals. In particular, extensive case law on the interpretation of Article 5(1) of the ECHR has been developed by the ECtHR. This establishes very similar principles to those expounded by the New Zealand courts interpreting the NZBORA.<sup>418</sup>

- 3.23 In summary, the key elements of the right not to be arbitrarily detained are:

- a distinction is made between mere “restrictions” on liberty and “deprivations” of liberty that reach the threshold of “detention”: the difference between the two is one of intensity;<sup>419</sup>
- any detention must clearly be authorised or justified by law;<sup>420</sup> the concept of arbitrariness is broader than unlawfulness;<sup>421</sup> and “arbitrary” has been defined as “inappropriate, unpredictable or disproportionate”;<sup>422</sup>
- although lawful at the outset the detention may become unreasonable and arbitrary by virtue of indefinite or prolonged duration or disproportionate consequences;<sup>423</sup>
- the aim is to *prevent* arbitrary detention occurring, so legal safeguards against deprivation of liberty should operate prospectively, not retrospectively;<sup>424</sup>
- laws authorising detention must be written so as to provide meaningful standards by which a person can know whether their detention is lawful; and

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<sup>417</sup> The Court awarded £28,000 in damages and held that the provisions of the MCA and use of restraint under s 6, are specifically designed to provide specified express pre-conditions for those dealing with people who lack capacity. Section 6 of the MCA imposes two important limitations on the acts which can be carried out with protection from liability under s 5. Firstly, the person using it must reasonably believe that it is necessary to do the act in order to prevent harm to the person lacking capacity; and secondly, the restraint used must be a proportionate response both to the likelihood of a person suffering harm and the seriousness of the harm.

<sup>418</sup> Butler and Butler, above n 397 at 1088.

<sup>419</sup> *Austin v United Kingdom* (2012) 55 EHRR 14 (ECtHR,GC) at [57]. The approach under the NZBORA is similar to that adopted by the ECtHR, which considers a range of factors relating to the alleged detention, and then evaluates whether there has been a mere “restriction” on liberty or a “deprivation” that reaches the threshold of “detention”: Butler and Butler, above n 397 at 1091.

<sup>420</sup> In a case involving interpretation of the Mental Health Act 1969, the High Court held that the Act must be interpreted in accordance with s 22 NZBORA; when a person is detained otherwise than in accordance with the law or principles which the law regards as appropriate for regulating a discretion, that detention will be deemed arbitrary: *Re M* [1992] NZLR 29 Gallen J.

<sup>421</sup> *Manga v Attorney-General* [2002] NZLR 65 at [44], Hammond J at [40].

<sup>422</sup> *Zaoui* above n 407 at [100].

<sup>423</sup> *Zaoui* above n 407 at [175].

<sup>424</sup> In this sense, the law is prophylactic: Butler and Butler, above n 397 at 1088.



- there must be speedy access to a court or tribunal (or other suitable process) that is sufficiently independent of the organisation responsible for the person's detention and is capable of directing the person's release.<sup>425</sup>

3.24 A key question is, therefore, whether New Zealand law currently meets these standards where the person detained lacks capacity. Before considering that question further, it is appropriate to consider the case law under the MCA, developed in light of the European Convention, and the steps taken in England to provide procedural safeguards for detained people who lack capacity, under the DoLS regime. As a result of these developments under the MCA, there is much greater clarity regarding situations in which there is a deprivation of liberty, and the kind of legal safeguards required.

### 3B: THE BOURNEWOOD GAP

#### The *Bournewood* case in the House of Lords

3.25 The *Bournewood* case arose in 1997, after HL, a 48-year-old man, was informally admitted to and detained at Bournewood Hospital in England. HL had suffered from autism and significant learning disabilities since birth, and he lacked capacity to consent or object to his medical treatment. Some years earlier, after 32 years living in Bournewood Hospital, he had been discharged to live with paid carers (or a paid foster family), with whom he lived for three years. Following an incident in which he became agitated at a day-care centre, HL was sedated and taken back to the Bournewood Hospital. No statutory authority was invoked for HL's "informal" admission to the hospital at this time, because the practice was not to use statutory powers when a person in his position was not resisting the arrangements.<sup>426</sup> HL's former carers, who disagreed with the arrangements made for him at Bournewood Hospital, filed a claim on his behalf for a writ of habeas corpus and damages for false imprisonment.

3.26 In the High Court the claim was unsuccessful; however, the decision was overturned in the Court of Appeal.<sup>427</sup> On further appeal, in a unanimous decision by the House of Lords, it was held that any actions taken by the hospital staff to detain HL that might otherwise have constituted an invasion of his rights, were justified on the basis of the common law doctrine of necessity.<sup>428</sup> Moreover, a majority of three of the five Law Lords held that HL had not been detained at all during the later stages of his treatment at the hospital, when he had stayed on an unlocked ward and had made no attempt to leave.

3.27 Lord Goff, for the majority, held that any question of detention of HL during the later stages of his treatment would have arisen only if he had attempted to leave the hospital and been prevented from doing so, which he did not do. The two Law Lords in the minority considered, however, that HL had been detained, because: he was sedated both to get him to the hospital

<sup>425</sup> European Convention on Human Rights, art 5(4); New Zealand Bill of Rights Act 1990, s 23(1)(c).

<sup>426</sup> Section 131(1) of the Mental Health Act 1983 (UK) preserved the common law principle of necessity as a justification for informally receiving in hospital or mental nursing homes compliant incapacitated patients.

<sup>427</sup> *Bournewood* above n 5; [1998] 2 WLR 764, CA. On the day of its decision HL was then "sectioned" under the Mental Health Act. He was released to his carers five weeks later and formally discharged a week after that. Meanwhile the hospital appealed to the House of Lords.

<sup>428</sup> *R v Bournewood Community and Mental Health NHS Trust*, Ex p. L [1998] All ER 289 at 299, Lord Goff. The common law power to detain and restrain patients who lack capacity to decide where to live where detention is necessary and in their own best interests: *Re F* [1990] 1 AC 2 applied.



and while he was there; he would have been “sectioned” under the MHA if he had tried to leave; his carers were at first prohibited from visiting him in case he wanted to leave with them; and the hospital was not prepared to release him back into the care of his carers until they thought him ready to leave. This amounted to complete and effective control by the staff over his freedom of movement, and was therefore “detention”.

- 3.28 Despite the Law Lords’ unanimous decision that, even if HL had been detained, this would have been justified under the common law doctrine of necessity, Lord Steyn identified the existence of a lacuna in the law. This has come to be known as “the Bournemouth gap”:<sup>429</sup>

The common law principle of necessity is a useful concept but it contains none of the safeguards of the 1983 Act. It places effective and unqualified control in the hands of hospital psychiatrists. ... [N]either habeas corpus nor judicial review are sufficient safeguards against misjudgements and professional lapses in the case of compliant incapacitated patients. ... The result would be an *indefensible gap* in our mental health law. ... The suggestion that HL was free to go is a fairytale. [Emphasis added]

- 3.29 It is therefore the absence of *procedural* “safeguards”, rather than the absence of any *criteria* governing the person’s effective detention, that is the feature of the “gap”. The criteria for lawful detention were provided by the common law principle of necessity, but there was no readily accessible procedure for reviewing that detention.

- 3.30 An application was then lodged on HL’s behalf with the European Court of Human Rights (ECtHR) effectively challenging the decision of the majority of House of Lords that HL was not detained in these circumstances, and challenging the notion that his detention would be lawful – under the doctrine of necessity – when no adequate process existed for its independent review.

### European Court of Human Rights decision – *HL v United Kingdom*

- 3.31 In *HL v United Kingdom*,<sup>430</sup> the ECtHR then held that during the later stages of his admission to Bournemouth Hospital, HL was deprived of his liberty (as the European Convention puts it), and his subsequent detention was a violation of Article 5(1) of the ECHR as it was not “in accordance with a procedure prescribed by law”.<sup>431</sup> The Court held that the use of the common law doctrine of necessity to detain compliant people who lacked capacity to object to their detention, rather than using the Mental Health Act 1983, was not adequate to protect people against the risk of arbitrary detention. The relevant parts of art 5(1) provide that:

Everyone has the right to liberty and security of person. No one should be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law.

- 3.32 One of “the following cases” encompassed by art 5(1), covers – and permits – “the lawful detention ... of persons of unsound mind”.<sup>432</sup> To be lawful, under the Convention, however, such detention must also be “in accordance with a procedure prescribed by law”.<sup>433</sup> Overall,

<sup>429</sup> Bournemouth, above n 5 at 493 and 495.

<sup>430</sup> Above n 4.

<sup>431</sup> European Convention on Human Rights, art 5(1).

<sup>432</sup> European Convention on Human Rights, art 5(1)(e). In *Winterwerp v the Netherlands* (1979) 2 EHRR 387, the ECtHR held that the need for “lawful” detention imports the need for both substantive and procedural safeguards.

<sup>433</sup> European Convention, art 5(1).

therefore, in determining if HL had been unlawfully deprived of his liberty, the ECtHR had to consider three issues: Was HL detained? Was he of unsound mind? And was his detention unlawful because it was not “in accordance with a procedure prescribed by law”?

3.33 The ECtHR found that HL was detained because the healthcare professionals treating and managing him “exercised complete and effective control over his care and movements”.<sup>434</sup> In effect, they agreed on this matter with the minority judges in the House of Lords. They said HL “was under continuous supervision and control and was not free to leave”. The Court accepted, however, that HL was “of unsound mind”. His detention could therefore be authorised by law.

3.34 So the remaining question was whether his detention was lawful. The ECtHR emphasised that the essential objective of art 5(1) was “to prevent individuals being deprived of their liberty in an arbitrary fashion”.<sup>435</sup> This required the “existence in domestic law of adequate legal protections” and “fair and proper procedures”.<sup>436</sup> English law did not provide this and so HL’s detention was unlawful – in effect, because English law provided insufficient procedural safeguards against arbitrary detention of a person in his situation.<sup>437</sup>

3.35 The ECtHR also held that there had been a breach of HL’s art 5(4) right to a speedy review of the lawfulness of his detention. Article 5(4) provides that:

Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.

3.36 The requirements of art 5(4) were not satisfied merely by the availability of habeas corpus or judicial review proceedings. They would have to be triggered by some person on HL’s behalf, and were reactive and not readily accessible.<sup>438</sup>

### Response to the “Bournewood gap” under the Mental Capacity Act

3.37 This decision of the ECtHR in *HL v United Kingdom* was highly significant in 2004 and remains so.<sup>439</sup> Around the same time, the UK Parliament was poised to enact the MCA, which would address a wide range of legal arrangements for people who lacked capacity. The ECtHR’s decision in *HL v United Kingdom* did not prevent the passage of this legislation but, as originally passed in 2005, the MCA contained no provisions to close the “Bournewood gap”. The *HL* decision of the ECtHR meant, however, that, in the absence of adequate legal provisions, there was now a large group of people in England who were being deprived of their liberty contrary to art 5(1) of the European Convention.<sup>440</sup>

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<sup>434</sup> *HL v United Kingdom*, above n 4 at 799.

<sup>435</sup> *Ibid.*

<sup>436</sup> *Ibid.*

<sup>437</sup> The ECtHR emphasised the lack of fixed rules for the admission and detention of compliant people and the strong contrast with the extensive network of safeguards for involuntary patients under the Mental Health Act 1983 (UK), *HL v United Kingdom*, above n 4 at 770.

<sup>438</sup> *HL v United Kingdom* above n 4 at 804.

<sup>439</sup> As early as 1985 the Mental Health Act Commission in England recognised this problem and asked for its remit to be extended to what would also be called “de facto detained patients”, G Richardson “*R v Bournewood Community and Mental Health Trust, ex parte L [1999]: Bournewood 15 Years On*” in J Herring and J Wall *Landmark Cases in Medical Law* (Hart Publishing, Oxford, 2015) at 129.

<sup>440</sup> In a submission to the House of Lords, the Mental Health Act Commission estimated there were at that time, 48,000 “informal” admissions to hospital each year of people who lacked capacity and had

- 3.38 The UK Government was therefore forced to respond. It previously had no “Plan B” as it was confident of winning the case in the ECtHR and that the Court would find there had been no deprivation of liberty.<sup>441</sup> The ECtHR’s conclusion, that detention under the common law principle of necessity failed to meet the requirements of art 5(1) due to the absence of adequate review process, therefore required the Government to make fairly radical reforms to the law, for which it was unprepared.<sup>442</sup>

## Deprivation of Liberty Safeguards (DoLS)

- 3.39 In its original form, the MCA gave all kinds of carers a general authority to act in the best interests of an incapacitated person, but that authority did not extend to depriving a person of their liberty.<sup>443</sup> The response of the UK Government to the *HL* decision was to enact a 2007 amendment to the MCA, combined with a supplementary Code of Practice that came into force in April 2009.<sup>444</sup> These reforms introduced the Deprivation of Liberty Safeguards, otherwise known as DoLS, to remedy the breaches of the European Convention.<sup>445</sup>
- 3.40 The DoLS seek to ensure the identification and better protection of people who lack capacity and are, or may be, deprived of their liberty in a hospital or care home. They require the decision to deprive the person of liberty to be externally reviewed and authorised, even if the person is not actively seeking to leave their care arrangements.<sup>446</sup> They apply on the whole to older people and people with disabilities who lack capacity. They require a hospital or care home<sup>447</sup> to apply to the local authority<sup>448</sup> for express authorisation of a deprivation of liberty.<sup>449</sup> If a person’s right to liberty needs to be infringed in other settings, authorisation must be sought from the COP.
- 3.41 Once a potential deprivation of liberty is identified, health and care professionals are required to conduct no less than six assessments, involving a minimum of two assessors (including a best interests assessor and a mental health assessor), to see if each of the six “qualifying requirements” under the DoLS regime are met.<sup>450</sup> In very broad terms, these assessors must

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restriction on their liberty. They also estimated that in anyone day there were 22,000 informal patients who lacked capacity compared to 13,000 patient detained under the MHA. Richardson, above n 439 at 130-131.

<sup>441</sup> Richardson, above n 439 at 135.

<sup>442</sup> Had the non-compliance been restricted to art 5(4), the introduction of an adequate mechanism for review might have been sufficient, but the decision found the entire process of admission to be unlawful. Richardson, above n 439 at 134.

<sup>443</sup> Under the MCA, the common law doctrine of necessity was codified under s 5 and authority for the use of restraint in s 6.

<sup>444</sup> *Mental Capacity Act 2005: Code of Practice*, above n 164.

<sup>445</sup> Sections 5 and 6 of the MCA were insufficient as they provided a defence to battery rather than prescribed a procedure and therefore did not meet the requirements of Article 5(1)(e) of the Act. Section 4A of the MCA prohibits the deprivation of liberty of a person under the Act other than where the court has made an order under s 16(2)(a); where it is authorised for a life sustaining or emergency treatment: s 4B; or where the deprivation is authorised under the procedure set out in Schedules A1 and 1A, otherwise known as DoLS.

<sup>446</sup> The DoLS fall into two categories - those that operate during the process for the issue of authorisation, and those that apply once an authorisation is in place.

<sup>447</sup> The managing authority of hospitals and care homes is usually the NHS body responsible for the running of the hospital in which the relevant person is, or is to be, a resident.

<sup>448</sup> The supervisory body of hospitals and care homes is a Primary Care trust, or a local authority.

<sup>449</sup> There is a duty on the managing authority of the hospital and care home to apply for a standard authorisation from its supervisory body to detain the person. *Mental Capacity Act 2005*, c 9 Sch A1 [13] – [20]. The duty also applies if a standard authorisation is in force and there is to be a change in the place of detention: at [25].

<sup>450</sup> The six qualifying requirements are: age (18 or older), mental health (mental disorder under MHA), mental capacity, (person lacks capacity) best interests (assessment includes needs and care plan, views

ascertain if a person lacks capacity to make decisions about their accommodation and whether it is in their best interests to be deprived of their liberty.<sup>451</sup>

- 3.42 When, following those procedures, a standard<sup>452</sup> (or urgent)<sup>453</sup> authorisation is then issued by a local authority, the decision can still be challenged through an administrative review procedure or in the COP.

### **Cheshire West – broadening the circumstances in which the procedural safeguards are required**

- 3.43 Subsequently, in March 2014, the UK Supreme Court delivered its judgment in two cases known as *Cheshire West*.<sup>454</sup> There were two appeals: one called *P v Cheshire West and Cheshire Council*, the other *P and Q v Surrey County Council*, though the composite decision is usually referred to as *Cheshire West*. This decision gave an expanded interpretation to the concept of deprivation of liberty under the MCA, so that it covered many more people in care homes and hospitals, as well as in community settings such as foster care placements, than had previously been understood. The legal test the Court applied – for when safeguards are needed – is referred to as the “acid test”.<sup>455</sup> This test is met when an individual is under the continuous supervision and control of those caring for them *and* is not free to leave. In these circumstances they are deprived of their liberty in terms of art 5(1) of the ECHR.
- 3.44 The *Surrey* arm of the appeal concerned P and Q (otherwise known as MIG and MEG). They are sisters with learning disabilities. MIG was placed with a foster mother to whom she was devoted. She never attempted to leave the foster home by herself but would have been restrained from doing so had she tried. MEG lived in a residential home for learning disabled adolescents with complex needs.
- 3.45 The *Cheshire* arm of the appeal concerned P who has cerebral palsy and Down syndrome and requires 24-hour care. Until P was 37 years old he had lived with his mother, but when her health deteriorated, the local authority obtained orders from the COP that it was in his best interests to live in accommodation arranged by it. They placed him in a situation of one-to-one support that enables him to leave the house where he lives with other residents, but forcible intervention is sometimes required when he exhibits challenging behaviour.
- 3.46 In a decision by the majority, the Supreme Court held that all three of these people – MIG, MEG and P – were deprived of their liberty, in their respective settings.<sup>456</sup> Their circumstances met the “acid test”. The fact that the living arrangements were comfortable and made their lives enjoyable made no difference – “a gilded cage is still a cage”.<sup>457</sup>

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of managing authority and interested persons), eligibility (potential status under the MHA) and no refusal: Mental Capacity Act 2005, c 9 Sch A1 [13] – [20].

<sup>451</sup> The standard by which a person’s best interests is to be assessed is set out in s4 of the MCA. See Chapter 5 Best Interests – a standard for decision-making.

<sup>452</sup> A standard authorisation required if it appears likely that there will be a deprivation of liberty within the next 28 days.

<sup>453</sup> An urgent authorisation is used where deprivation of liberty is for a maximum of 14 days.

<sup>454</sup> Above n 7.

<sup>455</sup> In *Cheshire West*, Lady Hale, at [48] began her analysis by asking “[s]o is there an acid test for the deprivation of liberty in these cases?”

<sup>456</sup> In the case of MIG and MEG, three of the Justices dissented. They considered that the degree of intrusion was relevant to the concept of deprivation of liberty, and noted that the care regimes were no more intrusive or confining than required for the protection and well-being of the persons concerned.

<sup>457</sup> *Cheshire West*, above n 7 Lady Hale at [46] - [49].

- 3.47 Speaking extra-judicially, in a speech in October 2014, Lady Hale summarised the judgment of the Supreme Court:<sup>458</sup>

We all held that the man had been deprived of his liberty, but three members of the Court held that the sisters had not been deprived of their liberty, while the majority held that they had. The acid test was whether they were under the complete control and supervision of the staff and not free to leave. Their situation had to be compared, not with the situation of someone with their disabilities, but with the situation of an ordinary, normal person of their age. This is because the right to liberty is the same for everyone. The whole point about human rights is their universal quality, based as they are upon the ringing declaration in Article 1 of the Universal Declaration of Human Rights that ‘all human beings are born free and equal in dignity and rights’.

- 3.48 The effect of *Cheshire West* has therefore been to clarify the position of people confined within a hospital or institutional care, and also to expand the reach of art 5 of the ECHR governing “deprivations of liberty” to cover living arrangements in a domestic setting, such as living in a foster home (provided the state has some significant involvement in the arrangements for the person’s care). In these situations compliance or a lack of objection by the person concerned is irrelevant to the application of the acid test.
- 3.49 The concept of deprivation of liberty also applies to 16 and 17 year olds, irrespective of their capacity to consent to their treatment or their living arrangements. Parental consent therefore cannot authorise the confinement of a child who has attained the age of 16, even if the confinement is “purely a private affair”, as such consent falls outside the scope of parental responsibility.<sup>459</sup> Such “private affairs” are considered the responsibility of the State because it must ensure that all mentally disabled people, including young persons, have the benefit of safeguards and reviews, to ensure their living arrangements are in their best interests.

## Replacement of the DoLS by the Law Commission

- 3.50 As a result of the 2014 House of Lords report and the Supreme Court judgment in *Cheshire West*, the operation and adequacy of this DoLS regime is subject to further review by the Law Commission of England and Wales (Law Commission).<sup>460</sup> Among several criticisms outlined by the Law Commission is the “disconnect” that exists between the DoLS, which are regarded as having a “strong flavour” of mental health legislation, and the wider provisions of the mental capacity legislation, which are based on principles of autonomy and empowerment.<sup>461</sup> The DoLS are also complex and have a narrow focus on compliance with art 5 of the ECHR. Increasingly, there is greater recognition of the need to balance this right with art 8 of the ECHR, and the right to respect private and family life. Article 5 of the ECHR is said to distract

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<sup>458</sup> B Hale “Psychiatry and the Law: An enduring interest for Lord Rodger” (Lord Rodger Memorial Lecture, 31 October 2014) at 24, <http://www.supremecourt.uk/docs/speech-141031.pdf>.

<sup>459</sup> *Birmingham City Council v D* [2016] EWCOP 8 Keehan J at [134]. D, aged 16 and who has Asperger syndrome, lacked capacity to consent to his residence and care arrangements where he lived on the hospital grounds and attended school in a locked unit. This case is the partner of a similar judgment, where the same child was 15 at the time and different rules apply to children under 16 years – referred to as *Gillick* competence: *Trust A v X and a Local Authority* [2015] EWHC 922(Fam).

<sup>460</sup> See Chapter 1C Overview of ongoing law reform of the MCA and the DoLS regime. The Law Commission’s project was commissioned by the Department of Health. Its consultation paper was issued in July 2015. The final report and draft legislation will be published before the end of 2016.

<sup>461</sup> Law Commission, above n 199 at 11. The House of Lords Report also emphasised that the DoLS did not have the same ethos of the MCA.



attention from the underlying issue of where it is best for the person to live, which is described by Mr Justice Jackson in the COP as the “nub of the matter”.<sup>462</sup>

- 3.51 In *Cheshire West*, Lord Neuberger observed that some people may be surprised to learn that those living in a domestic setting could complain of deprivation of liberty under art 5.<sup>463</sup> Nevertheless, the Law Commission has suggested that the right to personal liberty and art 5 safeguards are too important to be determined solely by reference to the home-like quality (or otherwise) of the setting.
- 3.52 Following extensive public consultation, the Law Commission has issued an interim statement indicating that they will be recommending a more “straightforward, streamlined and flexible” scheme for authorising a deprivation of liberty in any setting, which will not seek to go as widely as initially proposed under the “protective care” scheme.<sup>464</sup> The responsibility for establishing the case for a deprivation of liberty will be shifted to the commissioning body (such as the NHS or local authority) that is arranging the relevant care and treatment, and away from the care provider. In an effort to have a proportionate and affordable response to the vast numbers of people now considered to be deprived of their liberty following *Cheshire West*, some people will receive independent oversight of their deprivation of liberty by an official – referred to as an “Approved Mental Capacity Professional” – whose role would be to agree or not agree to the proposed deprivation of liberty. The simplified proposal continues to recommend comprehensive rights to advocacy as a feature of the replacement scheme, with right of access to challenge restrictive treatment and care decisions in either a specialist tribunal or the COP.
- 3.53 The ongoing development of the DoLS regime under the MCA and the associated case law has therefore helped clarified two aspects of the law: firstly, how to identify a “deprivation of liberty”, and, secondly, the positive obligations on the State to take preventative measures to avoid deprivations of liberty and provide an accessible review process.

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<sup>462</sup> *London Borough of Hillingdon v Neary* [2011] EWHC 1377 (COP), [2011] 4 All ER 584 at [151] to [152]. A young man with autism and severe learning disability was in respite care but subsequently prevented from returning home to live with his father and kept in a facility for nearly a year. The COP held that he was unlawfully deprived of his liberty and there was a subsequent damages award.

<sup>463</sup> *Cheshire West*, above n 7 at [71].

<sup>464</sup> Law Commission, Mental Capacity and Deprivation of Liberty, Interim Statement 25 May 2016 at 8. [www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty](http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty). Initially the Law Commission proposed a “protective care” scheme with a separate scheme of safeguards for those accommodated in hospital settings and palliative care as well as those people deprived of liberty in family homes or other domestic settings. The Law Commission is also of the view that there should not be parallel legal regimes for detaining people for mental health assessment and treatment in psychiatric and other hospitals. The scheme will therefore not be used to authorise deprivation of liberty in such cases. No additional mechanism will be inserted into the Mental Health Act to cater for compliant incapacitated patients.



## Defining a deprivation of liberty?

3.54 Deprivation of liberty is a human rights concept, and the term used to describe detention of a person in art 5(1) of the European Convention on Human Rights (ECHR).<sup>465</sup> It is understood, in European human rights jurisprudence, as having three elements, all of which need to be satisfied before a particular set of circumstances amount to a deprivation of liberty:<sup>466</sup>

- (1) the objective component of confinement to a particular restricted place for a not negligible period of time;
- (2) the subjective component of lack of valid consent (i.e. that the person does not consent or cannot freely give consent, if they do not have the capacity to do so) to that confinement; and,
- (3) the attribution of responsibility to the State.

3.55 In most of the key ECtHR cases applying the concept to the position of persons of “unsound mind”, it is common ground that consent is absent and the State has responsibility. Attention has been focused on the objective element, the nature of the confinement.<sup>467</sup> In a prescient comment in her mental health law textbook, prior to the *Cheshire West* decision of the UK Supreme Court, Lady Hale observed: <sup>468</sup>

*Deprivations of liberty are not always easy to spot. Liberty means the physical liberty of the person, not simply the freedom to live one’s life as one chooses. Deprivation is more than mere restriction, but it can cover more than being locked up in a prison cell.... The starting point has to be the actual situation of the person concerned and account must be taken of a whole range of factors: such as the type, duration, effects, the manner of implementation of the measure in question. (Guzzardi v Italy [1980] 3 EHRR 33, para 93) [Emphasis added]*

## Restraint versus deprivation of liberty

3.56 Thus a distinction is made between restraint (which, in England, may be permitted so long as it is reasonable and proportionate under ss 5 and 6 of the MCA), and deprivation of liberty, which will be arbitrary if not properly justified under art 5 of the European Convention. In *HL v United Kingdom*, the European Court of Human Rights held that: <sup>469</sup>

A deprivation of, and restriction upon, liberty is merely one of degree or intensity and not one of nature or substance.

3.57 In *HL v United Kingdom*, a key factor was that the healthcare professionals treating and managing HL exercised complete and effective control over his care and movements.

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<sup>465</sup> European Convention on Human Rights (entered into force 21 September 1971, as amended by Protocol No. 14 entered into 1 June 2010).

<sup>466</sup> *Cheshire West*, above n 7 at 37.

<sup>467</sup> Law Commission Report above n 199 at 3.

<sup>468</sup> Hale, above n 194 at 16.

<sup>469</sup> *HL v United Kingdom*, above n 4 at 791.

3.58 When considering the justification for intervention available to health professionals under sections 5 and 6 of the MCA, the Law Society Guidance suggests such interventions will lie along the following continuum:<sup>470</sup>

- (1) “Routine” decisions or interventions in an individual’s life to provide them with care and treatment. These will be taken on the basis of a reasonable belief that the individual lacks capacity to take the decision and that the professional is acting in the individual’s best interests: these can be carried out safe in the knowledge that the professional is protected from liability under s 5 MCA 2005;
- (2) Interventions that constitute “restraint”. Restraint does not merely mean the use of force, but can include the threat of the use of force, or restriction of the individual’s liberty, whether or not they resist.<sup>471</sup> By operation of s 6 MCA, a professional restraining an individual will be protected from liability provided the restraint is proportionate to the risk of and likelihood of harm and is only used where the professional reasonably believes it to be necessary to prevent harm to the person;
- (3) Interventions that go beyond “mere” restraint to a deprivation of liberty. The professional at that point cannot rely upon the provisions of ss 5 and 6 MCA, but authority will be required in the form of an authorisation.

3.59 In assessing the objective element of deprivation of liberty, a distinction can be made between the “neutral” question of whether a person is deprived of their liberty and the “evaluative” question of whether those arrangements are in their best interests.<sup>472</sup> Under the English DoLS regime, some commentators have queried this distinction, as it is difficult to distinguish between the two when there is a need to protect people against poor standards of care.<sup>473</sup> In this respect, the English legislative regime is not directly comparable to New Zealand law.<sup>474</sup> Here there is arguably a stronger patient protection regime under the Health and Disability Commissioner Act 1994 and the accompanying HDC Code. That said, the Commissioner only has retrospective, not prospective, powers to act on complaints, and therefore is not in a position to assess whether a person is deprived of their liberty and there is no statutory guidance (or advocate available to assist) on how a person’s best interests is to be assessed in these circumstances.<sup>475</sup>

3.60 Focusing on the standard of care provided to people who lack capacity in this context begs the essential question of whether a person is deprived of their liberty. Part of the reasoning in *HL v United Kingdom* concerned the need to independently determine the need for a person’s detention *in advance*, which is why the Court rejected the availability of judicial review or habeas corpus as inadequate remedies.<sup>476</sup>

## Positive obligations on the State

3.61 The Strasbourg case law establishes a positive obligation on the State to protect all its citizens against interferences with their liberty, whether by State agents or by private individuals. In

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<sup>470</sup> Law Society, above n 415 at 11 [2.4].

<sup>471</sup> Mental Capacity Act 2005, s 6(4).

<sup>472</sup> Law Society, above n 415 at 11.

<sup>473</sup> Allen, above n 202. Allen points out that the DoLS did nothing to prevent the abuse of people with disabilities at Winterbourne View. See *Winterbourne View: A Serious Case Review - Self Safe Guarding Adults*, (N Flynn) Gloucestershire, 2012.

<sup>474</sup> In England and Wales, the Care Quality Commission is now the independent regulator of health and social care, <http://www.cqc.org.uk/>.

<sup>475</sup> See Chapter 4: Best interests- a standard for decision-making.

<sup>476</sup> Gledhill, above n 403 at 130. As Gledhill points out, the Government Committee’s response on the draft Mental Health Bill in 2004 and the suggestion that DoLS authorisations would be given *after* people had been detained, “somewhat misses the point”.

legal terms, the State is responsible for an objective deprivation of liberty to which the individual in question subjectively cannot consent.<sup>477</sup> Article 5(1)(e) of the European Convention requires that formal authority is provided to render that detention lawful. The failures of public bodies to ensure that there is proper consideration, in advance of the decision being made, of the necessity of removing individuals from their home and placing them in institutional care in their best interests, have been evident in some high-profile cases where damages were awarded for the unauthorised deprivation of liberty.<sup>478</sup>

- 3.62 The positive obligation of the State to take measures “providing effective protection” extends to “private” deprivations of liberty (by an individual or body), even where the State has had no part in making the arrangements.<sup>479</sup> Applying these principles, in *A Local Authority v A*<sup>480</sup> it was held that where the State (in this case a local authority) “knows or ought to know” that a person is subject to restrictions imposed by a private individual that arguably amount to deprivation of liberty, then the State’s positive obligations under art 5 would be triggered. These obligations include the duty to investigate, in order to determine whether there is in fact a deprivation of liberty. If the State is satisfied there is no deprivation of liberty, it will have discharged its immediate obligations. However, its positive obligations in certain circumstances require ongoing monitoring of the situation.<sup>481</sup>
- 3.63 Thus, after Lord Steyn identified the Bournemouth gap, the decision of the ECtHR in *HL v United Kingdom* has been a catalyst for change in English law, leading to amendments to the MCA and development of the DoLS. In addition, the UK Supreme Court decision in *Cheshire West* has expanded the scope of the circumstances to which the procedural protections, provided by the DoLS, must apply. The European human rights jurisprudence also confirms that States must proactively ensure there are legal safeguards in place, supported by a speedy review process, to ensure that individuals who lack capacity are not arbitrarily detained.

<sup>477</sup> *Storck v Germany* (2006) 43 EHRR 6 [93] sets out the principle that the State may be accountable even for private deprivations of liberty. In this case, the state became involved when the applicant was brought back to a private psychiatric hospital after she escaped. In addition, the national court must apply the provisions of national law in a manner compatible with the rights protected by the Convention. This case was applied in *Cheshire West*.

<sup>478</sup> Cases where the COP has awarded damages for a deprivation of liberty include: *Hillingdon v Neary*, above n 462, where Mr Neary was awarded £35,000 plus costs; *A Local Authority v Mr and Mrs D* [2013] EWCOP B34, damages of £27,500 plus costs; and *Essex County Council v RF* [2015] EWCOP 1, where the authority was ordered to pay £60,000 for a substantive breach whereby RF would not have been detained if the authority had acted lawfully.

<sup>479</sup> *Stanev v Bulgaria* (2012) 55 HER 22 at [120]; *Re A and Re C* [2010] EWHC 978 (Fam), Munby J, at [95].

<sup>480</sup> *A Local Authority v A* [2010] EWHC 978 (FAM), Munby J.

<sup>481</sup> In *Staffordshire County Council v SRK & Ors* [2016] EWCOP 27, Charles J, when applying the decision in *Cheshire West*, had to consider when the State’s positive obligations under art 5 of the ECHR are engaged in the context of arrangements made by a deputy in administering a personal injury compensation payment. There was a private deprivation of liberty (as the arrangements were not made by the local authority) and there was a need to ensure that there were welfare orders and an ability to review the arrangements in place.

### 3C: NEW ZEALAND – IMPLICATIONS OF THE BOURNEWOOD GAP

#### Identifying the Bournewood gap in New Zealand

- 3.64 The case law under the ECHR and the MCA is highly relevant and likely to be influential in New Zealand courts due to the similarity in the principles – drawn from international and domestic laws – that protect the right not to be arbitrarily detained in Europe and New Zealand.<sup>482</sup> New Zealand is not a party to the ECHR, but the European jurisprudence is highly relevant to interpretation of the equivalent liberty rights that are guaranteed by the international human rights instruments to which New Zealand is a party; plus the English common law backdrop to such liberty rights – in the tort of false imprisonment and writ of habeas corpus – has been imported into New Zealand common law.
- 3.65 It is possible that a similar case to *Bournewood* could arise in New Zealand, under s 22 of the NZBORA. This is a similar provision to art 5 of the European Convention. In fact, a case concerning informal detention in a dementia unit has already arisen as a complaint under the HDC Code.
- 3.66 In *Taikura Trust*,<sup>483</sup> Ms A, a 43-year-old woman with a complex history of mental illness and alcohol abuse, was held in a secure dementia unit for almost a year, against her will, without legal authority. Although initially she had been admitted to hospital appropriately, having been assessed as not having the capacity to make decisions relating to her care and welfare, the hospital incorrectly assumed that a personal order under the PPPR Act had been obtained from the Court that covered her care. Despite expressing a wish for a more suitable placement, Ms A was effectively detained for over a year in this dementia unit, against her wishes and contrary to her needs. Moreover, despite her capacity changing over time, she was not reassessed.
- 3.67 The Health and Disability Commissioner found there was a failure to provide appropriate care, to Ms A under Right 4 of the HDC Code. Regardless of whether there was a court order placing Ms A in the dementia unit, it was still a breach of her right to receive proper care for the healthcare providers not to take the steps to reassess her capacity and address her inappropriate placement in the dementia unit. The case went to the Human Rights Review Tribunal, where the two Auckland service providers who were responsible agreed to pay compensation to Ms A's estate (as she had subsequently died after her release from unlawful detention).<sup>484</sup>

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<sup>482</sup> Butler and Butler, above n 397 at 95: "Reference to decisions of the ECtHR has been relatively frequent in New Zealand case law and this level of citation and consideration of European Cases is likely to be maintained as New Zealand courts continue to draw on decisions of the United Kingdom courts deciding cases under the Human Rights Act 1998 (UK), which incorporates much ... of the European Convention into UK law."

<sup>483</sup> *HDC Opinion 08HDC20957 Auckland District Health Board, Taikura Trust, Aranui Home and Hospital Ltd (Trading as Oak Park Dementia Unit)* (3 November 2010). The Commissioner's opinion and the case before the Human Rights Review Tribunal did not expressly address the right not to be arbitrarily detained under s 22 of the NZBORA.

<sup>484</sup> The Tribunal made declarations against Taikura Trust and Aranui Home and Hospital Limited (trading as Oak Park Dementia Unit) for failures of care and breaches of Ms A's rights by failing to provide services in a manner that respected her dignity and independence and failing to provide services with reasonable care and skill. This case has been referred to by many commentators and was raised by Dr Katie Elkin (Associate Commissioner, Health and Disability Commission) to Alison Douglass regarding this research project (18 August 2014). *Director of Proceedings v Taikura Trust – Needs Assessment and Service Co-ordination Service* HRRT No. 024/2011 [2012] NZHRRT 3 (22 March 2012) *Director of Proceedings v Aranui Home & Hospital Ltd – Rest Home* HRRT No. 025/2011 [2012] NZHRRT 4 (22 March 2012).

- 3.68 Right 7(4) of the HDC Code,<sup>485</sup> based on the common law principle or doctrine of necessity,<sup>486</sup> was not specifically relied upon to justify Ms A's detention in *Taikura Trust*. Ms A's initial admission to hospital for care was perhaps defensible on that basis, but her ongoing detention was not. The principle of necessity imposed a clear obligation on the staff, which was not met, to ensure the provision of secure care continued to be in her best interests. Furthermore, even when Ms A objected to her longer-term care, no independent review process was activated, particularly none involving a court or tribunal. Obtaining a retrospective PPPR Act order would not have addressed the problem of there being a lack of safeguards that are intended to operate in advance of the person's detention or, in this case, Ms A's ongoing detention. This case therefore illustrates the existence of the Bournemouth gap in New Zealand.
- 3.69 Right 7(4) of the HDC Code is a pragmatic response to the need for everyday decision-making, and for common sense decisions to be made on a short-term basis, for people who, for a range of reasons, are unable to consent to their healthcare. Martin has suggested that Right 7(4) is best seen as a set of protections for consumers who cannot consent to treatment.<sup>487</sup> In more strictly legal terms, however, the so-called right provides a defence for health practitioners to HDC Code liability, rather than a safeguard for people who lack capacity and are unable to consent.<sup>488</sup> It does not provide procedural protections, or an independent review process, for people who lack capacity on an ongoing basis, concerning decisions such as sedation, forcible restraint, or use of coercion in their detention, whether compliant or not, or concerning decisions about their living arrangements or their forcible transport to a place of residence.
- 3.70 There will be many instances where the lawfulness of a person's initial detention in care would be clearly justified under the principle of necessity but the original reasons for their detention may cease to be valid if their condition changes. Their ongoing detention may then become a disproportionate response to the situation, and a breach of s 22 of the NZBORA.<sup>489</sup> Moreover, under New Zealand law, the precise situations in which providers may rely on Right 7(4), or must, instead, seek a court order, are not fully clear. In practice, it seems that providers tend not to risk relying on Right 7(4) alone in more contentious cases, such as where a family dispute exists about where to place an older family member, where the person strenuously objects to the proposed arrangements (particularly their admission to a secure dementia unit), and where there is no obvious family member or friend available who is concerned about the person's long-term interests. In those cases, therefore, more formal legal arrangements may be sought. As a result, providers' conduct in this regard may be inconsistent and idiosyncratic.<sup>490</sup>

<sup>485</sup> HDC Code, Right 7(4) is set out in full in Appendix C Legislation and International Human Rights Conventions and is also discussed in Chapter 5 Best Interests and Chapter 6 Research on People who Lack Capacity.

<sup>486</sup> See Chapter 5 Best Interests and a discussion of a history of the declaratory jurisdiction and the doctrine of necessity. *Re F (Mental Sterilisation)* [1990] 2 AC 1. In England, the common law doctrine of necessity as established in *Re F* and refined in subsequent case law has largely been superseded in relation to acts of care and treatment by Mental Capacity Act 2005 ss 5 and 6.

<sup>487</sup> Martin, above n 389.

<sup>488</sup> Although a defence in its own right, Right 7(4) is subject to clause 3. This provides that healthcare providers will not be in breach of any of the rights in the HDC Code if they have taken 'reasonable actions in the circumstances'. This would include taking into account the urgency of the required treatment and resource implications.

<sup>489</sup> *Zaoui*, above n 407 at [175].

<sup>490</sup> Anecdotally, and in the writer's experience, there are inconsistent approaches by DHBs as to whether they will rely on Right 7(4) or seek a court order under the PPPR Act, in these circumstances in the absence of a court order.

## Current problems and practice

- 3.71 The lack of legal safeguards to protect the liberties of people with impaired capacity is therefore a major issue for health and disability providers, including clinicians and social workers, particularly those working with people with dementia who are in some form of secure or locked residential care.
- 3.72 There are also people with milder forms of dementia who may retain some degree of capacity or understanding but, with time, their dementia can expect to progress and their reasoning will deteriorate to the extent they will become unable to contribute to decision-making to any great extent. Furthermore, the “compliant” (or “non-dissenting”) person with dementia may not actively object to their placement, even if it does involve detention, but they may not be able to give meaningful consent to it. Whether detained in a secure dementia unit or in lower levels of hospital or residential care, they will face ongoing care decisions and financial questions concerning their care in circumstances where they are not capable of making, and in some circumstances participating in, decisions affecting them.
- 3.73 The case studies below, based on real situations, demonstrate the problems encountered when people who lack capacity are placed in residential care or supported living arrangements, and there is no adequate legal process for oversight or review of restrictions on their liberty. In all three cases the people would meet the “acid test” for deprivation of liberty: they are under the continuous supervision and control of those caring for them *and* not free to leave.<sup>491</sup>

### Case of Mrs A: older adult with dementia – compliant patient needing long-term residential care

- 3.74 Mrs A<sup>492</sup> is a 78-year-old woman who is brought to the hospital after her neighbours found she had fallen over outside her house. She is treated for delirium secondary to infection, but during the course of admission it becomes clear that she has an underlying dementia of at least a moderate degree. In the medical ward she is agitated, wanders, and resists care. On one occasion she flees the ward, apparently concerned that she is in imminent danger. She is subsequently admitted to the psychogeriatric inpatient unit under the MH(CAT) Act.
- 3.75 Mrs A settles on the ward, but remains at risk of falls and wandering. A visit by staff to her home reveals stockpiled prescribed medication and that she has been incapable of looking after herself or the house. Nevertheless, she now wants to return home without care, although discussions with her establish that she has little real appreciation of her mental and physical problems and the risks associated with them. Mrs A’s family agrees that, on discharge from hospital, she will need residential (and most likely dementia) care. Mrs A has not executed an EPOA and, as is often the case, the facility to which she will go therefore requires a court order to be in place to authorise her admission when she cannot consent to her care.

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<sup>491</sup> *Cheshire West*, above n 7.

<sup>492</sup> Case study provided by Dr Mark Fisher, consultant psychiatrist, Mental Health Services for Older People, Middlemore hospital, Counties Manukau DHB.



## Discussion

- 3.76 Mrs A's circumstance is a common scenario for people with dementia for whom residential care is proposed as part of their care. Even if Mrs A had an appointed attorney under an EPOA, or a welfare guardian, these decision-makers are not necessarily well equipped to navigate the admission or placement process on her behalf, and they may have a conflict of interest concerning the decision to admit her to residential care as their own personal situation may be significantly affected, for better or worse, by that decision. They are not necessarily well placed, therefore, to determine whether admission to residential care is in her best interests. Moreover, even if the Court is involved in ordering Mrs A's admission, and considers whether a less restrictive intervention is available, a court has limited ability to exercise ongoing oversight of the implementation of a "one-off" personal order of that kind.<sup>493</sup>
- 3.77 The health services, in this situation, are often caught in a dilemma, between wishing to discharge someone from a busy hospital ward (to prevent "bed blocking"), and taking the time and expense to seek orders from the court. Going to court may incur delays and may seem to impose an ongoing responsibility to see the court process through to its conclusion, some months later, even though by then the person's care will have been transferred to another provider.<sup>494</sup> The HDC Code requires health and disability services to be of an "appropriate standard of care", in a manner appropriate to a person's needs, that optimises their quality of life and with cooperation between providers.<sup>495</sup> Practices, therefore, as to when and how to use the court process, vary across DHBs, along with the extent to which DHBs expect their clinicians to rely on Right 7(4) of the HDC Code instead of getting an order from the court.<sup>496</sup>

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<sup>493</sup> An interim personal order can be for up to 6 months and extended again for a total of 12 months, followed by a final order for a maximum of 12 months: Protection of Personal and Property Rights Act 1988, ss 10, 14 and 17.

<sup>494</sup> Under s 7 of the PPPR Act, a wide range of people, including health professionals, social workers and managers of institutions can apply for interim personal orders, as can family members. There are a range of orders that may be obtained under s 10 of the PPPR Act, a "placement order" under s 10(1)(e) requires: "that the person be provided with living arrangements of a kind specified in the order". See Chapter 1B Overview of the PPPR Act and Appendix C New Zealand Legislation.

<sup>495</sup> HDC Code of Rights, Right 4 (3), (4) and (5). Right 4 (5) provides: "Every consumer has the right to co-operation among providers to ensure quality and continuity of services."

<sup>496</sup> In some regions, significant delays are experienced in progressing applications under the PPPR Act for a s 10 placement order. The Auckland DHB for example, is undertaking a PPPR Act project with the goal of streamlining the PPPR process to enable in-patients to be moved to long term accommodation as quickly as possible. There are often extended lengths of stay for patients in Auckland Hospital requiring PPPR applications before they can be discharged. There were many factors identified in causing the delays, including clinicians' understanding and confidence with capacity assessments and PPPR applications, and with long delays in the Family Court. The scope of this project is the Older Persons Wards and General Medical wards but there are also concerns across community and mental health teams. (Email communication from Lisa Swann, project leader, Auckland DHB 19 February 2016 and Interview with Wayne Campbell, social worker and advanced clinician, Auckland DHB, 23 February 2016).

## Case of Mrs D: refusal to leave home and admission into residential care

- 3.78 Mrs D lives at home in squalor.<sup>497</sup> Community professionals, including her GP, have expressed concerns about her severe cognitive decline. She lives alone, with her adult daughter being her main caregiver, although it is suspected the daughter abuses her mother. Mrs D has poor mobility and there are concerns about her personal care and nutrition (there is no food in the fridge). Mrs D has refused to let the community psycho-geriatric team enter her home, and neither a capacity nor a needs assessment has been undertaken.<sup>498</sup>

## Discussion

- 3.79 It is not uncommon for older adults to live at home in relatively isolated circumstances with no-one to act for them.<sup>499</sup> In this situation where persuasion may not be possible, clinicians may have to decide whether to use the compulsory assessment procedure under the MH(CAT) Act to admit them into care.<sup>500</sup> Very often, the person has a family, but the family is fractured and unable to make the necessary application under the PPPR Act for a personal order, or they are unwilling or unable to pay a lawyer to do so.<sup>501</sup> There are added complications where there is an abusive relationship, or family conflict, or sizable assets involved.
- 3.80 A court order – during its life – allows a facility to care for someone in a secure environment, but getting the person to that facility, from their home, can be difficult and involve coercion. It can involve a person being uplifted from their home, being transported against their will, and then being detained in the new environment. This situation is a very different dynamic to where a person has already left their home and has been admitted to hospital for medical care.

## Case of Mr G: high level of restriction and living in the community

- 3.81 Mr G<sup>502</sup> is 31 years of age. He has severe autism spectrum disorder, and, although he is unable to verbally communicate, his psychologist says his level of intellectual function is unable to be accurately assessed. He became increasingly difficult to manage at home during his teenage years and now lives in a different town to his parents. He lives alone, but is supported with 24-hour one-on-one staffing by a community trust in a rented house. His

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<sup>497</sup> Case study from Phil Sunitsch, Social Worker, Mental Health Services for Older People, Southern DHB.  
<sup>498</sup> Compare this case study with a case in the COP, *Re AJ (Deprivation of Liberty Safeguards)* [2015] EWCOP 5, Baker J, where a breach was found when the local authority failed to take appropriate steps to ensure any deprivation of liberty had been suitably authorised *prior* to removing AJ from her home and placed in care. See also *A Primary Care Trust v P and Ors* [2009] EW Misc 10, Hedley J.

<sup>499</sup> Email communication from Phil Sunitsch, social worker, Mental Health Services for Older People, Southern DHB (19 May 2015 and 31 March 2016).

<sup>500</sup> The legal criteria for mental disorder in s 2 of the MH(CAT) Act under the second limb is that the mental disorder (as defined) either (a) poses a serious danger to the health or safety of that person or others; or (b) seriously diminishes the capacity of that person to take care of himself or herself.

<sup>501</sup> A person does not need to have a lawyer to make a Court application and some assistance may be available from the Family Court office however, where the applicant is unrepresented the Court-appointed lawyer to represent the person subject to the application is often put in the position of providing assistance at least to make sure all the relevant information is before the Court.

<sup>502</sup> The writer represented Mr G in the Family Court for the purpose of the appointment of his welfare guardian (Family Court reference suppressed).

welfare guardian is a former carer who has maintained a good relationship with him, and, although moving to another city, has kept in regular contact with his current carers.<sup>503</sup>

- 3.82 Mr G poses significant management difficulties. He is at risk of harming himself directly, if unsupervised, through, for example, severe bites to himself, or indirectly, by running out on to the road, and being hit by traffic. To manage his behaviour, his liberty is severely restricted through the use of locks, including deadlocks on his bedroom windows and bedroom door in the house.<sup>504</sup>

## Discussion

- 3.83 Mr G is completely dependent upon the community trust that cares for him and has limited contact from his welfare guardian. While the welfare guardian is involved with significant decisions with respect to his care, there is no ongoing oversight of the restrictions on his liberty, or the restraints, that are necessary to manage his care. There is only the trust's own care plan, including a risk assessment. On occasions, there has been tension between the welfare guardian's views on suitable restrictions and the community trust's understandably risk-averse approach to managing his care.<sup>505</sup> Mr C is receiving excellent care, but in fact he is subject to greater physical and psychological isolation and restrictions on his liberty than would be the case for some people with an intellectual disability detained with court orders under the IDCCR Act.<sup>506</sup>

## The role of needs assessments

- 3.84 A complicating factor in all these cases is the needs assessment process and the extent to which such assessments determine the level of care that a person will receive, and correspondingly, the level of restriction imposed on their liberty. A "needs assessment" refers to a clinical assessment (often of an older person or a younger adult with disabilities) to determine their level of functioning and the level of funding they require, in the provision of long-term DHB-funded disability support services. It is usually conducted by the Needs Assessment and Service Coordination service (NASC)<sup>507</sup> and occurs around the time a decision is made to discharge a person from hospital or move them to alternative living

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<sup>503</sup> Mr G is very fortunate in this respect because there are many people in his situation who do not have a welfare guardian and there is no public guardian or advocate that can fulfil this role other than voluntary welfare guardian trusts.

<sup>504</sup> Compare this case study with *A Local Authority v PB and P* [2011] EWHC 2675 (COP), Charles J, where it was determined it was in P's best interest to remain living in a supportive care regime rather than be returned home to his mother, given P's high level of needs.

<sup>505</sup> For example, there was a period when Mr G "trashed" his flat in response to deadlocks being put on his windows and door to his bedroom. The welfare guardian considered this behaviour entirely predictable and an inevitable consequence of placing further restrictions upon him.

<sup>506</sup> In this case, the disparity between the high level of restrictions whilst under a PPPR Act order compared to the potential for a lower level of detention for compulsory care under the IDCCR Act was observed by the lawyer, the psychologist, the GP, and by the Family Court Judge who made the welfare guardian order.

<sup>507</sup> See M Duggal "Health Services for Older People: the role of District Health Boards" in Diesfeld and McIntosh, above n 228 at 207. Ministry of Health 2014/15 Service Coverage Schedule (23 December 2013). Responsibility for providing long-term disability support services to older people devolved to the DHBs from the Ministry of Health in October 2003 by the Health Sector Transfers (Provider Arrangements Order 2003).

arrangements. It may effectively determine whether they need secure dementia care or hospital level care, or whether they can remain in their own home with support.<sup>508</sup>

- 3.85 The needs assessor considers the person's mental health and cognitive impairment when assessing their level of functioning, but the process does not purport to be a legal assessment of a person's capacity for decision-making. The particular NASC can be either a contracted external agency or a department within a DHB, the latter giving rise to the perception, if not the possibility, of a conflict of interest.<sup>509</sup>

### **The mental health legislation (MH(CAT) Act) and its interface with the PPPR Act**

- 3.86 While the MH(CAT) Act and the PPPR Act are overlapping regimes, they serve different purposes and operate differently.<sup>510</sup> Incapacity to consent to treatment is not required for a person to be subject to the MH(CAT) Act, yet some people are subject to both laws in the course of receiving healthcare, or regarding their living arrangements. An international review has highlighted that there may be at least a third of all patients in healthcare settings, and 45 percent patients in psychiatric settings, who do not have capacity for decision-making.<sup>511</sup> When considering how legal safeguards for deprivation of liberty might work, it is therefore important to address the interface between these two regimes.
- 3.87 Under the MH(CAT) Act, where a person has been certified by two doctors as meeting the complex statutory definition of "mental disorder", a person can be detained, and assessed, and treated by a psychiatrist (referred to as their responsible clinician).<sup>512</sup> Then, after about a month's assessment, an application can be made for them to be placed under a compulsory treatment order (CTO) – either an in-patient or community order – provided they continue to meet the relevant criteria. The MH(CAT) Act covers only "treatment for mental disorder", but it authorises various forms of restraint, including detention in order to keep the person safe and to make sure they are receiving the treatment and investigations deemed necessary.<sup>513</sup>
- 3.88 Whether undergoing assessment, or receiving treatment under a CTO, the person has recourse to a number of legal protections under the MH(CAT) Act.<sup>514</sup> They can challenge

<sup>508</sup> In 2003, the Ministry of Health released best practice guidelines for the assessment processes of older people. New Zealand Guidelines Group *Assessment Process for Older People* (NZGG, Wellington, 2003) [https://www.health.govt.nz/system/files/documents/publications/assess\\_processes\\_gl.pdf](https://www.health.govt.nz/system/files/documents/publications/assess_processes_gl.pdf).

<sup>509</sup> The NASC are not accountable as providers under the HDC Code as they do not fall within the definition of "disability services" under the Health and Disability Commissioner Act 1994 and therefore are not subject to complaints under the HDC Code. In 2009, former Commissioner Paterson recommended the NASC be included in this definition among other changes to the Act, but these changes were not expressly supported by the current Commissioner Hill's 2014 review of the Act and HDC Code: New Zealand Law Society submission on the 2014 review of the Health and Disability Commissioner Act and HDC Code, 17 February 2014. [http://www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0012/75999/I-HDC-Act-and-Code-Review-17-02-14.pdf](http://www.lawsociety.org.nz/_data/assets/pdf_file/0012/75999/I-HDC-Act-and-Code-Review-17-02-14.pdf).

<sup>510</sup> As observed by Atkin and Skellern, given the two Acts deal with the same people and similar issues, "it is a little surprising that the disparity is so great and the gaps so obvious", B Atkin and A Skellern, 'Adults with Incapacity: the PPPR Act' in Dawson and Gledhill, above n 92 at 347.

<sup>511</sup> Lepping, Stanly and Turner, above n 29.

<sup>512</sup> Mental Health (Compulsory Assessment and Treatment) Act 1992, s 2. The legal criteria for mental disorder in s2 of the MH(CAT) Act under the second limb is that the mental disorder (as defined) either (a) poses a serious danger to the health or safety of that person or others; or (b) seriously diminishes the capacity of that person to take care of himself or herself.

<sup>513</sup> Mental Health (Compulsory Assessment and Treatment) Act 1992, s 28.

<sup>514</sup> Specific rights are listed in Mental Health (Compulsory Assessment and Treatment) Act 1992, ss 63A – 75.

their detention (or their compulsory status) before a court while undergoing assessment;<sup>515</sup> the CTO itself must be made (and be reviewed after six months) by the Family Court,<sup>516</sup> after a hearing, and they can apply periodically to the Mental Health Review Tribunal to be discharged from a CTO if it is made indefinite by the Court.<sup>517</sup> A particular concern about the operation of the MH(CAT) Act and relevant to the issue of ongoing detention under this legislation, is the extensive use of the indefinite form of compulsory patient status, when these CTOs are renewed a second time, about a year after the initial order is made. These indefinite orders, and the small numbers of patients who apply to the Tribunal for discharge from them, are described as “a defining feature of the Act” and it is suggested they should be abolished.<sup>518</sup>

- 3.89 A person can only be placed under a CTO by the court and they can be provided with legal representation (although many people are not legally represented for this process). Their legal status and detention is kept under oversight by District Inspectors, who have an ombudsman-type role, and are independent of care providers.<sup>519</sup> There is also provision for regular review of their legal status by the responsible clinician to ensure they still meet the criteria for detention (or compulsory status) whether detained under an in-patient or an community CTO under the MH(CAT) Act. Sometimes the MH(CAT) Act is used to enforce detention and management of a person with dementia in a residential facility, by placing them under an in-patient order and then placing them on leave, with a specified condition of their leave being that they reside in residential care and comply with mental health treatment.<sup>520</sup>
- 3.90 In New Zealand, there is no obvious legal obligation to place compliant, “non-dissenting” patients under this regime established by the MH(CAT) Act. The upshot is that such patients – who may nevertheless be under the continuous supervision and control of those caring for them and are not free to leave – do not have adequate access to an independent process that reviews the necessity for that form of supervised care. These were the exact circumstances that led to the major legal developments in England, specifically the enactment of the DoLS regime.

### Monitoring places of detention in New Zealand

- 3.91 A further aspect to the human rights framework in New Zealand is the national monitoring mechanism for places of detention carried out by a number of government agencies including the Human Rights Commission and the Ombudsman. These mechanisms give effect to New Zealand’s obligations under the United Nations Optional Protocol for the Convention Against

<sup>515</sup> Mental Health (Compulsory Assessment and Treatment) Act 1992, s 12(12).

<sup>516</sup> Mental Health (Compulsory Assessment and Treatment) Act 1992, ss 14(4) and 18.

<sup>517</sup> Mental Health (Compulsory Assessment and Treatment) Act 1992, s 79.

<sup>518</sup> Dawson and Gledhill, above n 92 at 22. This feature of the MH(CAT) Act was also criticised in the UN Committee’s concluding observations on New Zealand in respect of the CRPD: ODI, above n 261 at 3 [22]. See also recent media attention concerning the case of Ashley Peacock and the ongoing use of seclusion while under an indefinite CTO, raising concerns about how deprivations of liberty are assessed and monitored under the MH(CAT) Act: K Johnston, New Zealand Herald, “Autistic man locked in isolation for five years: he’s had everything stripped from him”, 7 June 2016. [http://www.nzherald.co.nz/nz/news/article.cfm?c\\_id=1&objectid=11648771](http://www.nzherald.co.nz/nz/news/article.cfm?c_id=1&objectid=11648771)

<sup>519</sup> Mental Capacity Act 2005, ss 94 – 99. District Inspectors are not advocates for patients under the MCA but are described as the “the watchdogs of patients’ rights”. However, they have no jurisdiction over informal patients who are not subject to the MCA. See K Thom, K Prebble “District Inspectors: Watchdogs of Patients’ Rights” in Dawson and Gledhill, above n 92 at 131.

<sup>520</sup> The “detention” in a rest home while on “leave” under 31 and 30(2)(b), could be challenged as s 113 of the MH(CAT) Act only expressly authorises the detention of those under in patient orders in “hospital”.



Torture (OPCAT).<sup>521</sup> Until now, this monitoring has mainly focused on prisoners in correction facilities, and on people detained under the IDCCR Act and the MH(CAT) Act.

3.92 The most recent monitoring report under the OPCAT has expressed concern that there are many situations in which people are deprived of their liberty that are not currently monitored.<sup>522</sup> This includes detention in facilities approved by substitute decision-makers, such as detention in locked aged-care facilities, dementia units, compulsory care facilities, community-based homes and residences for disabled persons. Currently, an estimated 138 aged-care providers in New Zealand with locked facilities potentially fall within the scope of OPCAT. The report recommends that the Government review the scope of the OPCAT mandate in New Zealand and identify ways to address the gaps in its monitoring of places of detention.

3.93 A further report in 2014 by the United Nations Working Group on Arbitrary Detention expressed concerns about the protection gaps in New Zealand's legal framework that exist for older persons in care settings. This report refers to the PPPR Act and the HDC Code as "the only pieces of legislation that are loosely relevant in this context", and:<sup>523</sup>

It is clear that these laws do not set out sufficiently detailed processes by which persons lacking legal capacity may become subject to detention.

### 3D: REFORM OPTIONS: A PROPORTIONATE RESPONSE

#### Liberty safeguards – filling the Bournemouth gap

3.94 International and domestic human rights law affirms the right to freedom from arbitrary detention. As identified, New Zealand has a Bournemouth gap that is not filled by the MH(CAT) Act and its accompanying safeguards. There is a broad range of settings where the State is involved with the provision of health and social care to people who lack capacity and are unable to consent or object to their care and living arrangements. Examples include: informal psychiatric patients who are not under the MH(CAT) Act; older adults who may be discharged from hospital into care, including secure dementia units and/or ongoing residential care with various levels of restrictions; those adults who do not wish to leave their home for more institutionalised care; or people with learning disabilities who have supported living arrangements in the community but have substantial restrictions placed upon their liberty. In these circumstances, the people concerned are under the continuous supervision and control

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<sup>521</sup> Optional Protocol to the Convention against Torture and other Cruel, Inhuman or Degrading Treatment or Punishment (opened for signature 18 December 2002, entered into force 22 June 2006). OPCAT establishes a dual system of preventive monitoring, undertaken by international and national monitoring bodies. The international body, the United Nations Subcommittee on Prevention of Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment (SPT), periodically visits each State Party to inspect places of detention and make recommendations to the State. At the national level, independent monitoring bodies called National Preventive Mechanisms (NPMs) are empowered under OPCAT to regularly visit places of detention, and make recommendations aimed at strengthening protections, improving treatment and conditions, and preventing torture and ill-treatment.

<sup>522</sup> Human Rights Commission (2014) *Monitoring Places of Detention: Annual report of activities under the Optional Protocol to the Convention Against Torture (OPCAT)*, 2013–2014. [www.hrc.co.nz](http://www.hrc.co.nz), at 45 noted that, "People detained in these facilities potentially are vulnerable to ill-treatment that can remain largely invisible."

<sup>523</sup> United Nations Human Rights Council (2014) *Report of the Working Group on Arbitrary Detention* A/HRC/30/36/Add.2 at [88].



of those who care for them *and* are not free to leave: the acid test for when safeguards are needed in *Cheshire West*.

- 3.95 The Bournemouth gap exists in New Zealand because there are no specific legal safeguards that apply to these situations of detention. Reliance on the common law doctrine of necessity – as is often the case in New Zealand – was rejected by the ECtHR in *HL v United Kingdom* as an inadequate basis for the ongoing detention or monitoring of situations where people are deprived of their liberty. Neither the court procedures currently available under the PPPR Act (personal orders or the appointment of a welfare guardian) nor Right 7(4) of the HDC Code are designed to be effective in identifying deprivations of liberty in advance of a person's detention. Nor do they provide ongoing monitoring of a person's detention to ensure that such decisions are the least restrictive option and are made in their best interests. While the interface with the current mental health legislation will need to be addressed, the MH(CAT) Act is not the proper place for the necessary legal safeguards to be located, as it is intended to serve a more limited purpose – authorising and regulating compulsory psychiatric treatment.
- 3.96 The English response to its human rights obligations – enacting the DoLS regime – could be seen as an excessive response to the problem of providing a mechanism to safeguard the interests of people who lack capacity. It has been said: “A sledgehammer must not be used to crack a nut.”<sup>524</sup> There are also aspects of the English legislation, both the MCA and the MHA, which are specific to their legal framework and would not apply in New Zealand.<sup>525</sup> Plus there is the different population size and different cultural context in which the English law is formed, and the need for the UK to comply strictly with the ECHR. Nonetheless, England has filled the Bournemouth gap and other comparable jurisdictions have taken steps in that direction.<sup>526</sup>
- 3.97 The Victorian Law Reform Commission (VLRC)<sup>527</sup> also undertook a review of the law governing restrictions on liberty, including restraint policies in residential care facilities.<sup>528</sup> There are two striking features of this review: firstly, the extent to which the review found that other countries have extra-judicial processes for appointing substitute decision-makers where no other person is available;<sup>529</sup> and secondly, that Australia, Canada, and England and Wales, all have a publicly-appointed person (such as a public advocate),<sup>530</sup> or a public body or agency

<sup>524</sup> *Moonen v Film and Literature Board Review* [2000] 2 NZLR 9 (CA) Baragwanath J, at 14.

<sup>525</sup> For example, the system of informal patients under the MHA, s 131(1); the guardianship regime under the MHA to determine residence of some patients under the Act, and that people with learning disabilities come within the MHA.

<sup>526</sup> The Victorian Law Reform Commission (VLRC) recommended for example, the introduction of a new a three-person collaborative authorisation process (the person in charge of the residential facility, a medical practitioner and the person's health decision-maker) limited to deprivations of liberty for persons in residential care who lack capacity to consent to restrictive living arrangements that are imposed for their own health or safety. The VLRC recommendations were prior to *Cheshire West* and the broadening of the scope of DoLS and these particular recommendations have not as yet been acted upon. See also the Mental Capacity Bill, recently passed in Northern Ireland. Above, Chapter 1C Overview of the MCA. There is provision for additional safeguards for “serious interventions” and authorisations for deprivation of liberty (Chapter 4 of Mental Capacity Bill (NI)).

<sup>527</sup> See Australian Law reform in Chapter 2A above.

<sup>528</sup> The VLRC released a background paper of legislative schemes regulating deprivation of liberty in residential care settings in the UK, Queensland, Ontario, British Columbia and the Yukon: [http://www.lawreform.vic.gov.au/sites/default/files/Guardianship\\_final\\_report\\_background\\_paper\\_deprivation\\_of\\_liberty\\_safeguards.pdf](http://www.lawreform.vic.gov.au/sites/default/files/Guardianship_final_report_background_paper_deprivation_of_liberty_safeguards.pdf).

<sup>529</sup> Powers of Attorney Act 1998 (Qld), s 63; Health Care Consent Act (SO) 1996 c 2, sch A; Health Care (Consent) and Care Facility (Admission) Act (RSBC) 1996, c 181; Care Consent Act (SY) 2003 c 21, sch B, s 12(1)(c).

<sup>530</sup> Queensland, Victoria, Western Australia and South Australia all have an Office of the Public Advocate to aid in implementing guardianship legislation.

(such as a Public Guardian)<sup>531</sup> available for this purpose, or to manage this process. By comparison, in New Zealand there is no network of public advocates, and no Public Guardian's office, to produce a substitute decision-maker when no other candidate steps forward. There is currently a need for independent welfare guardians, as evidenced by the establishment of volunteer community trusts.<sup>532</sup> In addition, where a person's capacity is already impaired, substitute decision-makers cannot be appointed through an extra-judicial process, but only through the Court.

- 3.98 The English experience demonstrates that the key concern is not *whether*, but *how* deprivation of liberty safeguards are provided and how far the revised scheme should extend.<sup>533</sup> The expanded interpretation of the concept of deprivation of liberty by the UK Supreme Court in *Cheshire West* means that under the MCA these safeguards are needed for many more people in care homes and hospitals, as well as in community settings such as foster care placements, than had previously been understood. The starting point for policy makers in New Zealand, however, is to accept the need, in principle, to fill the Bournemouth gap, and then to consider how widely detention should be interpreted and to respond appropriately within the New Zealand context.
- 3.99 The number of people in supported residential or hospital care is likely to grow quite substantially in New Zealand as the community ages and life expectancy increases. It is an ongoing challenge to devise sufficiently flexible and efficient care as well as practical legal safeguards for people likely to need support in deciding where they will live, especially where restrictions are placed on their liberty, even if for their own welfare.
- 3.100 There needs to be a concerted policy and legislative response that reflects the importance of personal liberty and freedom of movement, set within the wider review of mental capacity legislation. Subordinate legislation or guidelines alone would not be sufficient or effective to ensure that an adequate legal framework exists to protect the interests of this vulnerable group. Along with better provision for supported decision-making, proper legal safeguards for people who lack capacity and are deprived of their liberty are urgently required for New Zealand to comply with its obligations under arts 12(4) and 14 of the CRPD.

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<sup>531</sup> In Ontario, the Public Guardian has a wide ranging role in protecting the rights and interests of mentally incapable adults (<https://www.attorneygeneral.jus.gov.on.ca/english/family/pgt/overview.php>). Office of the Public Guardian under the MCA (England and Wales) (<https://www.gov.uk/government/organisations/office-of-the-public-guardian/about>). See Chapter 1C Overview of MCA.

<sup>532</sup> For example, the Otago Welfare Guardians Trust and the Wellington Welfare Guardians Trust, <http://welfareguardians.nz/>.

<sup>533</sup> Law Commission, above n 199 at 31.

## RECOMMENDATIONS FOR LIBERTY SAFEGUARDS

1. Revised mental capacity legislation should provide legal mechanisms, criteria, and procedures, to govern decisions involving the deprivation of liberty of people who lack capacity, referred to as “Liberty safeguards”,<sup>534</sup> including:
  - a) a two-step authorisation process to, initially, identify a deprivation of liberty, and then to monitor an ongoing deprivation of liberty;
  - b) rules governing how such decisions are to be made, by whom, and under what process; when the liberty safeguards are to be used; their duration and discharge;
  - c) a standard stating that decisions should be made in the best interests (and according to the known will and preferences) of the person, when the liberty safeguards apply;
  - d) a speedy mechanism for the designated decision-maker, whether an independent individual (for example, the equivalent of the District Inspector under the MH(CAT) Act) or a public body that can provide independent oversight to authorise a deprivation of liberty, with ready access thereafter to review of the decision by a Tribunal or the Family Court;
  - e) a Code of Practice for health and social service providers to operationalise the liberty safeguards;
  - f) a publicly appointed and independent person or body to be available to act an advocate for people who lack capacity and who have no other suitable person to support and represent them in the liberty safeguarding process; and
  - g) options for ensuring the oversight and monitoring of compliance of these liberty safeguards by a public body or agency (such as a Public Guardian) established under the legislation.
2. A comprehensive review should be undertaken of legislative schemes regulating deprivation of liberty in comparable jurisdictions, including the proposed legislation and changes to the MCA to be recommended by the English Law Commission (due end of 2016).
3. Consultation with the health and disability sector in the development of the liberty safeguards that could be enacted that would have sufficient flexibility to cover the range of environments where deprivations of liberty occur, and could operate in the most effective and cost-efficient way.

<sup>534</sup>

The term “liberty safeguards” is suggested as preferable to “deprivation of liberty safeguards”. According to the English Law Commission, the naming of the proposed new safeguards has provoked the most debate in the Law Commissions proposals to date. This is because some consultees understood the phrase “deprivation of liberty safeguards” to mean that people were being denied access to legal rights. The English Law Commission is consulting further on this aspect of its review of the legislation: Law Commission, Interim Statement, above n 225.

# Chapter 4

## **Defining Capacity**

## Chapter 4: Defining Capacity

Chapter 4 is in three sections:

- A. An overview of important concepts of capacity.
- B. An analysis of the four legal tests of capacity in the Protection of Personal and Property Rights Act 1988 (PPPR Act).
- C. The test for capacity under ss 2 and 3 of the Mental Capacity Act (England and Wales) 2005 (MCA).

### Capacity and best interests

- 4.1 “Capacity” and “best interests” are two fundamental concepts that underlie the English legislation. As capacity (or incapacity) is the “brightline” for determining whether the law permits intervention in people’s lives, it is essential that there is a clear test.<sup>535</sup> If a person is unable to make a decision as defined in law, the best interests standard provides a legal and an ethical imperative for the person’s will and preferences to remain central to the decision-making that affects them.<sup>536</sup> These clearly defined concepts in the MCA give integrity to the legal framework and make the law more accessible to everyone that uses it.
- 4.2 The principles and philosophy of the PPPR Act and MCA are very similar, as is the functional approach to defining capacity, based on an assessment of a person’s decision-making ability, not the decision made. Any definition of capacity must be considered in light of the key concepts that are used to interpret how the definition is applied.<sup>537</sup>
- 4.3 In this chapter, the problems and complexity of the multiple tests for capacity found in the PPPR Act and the lack of a definition of competence within the HDC Code are identified. The functional test in s 3 of the MCA is considered in light of current English case law.
- 4.4 The essence of the recommendations in Chapters 4 and 5 is that revised legislation should provide a single and unified legal test for capacity, as well as a transparent standard for decision-making, referred to as the “best interests” standard.

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<sup>535</sup> An introduction to the legal concept of capacity is set out in Chapter 1A.

<sup>536</sup> Chapter 2 of this report has argued that the best interests standard as understood in s 4 of the MCA is an essential complement to a supported decision-making framework.

<sup>537</sup> The common legal principles of the PPPR Act, the HDC Code and the MCA are considered in Chapter 2B.

## 4A: IMPORTANT CONCEPTS OF CAPACITY

### Presumption of capacity

- 4.5 One of the most important concepts that underlies both the PPPR Act and the HDC Code, as well as the MCA, is the presumption of capacity.<sup>538</sup> This presumption means that the burden of proving lack of capacity to make a specific decision (or decisions) always lies with the person who considers that it may be necessary to take a decision on the person's behalf (or who will invite a court to take such a decision). The standard of proof is the balance of probabilities.<sup>539</sup> Therefore, it will always be for the decision-maker to prove that it is more likely than not that a person lacks capacity.
- 4.6 A presumption of capacity does not diminish the duty of care owed to patients in the delivery of healthcare. Both the House of Lords' report on the MCA and opinions of the Health and Disability Commissioner in New Zealand affirm that the presumption of capacity does not displace the duty to assess capacity as part of the provision of appropriate care.<sup>540</sup>

### The functional approach

- 4.7 There is a wide variety of laws regulating legal capacity across jurisdictions, and it has been stated that there are as many different operational definitions of mental (in)capacity as there are jurisdictions.<sup>541</sup> In keeping with many other countries, New Zealand has rejected the "status" approach (based on a person's disability or medical condition) and the "outcome" approach (based on an evaluation of the decision made), and instead uses a "functional" approach to defining capacity. A functional test focuses on the individual's ability to make a particular decision at a particular time and the processes followed by the person in arriving at the decision.<sup>542</sup>
- 4.8 A functional approach is more likely to be compliant with the CRPD because it avoids directly discriminating against people merely because they have a disability. The basis of differential treatment under a functional test is the presence or absence of decision-making ability. In some instances, such as a person in a persistent coma, the fact that a person lacks ability to make decisions is clear-cut. There may also be an objective measurable difference, for example, between a patient with very advanced dementia, who has short-term memory of less than one minute, as opposed to a patient in the early stages of Alzheimer's, who may struggle with memory but can still retain information for long enough to discuss treatment options with her doctor and family. The difference between these two individuals is not a matter of subjective opinion; it is an objective measurable difference.<sup>543</sup>

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<sup>538</sup> This presumption is referred to as the "presumption of competence" in the PPPR Act, s 5 and in the HDC Code, Right 7(2). In the MCA, the presumption is referred to as the, "assumption of capacity". Section 1(2) states: "A person must be assumed to have capacity unless it is established that he lacks capacity."

<sup>539</sup> Mental Capacity Act 2005, s 2(4).

<sup>540</sup> Chapter 1B and Appendix B A Review of the Health and Disability Commissioner's Opinions about Capacity.

<sup>541</sup> Bach and Kerzner, above n 33 at 18.

<sup>542</sup> Letts, above n 282.

<sup>543</sup> Szerletics, above n 209 at 18.



## Unwise decisions and avoiding the “protection imperative”

4.9 The principle that a person should not be assumed to lack capacity to make a decision just because other people think their decision is unwise or imprudent is meant to deflect the outcome approach to capacity, recognising that everybody has their own values, beliefs, preferences and attitudes that inform their decisions. There may be triggers, however, that call a person’s capacity into question: for example, where a person is at significant risk of harm or exploitation, or the decision is obviously irrational or out of character for that person.

4.10 There have been several judicial statements in the COP that have cautioned against taking an overly protective approach towards determining a person’s capacity, referred to as the “protective imperative”, and reflecting the right to make unwise decisions.<sup>544</sup> Baker J has described this protective imperative as follows:<sup>545</sup>

There is a risk that all professionals involved with treating and helping a person – including of course a Judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out the appropriate assessment of capacity that is both detached and objective.<sup>546</sup>

4.11 In more borderline cases, however, the extent to which the functional approach can provide an objective basis for assessing a process of decision-making is more difficult.<sup>547</sup> Objective standards are hard to formulate and apply. There can be a tendency to conflate the clinical concept of “insight” with the legal concept of capacity, although the term “insight” does not appear in any mental health or mental capacity legislation.<sup>548</sup> Whether standards of capacity should be risk-related and viewed on “a sliding scale of competence” is controversial,<sup>549</sup> as is the extent to which the rationality of a decision is relevant,<sup>550</sup> and whether sufficient weight is given to the role of values and emotion.<sup>551</sup> All these factors influence how capacity is assessed and how the legal tests for capacity are applied in legal decisions.<sup>552</sup>

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<sup>544</sup> *CC v KK*, above n 362, at [65].

<sup>545</sup> *A NHS Trust v Dr A*, above n 214, at [34].

<sup>546</sup> Similarly see statement by Lord Donaldson MR in *T (Adult: Refusal of Treatment)* [1992] 4 All ER 649, CA at 664 regarding rationality cited in Jones, above n 151 at 16.

<sup>547</sup> N Banner “Can procedural and substantive elements of decision-making be reconciled in assessments of mental capacity?” (2013) 9 Int J Law Context 71.

<sup>548</sup> N Allen “Is Capacity ‘In Sight’?” (2009) Mental Health L 165. Yet insight is described as the single most consistently discussed symptom of mental illness amongst Mental Health Tribunal members: K Diesfeld, “Insight on ‘insight’: the impact of extra-legislative factors on decisions to discharge detained patients” in K Diesfeld and I Freckleton (eds) *Involuntary Detention and Therapeutic Jurisprudence: International Perspectives on Civil Commitment* (Aldershot, Burlington Vt, 2003) at 359-382.

<sup>549</sup> M Jonas “Competence to Consent” in RE Ashcroft, A Dawson, H Draper and others (eds) *Competence to Consent in Principles of Health Care Ethics* (2<sup>nd</sup> ed, John Wiley and Sons Ltd, Chichester, 2007) at 255.

<sup>550</sup> In the long build up to the MCA, the English Law Commission in its 1991 report rejected a test based on rationality as it considered that the test would inevitably slide into an assessment of the “reasonableness” of a particular decision which could not be applied in an objective or non-discriminatory way. Law Commission *Mentally Incapacitated Adults and Decision-making: An Overview*, Consultation paper No 119 (HMSO, London, 1991) at 30.

<sup>551</sup> LC Charland “Mental Competence and Value: the Problem of Normativity in the Assessment of Decision-making Capacity” (2001) 8 Psychiat Psychol L 135.

<sup>552</sup> See Chapter 7 Code of Practice and the Toolkit for Assessing Capacity in Appendix D.

## Capacity is decision specific

- 4.12 The functional approach reinforces the idea that capacity is decision specific and time specific. Thus, it is often wrong to say that someone “lacks capacity”; rather, it should be said that the person lacks capacity to make a particular decision at a particular time.
- 4.13 The idea that incapacity can be viewed as “global”, so that a person’s incapacity embraces every aspect of a person’s life, has been rejected in favour of a decision and task-relative approach.<sup>553</sup> As explained by Buchanan and Brock, the idea behind the task-relative approach is as follows: <sup>554</sup>

The statement that a particular individual is (or is not) competent is incomplete. Competence is always competence for some task – competence to do something. The concern here is with competence to perform the task of making a decision. Hence competence is to be understood as decision-making capacity. But the notion of decision-making capacity is itself incomplete until the nature of the choice as well as the conditions under which it is to be made are specified. Thus, competence is decision-relative, not global.

## Capacity and proportionality

- 4.14 A decision-specific approach to capacity is in keeping with the notion that the assessment of capacity takes into account the level of the person’s residual ability and determines capacity in proportion to the seriousness of the decision(s) they must make. As envisaged by Lord Donaldson, in *Re T (Refusal of Treatment)*:<sup>555</sup>

What matters is that doctors should consider whether at the time [the patient] had a capacity which was commensurate with the gravity of the decisions which he purported to take. The more serious the decisions, the greater the capacity required.

## 4B: PPPR ACT – LEGAL TESTS

- 4.15 As with the MCA, a finding of impairment of capacity under the PPPR Act is fundamental to any resulting intervention that may be made on the person’s behalf, such as a court order or the activation of an EPOA.<sup>556</sup>

The question of capacity to make the decision that is the subject of an application (under the Act) is a threshold question that must be considered in every case; because jurisdiction to make any order ... depends on it.

- 4.16 In general, a person lacks capacity if they cannot understand the nature and foresee the consequences of decisions, or are unable to communicate them. However, there are four subtly different legal tests for incapacity in the PPPR Act, depending on the kind of substitute decision-maker appointed, and on whether care and welfare, or property decisions, are involved. Nevertheless, the different legal tests in the PPPR Act follow a common functional

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<sup>553</sup> M Jonas, above n 549 at 255.

<sup>554</sup> Buchanan and Brock, above n 35 at 18.

<sup>555</sup> *Re T (Adult: Refusal of Treatment)* [1992] 3 WLR 782; [1993] Fam 95 at 113.

<sup>556</sup> *KR v MR* (2004) 2 NZLR 847 at [25]. Also reported as *X v Y (Mental Health: Sterilisation)* [2004] 23 FRNZ 475.

approach and in this respect are similar to the single legal test in the MCA, and codify the prior common law (case law).<sup>557</sup>

- 4.17 The key difference between the tests in the PPPR Act and the MCA is that there is no disability precondition in the PPPR Act. Under the MCA, the inability to make a decision (the functional test) must have a causal link to “an impairment of, or a disturbance in the functioning of, the mind or brain” (the diagnostic test).<sup>558</sup> There is no equivalent in the PPPR Act.

## Four legal tests

- 4.18 The four threshold tests in the PPPR Act and the corresponding interventions are as follows:
1. “partly” lacks capacity: for making a personal order and appointing a property manager;<sup>559</sup>
  2. “wholly” lacks capacity: for appointing a welfare guardian;<sup>560</sup>
  3. “not wholly competent”: for activating a property-related EPOA;<sup>561</sup> and
  4. “lacks the capacity”: for activating a care and welfare-related EPOA.<sup>562</sup>

### *Test no. 1: “partly” lacks capacity – personal order*

- 4.19 Section 6 provides the foundation of the jurisdiction to make personal care and welfare orders. This jurisdiction is dependent on a finding that the “subject person” either:

Lacks wholly or partly the capacity to understand the nature and foresee the consequences of decisions in respect of matters relating to his or her personal care and welfare; or

Has the capacity to understand the nature and to foresee the consequences of such decisions but wholly lacks the capacity to communicate decisions in respect of such matters.

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<sup>557</sup> The English cases that developed the functional test were mainly concerned with capacity to consent to or refuse medical treatment. For example, *St George’s Healthcare NHS Trust v S* [1998] 3 All ER 673, where a competent woman’s refusal of a Caesarean section in which the baby would die was overridden and carried out but was subsequently held to be unlawful, affirming the right to bodily integrity. See also *Re C (Adult: Refusal of Treatment)* [1994] 1 All ER 819, an influential case for the “use or weigh” criteria in the MCA test, where Thorpe J at 822 described the test as follows: (1) Can the patient take in and retain treatment information? (2) Does he believe it? (3) Can he weigh that information, balancing risks and needs? Thorpe J referred to the developing test in Law Commission *Mentally Handicapped Adults and Decision-making* Consultation paper No 129 (HMSO, London, 1992) at [2.20].

<sup>558</sup> Mental Capacity Act 2005, s 2(1), discussed below.

<sup>559</sup> Protection of Personal and Property Rights Act 1988, s 6: personal order, s 10; order for the administration of property, s 11; and order for the appointment of a property manager, (“wholly or partly”), s 25 (2)(b).

<sup>560</sup> Protection of Personal and Property Rights Act 1988, ss 6 and 12.

<sup>561</sup> Protection of Personal and Property Rights Act 1988, s 94(1).

<sup>562</sup> Protection of Personal and Property Rights Act 1988, s 94(2).

- 4.20 Whether the person is partly or wholly incapable of managing their affairs is relevant to the kind of orders the court can make.<sup>563</sup> A person need only partly lack capacity for the court to make a personal order, such as an order for medical treatment, provision of services or living arrangements under s 10, or a low-level order for the administration of property under s 11. Personal orders of this kind are frequently used by the Family Court as a fall-back order where the person does not meet the threshold of “wholly” lacking capacity for the appointment of a welfare guardian. This reflects the primary objective of the Act, which is to impose the least restrictive intervention tailored to the person’s specific needs.<sup>564</sup>
- 4.21 The problem lies in understanding what the legal test of “partly” lacking capacity actually means. Applying a decision-specific approach, partial lack of capacity suggests something less than incapacity for that specific decision. Alternatively, it could suggest that a person lacks capacity in respect of the decision regarding which the court is going to make an order and not other decisions. However, rather confusingly, section 6 refers to partly lacking capacity in respect of “decisions” in general and not in a specific sense.<sup>565</sup>
- 4.22 Either way, with such an apparently low legal threshold for incapacity, significant decisions can be made regarding a person’s medical treatment or living arrangements, under this test.

*Test no. 2: “wholly” lacks capacity – welfare guardian*

- 4.23 For the appointment of a welfare guardian, both ss 6 and 12 apply. In addition to the test set out in s 6, quoted above, for the appointment of a welfare guardian under s 12, the person must “*wholly* lack capacity”, the highest threshold in the Act. The Court must be satisfied that:<sup>566</sup>
- (a) the person ... *wholly* lacks the capacity to make *or* communicate decisions relating to any particular aspect(s) of the personal care and welfare of that person; *and*
  - (b) the appointment of a welfare guardian ... is the *only* satisfactory way to ensure the appropriate decisions are made.... [emphasis added].
- 4.24 Although “wholly” is a much more stringent threshold than simply “lacks” or “partly lacks” capacity, it has not been interpreted by the Court to mean that the threshold is crossed only where the person is totally incapable of making decisions *at all*, for example, where a person has advanced dementia or is in a persistent vegetative state. If a person has limited capacity to make some decisions but has no capacity to make others, it is sufficient that the person “wholly” lacks the capacity in respect of “particular aspect or aspects” of their care and welfare over which decisions will be transferred.<sup>567</sup> The notion that capacity is decision-specific is,

<sup>563</sup> The Family Court can also choose not to make an order and instead make recommendations.

<sup>564</sup> Protection of Personal and Property Rights Act 1988, s 8(1). The Family Court only has power to make an order to provide medical treatment (PPPR Act, s 10(1f)); not to withhold or withdraw it; such applications for withdrawal or withholding treatment which would require an application to the High Court under the *parens patriae* jurisdiction which is recognised in the PPPR Act, s 114.

<sup>565</sup> In *Re L* [2001] NZFLR 310, the threshold “partly” lacking capacity was interpreted to include a woman whose capacity fluctuated with the state of her mental health due to psychotic episodes in which she had impaired mental functioning. Such an interpretation is contrary to the decision specific nature of capacity and appears more focussed on a status approach in managing people with mental disabilities whose capacity for decision-making may fluctuate.

<sup>566</sup> Protection of Personal and Property Rights Act 1988, s 12(2).

<sup>567</sup> *Re G* [1994] NZFLR 445. See also G Rossiter “Capacity Issues under the PPPRA” (2005) NZLJ 204. There has been little case law on the meaning of “wholly” in the 20 years since the initial decisions after the enactment of the PPPR Act in 1988. The High Court in *KR v MR* (above, n 556) considered this

however, undermined where Court orders are made in respect of “all aspects” of a person’s care and welfare, effectively making the welfare guardian a global decision-maker for a wide range of decisions.<sup>568</sup>

- 4.25 Yet there is a place for the appointment of the welfare guardian on an ongoing basis, where, for example, a person with severe dementia has a deteriorating condition, or in the case of a severely disabled young adult with high needs. These orders may allow some flexibility and understanding of a person’s needs in a range of circumstances, where some form of ongoing decision-making is pragmatically required to support a person whose capacity is impaired in many areas.
- 4.26 It is unrealistic, however, to require a person to “wholly” lack capacity before a welfare guardian can be appointed, and it is unlikely that this test is strictly applied in practice. The test was initially interpreted as permitting the appointment of a welfare guardian only as “an extreme form of intervention”.<sup>569</sup> Nevertheless, even though it is intended in this way to set a high threshold for instituting substitute decision-making in respect of specific decisions, in practice it is not always applied in this way.<sup>570</sup>

### *Test no. 3: “not wholly competent” – property EPOA*

- 4.27 The 2007 amendment to the PPPR Act added two further legal tests for the purpose of activating EPOAs relating to decisions about property, and care and welfare respectively.<sup>571</sup> To confirm that the EPOA can be activated, capacity assessors are required to certify that the person is “mentally incapable”.<sup>572</sup> EPOAs for both property, and care and welfare decisions require this. However, two different tests apply.
- 4.28 For the purposes of activating a property EPOA, the donor is mentally incapable if:<sup>573</sup>
- ... not wholly competent to manage his or her own affairs in relation to his or her property.
- 4.29 This test of “not wholly competent” implies the threshold is something less than not “wholly” lacking competence. This again leaves some doubt about the level of impairment of decision-making required to activate a property EPOA.<sup>574</sup> A further inconsistency is that, for the court

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issue. See also, *R v R* (2010) Fam-054-000472, where Judge Somerville held that a welfare guardian should be appointed for person with brain injuries. The order was made not on a global assessment, but in respect of task specific decisions from simple personal care decisions to more complicated aspects of care and welfare where the person’s capacity was said to be wholly lacking.

<sup>568</sup> Under s 16(4)(a) of the MCA, a decision by the Court is to be preferred to the appointment of a deputy to make a decision and the powers conferred on a Deputy are to be limited in scope and duration as is “reasonably practicable in the circumstances”. There is said to be some “slippage” and that deputies may in fact make more decisions. (A Douglass, presentation to the Manchester School of Law, Manchester 30 April 2015).

<sup>569</sup> *Re G*, above n 567, at 448-449.

<sup>570</sup> There are wider problems of how these welfare guardian orders are implemented, the limited ability of the Court to review and monitor the orders, and the lack of availability of people to be appointed as welfare guardians in the first place. See Chapter 1B: Overview of Mental Capacity Law in New Zealand.

<sup>571</sup> Protection of Personal and Property Rights Act 1988, ss 94(1) and 94(2).

<sup>572</sup> As at December 2015, the Statutes Amendment Bill 2015 proposed to make minor amendments to Part 9 of the PPPR Act and to amend the requirement for a prescribed certificate, instead requiring “prescribed information”, although what the nature and content of that information is not stated.

<sup>573</sup> Protection of Personal and Property Rights Act 1988, s 94(1).

<sup>574</sup> In *Treanery v Treanery* (2008) 27 FRNZ 78, the Court considered that loss of competence must be “total” and equated it to a s 12 test. While the High Court overturned much of the Family Court’s findings ([2009] NZFLR 1062) on the grounds that the judge erred in conflating the daughter’s lack of suitability

to appoint a property manager, the person need only be “partly” lacking competence – a subtly different formulation.<sup>575</sup>

#### *Test no. 4: ‘lacks the capacity’ – care and welfare EPOA*

4.30 Section 94(2) provides a fourth incapacity test for the purpose of activating a care and welfare EPOA. The donor is “mentally incapable” if the donor:

- (a) *lacks the capacity –*
  - (i) to make a decision about a matter relating to his or her personal care and welfare; *or*
  - (ii) to understand the nature of decisions about matters relating to his or her personal care and welfare; *or*
  - (iii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or any failure to make such decisions; *or*
- (b) lacks the capacity to communicate decisions about matters relating to his or her personal care and welfare. [Emphasis added]

4.31 This test is consistent with the functional approach in the MCA, and it is disjunctive (“or”), so only one of the criteria needs to be established. The person may satisfy the test if, for example, they understand the nature of the decision but do not foresee the consequences of it. There may be some circumstances where it is unclear why a person is unable to make a decision, for example, if the person has suffered a stroke and may be depressed. They may be “able” to communicate but do not do so. It is questionable, however, whether the stand-alone criterion of lacking capacity to “make a decision” under s 94(2)(i) adds anything to the overall test because the three functional criteria that follow are all grounds for being unable to make a decision: understanding the nature of decisions, foreseeing the consequences (and failing to make “such decisions”), and the inability to communicate.<sup>576</sup> This test – of “lacks the capacity” – for the appointment of a personal care and welfare attorney is, however, a lower threshold than the “wholly” lacking capacity criterion for the appointment of a welfare guardian.

#### **Multiple tests and no clear definition**

4.32 This use of multiple legal tests throughout the legislation produces unnecessary complexity, especially for health professionals who are required to understand the different legal thresholds and undertake capacity assessments in relation to each of them. Since the early decisions of the PPPR Act, there have been few cases that have examined the meaning of the different thresholds. Moreover, there are few reported cases under the PPPR Act where capacity has been contested, and the reports of some cases suggest that these thresholds have not been correctly applied.<sup>577</sup> Even where careful consideration has been given to a

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to be her mother’s property manager with her suitability to be a welfare guardian, the High Court did not address Judge Murfitt’s statement that there must be total lack of competence before an EPOA for property is activated.

<sup>575</sup> Protection of Personal and Property Rights Act 1988, s 25(2).

<sup>576</sup> Protection of Personal and Property Rights Act 1988, ss 94(2)(a)(ii), (iii) and 94(2)(b). By comparison, under the MCA the definition of being unable to make a decision in s 2 is further defined in s 3 entitled, “Inability to make decisions” followed by the four elements of the functional test.

<sup>577</sup> See Appendix A for a review of selected PPPR Act cases accessed from the Ministry of Justice database.



person's capacity,<sup>578</sup> often little, if any, consideration is given to the relative difference between "partly" lacking capacity and the higher threshold of "wholly" lacking capacity, for the purposes of establishing jurisdiction.

- 4.33 In summary, the two original tests under the PPPR Act and subsequent additional tests for activating EPOAs, have created an unnecessarily complicated schema of legal tests, with a spectrum from an impossibly high threshold, "wholly", through to an unacceptably low threshold of "partly" lacking capacity.

## No definition of capacity in the HDC Code

- 4.34 Capacity is an essential component of valid consent. A valid consent is generally taken to consist of four elements: information provision, voluntariness, the opportunity to deliberate, and capacity (or competence).<sup>579</sup> Under the HDC Code, consent to treatment is necessary in many situations, as required by the HDC Code or by other legislation or the common law.<sup>580</sup> Right 7 of the HDC Code enshrines the right to make an informed choice and give informed consent. This is buttressed by two important principles: the presumption of competence, and encouraging the participation of those with diminished competence.<sup>581</sup> In addition, Right 7(4) provides a mechanism for making decisions for a person who is assessed as lacking capacity where there is no substitute decision-maker available.<sup>582</sup>
- 4.35 Nevertheless, despite the fact that healthcare decisions involving people with impaired capacity are made every day, and the importance of capacity to informed consent, neither the Health and Disability Commissioner Act 1994, nor the HDC Code (a regulation issued under that legislation), defines the concept of capacity (referred to as "competence") or provides clear legal standards against which capacity is to be assessed.<sup>583</sup>

## 4C: MCA – LEGAL TEST

- 4.36 There is a single legal test in the MCA defining lack of capacity. The key provision for determining capacity is s 2(1) of the MCA.<sup>584</sup>

For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

<sup>578</sup> See for example, *VJM on behalf of the Hawkes Bay District Health Board v MH* (2011) FAM-2011-041-516, where Judge Callinicos undertook a thorough analysis of the independent psychiatrist's evidence and was satisfied that MH's inability to make a reasoned decision about the arrangements for her discharge from hospital was a "tipping point", and that the Court had jurisdiction.

<sup>579</sup> Jonas, above n 549 at 255.

<sup>580</sup> HDC Code, Right 7(1). See discussion by PDG Skegg "Justifications for Treatment without Consent" in P Skegg and R Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) at 188 and 214.

<sup>581</sup> HDC Code, Rights 7(2) and 7(3).

<sup>582</sup> An overview of the HDC Code is discussed above Part 1B.

<sup>583</sup> Appendix B is a review of the Health and Disability Commissioner's opinions where a person's capacity has been at issue.

<sup>584</sup> Mental Capacity Act 2005, s 2(1).

- 4.37 There are two limbs to the capacity test in s 2. These are:<sup>585</sup>
1. Whether the person is “unable to make a decision for himself” (functional test – as defined in s 3); and
  2. Whether that inability is because of “an impairment of, or a disturbance of the functioning of, the mind or the brain” (diagnostic test – as set out in s 2).
- 4.38 Section 3 defines what it means to be unable to make a decision in terms of the functional approach. In summary, the four elements of the functional test are the inability to: understand, retain, or use or weigh the relevant information as part of the decision-making process, or communicate their decision.<sup>586</sup>
- 4.39 The MCA definition of capacity reinforces that capacity is time-specific (at the material time) and decision-specific (unable to make a decision). It applies for the purposes of the Act, which in English law includes questions of capacity in relation to medical treatment decisions.<sup>587</sup> Common law definitions of capacity such as capacity to make a will are not affected.<sup>588</sup> When cases on such matters outside the Act come before the courts, judges can adopt the definition of capacity contained in this section and s 3 if they think it is appropriate.<sup>589</sup>
- 4.40 A difficulty in applying a strictly decision- or act-specific approach to capacity, within the MCA, has arisen in cases involving vulnerable women with learning disabilities that have been concerned with whether the women had capacity to consent to cohabit or have sexual relations.<sup>590</sup> In *IM v Liverpool*,<sup>591</sup> LM was found to have capacity to consent to sex, where the man involved challenged the supervision of his contact with LM that was carried out by the local authority. The Court of Appeal followed an act-specific approach, based on whether the person understood at a general level the nature of sex, to which they were apparently consenting, in contrast to a person-specific approach, requiring a more contextual analysis of the circumstances of the particular person.<sup>592</sup> This reasoning suggests that the test of capacity to consent to sex merely involves being able to understand the nature of the activity, rather than having the ability to use or weigh information about it. The extent to which the capacity test in the MCA deals with these hard cases, where the person’s ability for autonomous decision-making is impaired, has therefore been called in question.<sup>593</sup>

<sup>585</sup> A Ruck-Keene, V Butler-Cole, N Allen and others, above n 201.

<sup>586</sup> The functional test in s 3 of the MCA is discussed below. Both ss 2 and 3 of the MCA are set out in full in Appendix C.

<sup>587</sup> In New Zealand, the HDC Code provides the basis of the law of consent in relation to healthcare procedures but there is no definition of “competence”, discussed below.

<sup>588</sup> *Banks v Goodfellow* (1869-70) LR5 QB 549. The Code of Practice recognises the common law tests of capacity to make a will, gift, enter a contract, to litigate and to enter a marriage.

<sup>589</sup> *Local Authority X v MM and KM* [2007] EWHC 2003 (FAM) at [80], Munby J.

<sup>590</sup> The consequences of finding that a person lacks capacity to consent to sex means that nobody else can consent to sexual relations on their behalf: Mental Capacity Act 2005, s 27(1)(b).

<sup>591</sup> *IM v LM and Liverpool City Council* [2014] EWCA Civ 37. Another case, *PC and NC v City of York Council* [2013] EWCA Civ 478, McFarlane LJ, is discussed below in respect of causation.

<sup>592</sup> The person or situation-specific test was supported by Lady Hale in a criminal law case involving consent: “One does not consent to sex in general. One consents to this act of sex with this person at this time and in this place” *Regina v Cooper* (2009) UKHL 42 at [27].

<sup>593</sup> J Herring and J Wall “Capacity to Consent to Sex” (2014) 0 Med L Rev 1.

## MCA – the functional test

4.41 As with the PPPR Act, the MCA therefore mainly adopts a functional approach to defining capacity. The key difference is that there is just one legal test to follow, set out as four logical steps. A person is unable to make a decision if they cannot:<sup>594</sup>

1. understand the information relevant to the decision; or
2. retain that information in their mind; or
3. use or weigh that information as part of the decision-making process; or
4. communicate their decision (whether by talking, using sign language or any other means).

4.42 Section 3 is based on the common law test of capacity and there is no relevant distinction between them.<sup>595</sup> In *IM v LM*, the Court of Appeal said that:<sup>596</sup>

Every single issue of capacity which falls to be determined under Part 1 of the Act must be evaluated by applying s 3(1) in full in considering each of the four elements of the decision-making process that are set out at (a) to (d) .... The extent to which, on the facts of any individual case, there is a need either for a sophisticated, or for a more straightforward, evaluation by either of these four elements will naturally vary from case to case and from topic to topic.

4.43 The four elements in this test are considered below.

### Understand the information

4.44 It is not necessary that the person understands every element of what is being explained to them. The information relevant to a decision includes information about the reasonably foreseeable consequences of deciding one way or another, or failing to make a decision.<sup>597</sup> An explanation of all relevant information must be given to the person using appropriate means of communication given their particular circumstances.

4.45 Being able to understand the information is not the same as being able to pass an exam on it: the person should have a broad understanding of the basic information relevant to the decision. This concept is familiar to most lawyers, but may not be so familiar to doctors, who may set the bar too high.<sup>598</sup>

4.46 In *Heart of England NHS Foundation Trust v JB*,<sup>599</sup> JB suffered from severe schizophrenia and vascular disease. She was found to have capacity to refuse surgical treatment of her gangrenous leg against “shifting medical opinion”. Peter Jackson J held:

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<sup>594</sup> Mental Capacity Act 2005, s 3(1).

<sup>595</sup> *Local Authority X v MM and KM*, above n 589 at [74], Munby J.

<sup>596</sup> Above n 589 at [73].

<sup>597</sup> Mental Capacity Act 2005, s 3(4).

<sup>598</sup> *PH and A Local Authority v Z Limited and R* [2011] EWHC 1704 (FAM).

<sup>599</sup> Above n 363 at [26]. Peter Jackson J “happily” distinguished the earlier and famous decision of Thorpe J in *Re C (Adult: Refusal of Treatment)* [1994] 1 WLR 290 at 295, the first reported case to give any clear guidance on questions of capacity in relation to medical treatment decisions, even though both cases involved people with delusional beliefs. In refusing amputation of his gangrenous leg, C preferred

[w]hat is required here is *a broad, general understanding of the kind that is expected from the population at large*. JB is not required to understand every last piece of information about her situation and her options: even her doctors would not make that claim. It must also be remembered that common strategies for dealing with unpalatable dilemmas – for example *indecision, avoidance or vacillation* – *are not to be confused with incapacity*. *We should not ask more of people whose capacity is questioned than of those whose capacity is undoubted*. [Emphasis added].

- 4.47 Having the appropriate information, including the options available, to make the decision is vital to this process and is consistent with supporting people to make their own decisions, where possible. So it is said that a person must not start with a “blank canvas”.<sup>600</sup>

## Retain the relevant information

- 4.48 Retaining information for even a short time may be adequate in the context of some decisions. This will depend on what is necessary for the decision in question. The MCA specifies that “the fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision”.<sup>601</sup>
- 4.49 Aids to recollection, such as notes, pictures, photographs and voice recordings, and parts of the mental state examination, may be helpful to assess how long the person can retain information. Can they remember three words? If they can’t, can they still give consistent answers when questioned about their decision?<sup>602</sup>
- 4.50 The ability to retain information is a discrete element of the MCA test and logically follows from the requirement to understand the information. There is no equivalent element in the PPPR Act tests. It is an important consideration, particularly with older adults or people with deteriorating memories.<sup>603</sup>

## Use or weigh the Information

- 4.51 Using and weighing information is the evaluative component of the MCA test. It requires the ability to reason about, or weigh up, information and to appreciate the consequences. This may be the most difficult element of assessing capacity as an unwise or irrational decision does not necessarily establish that a person has failed to use or weigh the information.
- 4.52 The standard of “weighing up” or “using information” can be difficult if the person is weighing up the important information against their personal convictions, beliefs or values. It recognises that “different individuals may give different weight to different factors.”<sup>604</sup> In *Kings*

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<sup>600</sup> “to die with two feet than live with one”. Note also earlier discussion of capacity in, *Re T*, above n 555 and although the ultimate decision was unanimous, each of the four judges involved decided the question of the person’s capacity differently.

<sup>601</sup> *CC v KK*, above n 362. This case is discussed in Chapter 2E: Supported Decision-making in practice and in case law.

<sup>602</sup> Mental Capacity Act 2005, s 3(3).

<sup>603</sup> Interview with Dr Frances Matthews, lawyer and GP (A Douglass, Dublin, June 2015).

<sup>604</sup> Ruck Keene, Butler-Cole, Allen and others, above n 201 at [30].

<sup>604</sup> *LBL v RYJ and VJ* [2010] EWHC 2665 (COP) Macur J cited with approval by Baker J in *CC v KK* at [65]: “There is, I perceive, a danger that professionals, including judges, may objectively conflate a capacity assessment with a best interests analysis and conclude that the person under review should attach greater weight to the physical security and comfort of a residential home and less importance to the emotional security and comfort that the person derives from being in their own home.”

*College NHS Foundation Trust v C and V*,<sup>605</sup> the COP had to consider whether C had the capacity to consent to life-saving renal dialysis that her doctors wished to give her following an attempted suicide. If the treatment were to have been administered the likelihood was that C would require dialysis for the rest of her life, and, if not, the inevitable outcome was that she would die. C's refusal to consent was supported by her two daughters.<sup>606</sup> In finding that C had the capacity to refuse treatment, MacDonald J held, contrary to the opinion of two experienced psychiatrists, that it had not been shown that C was unable to use and weigh the information relevant to the decision.<sup>607</sup>

I am not satisfied that C lacks belief in her prognosis or a future that includes her recovery to the extent she cannot use that information to make a decision, or that C is unable to weigh her positive prognosis and the possibility of a future recovery in the decision making process....

... it is also important in this case not to confuse a decision by C to give no weight to her prognosis having weighed it with an inability on her part to use or weigh that information.<sup>608</sup>

4.53 In concluding, MacDonald J noted that the decision was an unwise one.<sup>609</sup>

The decision C has reached to refuse treatment dialysis can be characterised as an unwise one. That C considers that the prospect of growing old, the fear of living with fewer material possessions and the fear that she has lost, and will not regain, "her sparkle" outweighs a prognosis that signals continued life will alarm and possibly horrify many, although I am satisfied that the ongoing discomfort of treatment, the fear of chronic illness and the fear of lifelong treatment and lifelong disability are factors that also weigh heavily in the balance for C.

4.54 There are also cases where the person concerned can understand information but where the effects of a mental disability prevent them from using that information in the decision-making process. For example, a person with anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore.<sup>610</sup> Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it.<sup>611</sup> Undue influence and the overpowering will of a third party are also considered to have a role in this aspect of

<sup>605</sup> *Kings College NHS Foundation Trust v C* [2015] EWCOP 80 at [8]. C was said to live an unconventional life where she placed a "significant premium on youth and beauty and on living a life that, in C's words, 'sparkles'".

<sup>606</sup> C made statements such as "They are doing their best to do everything they can for me and unfortunately that is not what I want" and "I know they need to save lives. But I have chosen a different route" at [87].

<sup>607</sup> *Kings College NHS Foundation Trust v C* at [72]. At [35], MacDonald J suggested that a finding of incapacity requires the person asserting lack of capacity to demonstrate *both* an inability to use *and* weigh relevant information however this reasoning has been questioned as not an accurate interpretation of "use or weigh" and that s 3(1)(c) can be satisfied either by establishing that a person is unable to use *or* by establishing a person is unable to weigh. W Martin and F Freyenhagen of the Essex Autonomy Project "Use or Weigh? Or Use and Weigh? A Note on the Logic of MCA sec. 3(1)" (2015) 61 *Ment Capac Law News* 15.

<sup>608</sup> *Kings College NHS Foundation Trust v C* at [86].

<sup>609</sup> *Kings College NHS Foundation Trust v C* at [97].

<sup>610</sup> In *Re E (Medical Treatment Anorexia)* [2012] EHC 1639 (COP) Peter Jackson J at [49] "E's obsessive fear of weight gain makes her incapable of weighing the advantages and disadvantages of eating in a meaningful way". E could understand and retain the information relevant to her decision to refuse to eat, but she was unable to assign relative weight to the advantages, disadvantages and consequences associated with the decision to eat since, "the compulsion to prevent calories entering her system has become that card that trumps all others".

<sup>611</sup> *Mental Capacity Act Code of Practice*, above n 285 at 48.

the capacity test, especially where a person with borderline capacity may be less able to resist pressure applied by others.<sup>612</sup>

- 4.55 The nearest equivalent under the PPPR Act to the MCA's criterion of "use or weigh" is its requirement "to foresee the consequences" of decisions. There is, however, a nuanced difference, as the MCA test focuses on the evidence of using or weighing information as part of the decision-making process rather than on predicting the outcome or the consequences of the decision itself. The difficulty with the PPPR Act's concept of "foreseeing the consequences" concerns the extent to which anyone, with capacity or not, can be said to value or fully evaluate the consequences of a decision if that requires the risks and benefits of the decision to be internalised.<sup>613</sup>
- 4.56 The concept of "appreciating" that nature of the decision is used in this context in the United States.<sup>614</sup> In the recently passed Mental Capacity Bill in Northern Ireland, the notion of "appreciate the relevant information" has been added to the element of "use or weigh" in the MCA test.<sup>615</sup> It arguably adds a subtle evaluative aspect to the MCA test by importing the notion that the ability to "use or weigh" requires an appreciation of the significance of the person's situation and the probable consequences of the treatment options.

## Communicate the decision

- 4.57 The inability to communicate a decision is also recognised in the PPPR Act tests and is a stand-alone ground for incapacity, even if rarely employed. Examples where it would apply would include people who are unconscious or in a coma or those with a rare condition sometimes referred to as "locked-in syndrome", who are conscious yet totally unable to communicate.<sup>616</sup> Any form of communication suffices so long as the person can make themselves understood.<sup>617</sup> The MCA and its Code of Practice also require that an explanation of the relevant matters be communicated to the person in a way that is appropriate to their circumstances (using simple language, visual aids or other means).<sup>618</sup>
- 4.58 Where an individual cannot communicate a decision in any possible way, the MCA considers the individual unable to make a decision for themselves.<sup>619</sup> People who have suffered a stroke, for example, are particularly disadvantaged, as their difficulty in communicating can

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<sup>612</sup> *Re T*, above n 555 at 797, Lord Donaldson MR. The role of undue influence in the test of capacity was recognised by the Law Commission, above n 311 at 38.

<sup>613</sup> P Appelbaum and T Grisso "Assessing Patients' capacities to consent to treatment" (1988) 319 N Eng L Med 1635. Some New Zealand decisions have referred to 'appreciate' instead of "foresee the consequences" test when applying the s 6 PPPR Act test: *KR v MR*, above n 556.

<sup>614</sup> In relation to treatment decisions, the criteria expressed by Grisso and Appelbaum are: the ability to express a choice about treatment, to understand information relevant to the treatment decision, to appreciate the significance of the treatment information.

<sup>615</sup> Mental Capacity Bill (Northern Ireland) 2015. The meaning of "unable to make a decision" in s 4(l) includes "(c) is not able to appreciate the relevance of that information and to use and weigh that information as part of the process of making the decision." This element refers to "use *and* weigh" not "use *or* weigh" under s3(1)(c) of the MCA.

<sup>616</sup> One of the few cases is the New Zealand case of *Area Health Board v Attorney General* [1993] 1 NZLR 235, where the person had Guillain Barre syndrome.

<sup>617</sup> There are tools for communication with people with disabilities and recognition of the transactional nature of communication to support people in making decisions for themselves: Kim Rosen "Communication the keystone to supported decision-making" presentation to the Capacity Australia conference (November 2015, Sydney) see [www.capacityaustralia.org.au/](http://www.capacityaustralia.org.au/).

<sup>618</sup> Mental Capacity Act 2005, s 3(2).

<sup>619</sup> Mental Capacity Act 2005, s 3(1)(d).



mask capacity that would normally be revealed in conversation.<sup>620</sup> There is increased focus on this element of capacity with the shift towards supported decision-making for people with disabilities under the CRPD.<sup>621</sup>

## The “diagnostic threshold” and causation

- 4.59 The main difference between the PPPR Act and the MCA’s tests for mental incapacity is that the MCA combines a functional test for decision-making ability with the so-called “diagnostic threshold”. The requirement of an “impairment of, or a disturbance in the functioning of, the mind or brain” is very broad and it is a misnomer to call it a diagnostic threshold.<sup>622</sup> It may be permanent or temporary.<sup>623</sup> It may include conditions associated with some forms of mental illness, dementia, significant learning disabilities, the long-term effects of brain damage, physical or medical conditions that cause confusion, drowsiness or loss of consciousness, concussion following a head injury, and the symptoms of alcohol or drug use. The essential characteristic is a disturbance in the functioning of the mind, so many mental illnesses could potentially include an inability to make decisions, although most of them do not.<sup>624</sup>
- 4.60 The Essex Autonomy Project Report found that the diagnostic threshold was discriminatory of people with disabilities in terms of the CRPD and recommended that it be removed.<sup>625</sup> However, it was argued that the MCA’s use of the functional test under s 3(1) as a trigger for substitute decision-making justifies a practice which would otherwise be discriminatory as it disproportionately impacts on persons with disabilities. Primarily, this is because the central aims of the MCA, as with the CRPD, are to empower people to make their own decisions wherever possible, and to protect people with impaired decision-making capacity who find themselves facing circumstances of risk.
- 4.61 For a person to be found to lack capacity there must also be a causal connection between being unable to make a decision by reason of one or more of the functional elements set out in s 3(1) of the MCA (the functional test) *because of* an impairment of the mind or brain under s 2(1) (the diagnostic test). In *PC and NC v City of York Council*,<sup>626</sup> the issue of causation made all the difference in finding that PC, a woman with learning disabilities, had capacity to live with her seriously risky husband upon his release from prison. The Court of Appeal overturned the decision of the COP and held that while PC lacked capacity to understand the information and weigh it to make the decision to resume living with husband, PC’s difficulties in decision-making (although “significantly related to her mild learning disability”), were not shown to be a result of her mental impairment.<sup>627</sup>

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<sup>620</sup> A Patchet, L Allan and L Erskine “Assessment of Fluctuating Decision-Making Capacity in Individuals With Communication Barriers: A Case Study” (2012) 19 *Top Stroke Rehabil* 75.

<sup>621</sup> See Chapter 2E: Supported decision-making in Practice and in Case Law.

<sup>622</sup> It is not necessary for the impairment or disturbance to fit into one of the diagnoses in psychiatric diagnostic manuals such as ICD-X or DSM-V. (A Douglass, Interview with Dr Gareth Owen, psychiatrist, Kings College, London, 22 April 2015).

<sup>623</sup> Mental Capacity Act 2005, s 2(2).

<sup>624</sup> Hale, above n 194.

<sup>625</sup> W Martin, S Michalowski, T Jutten and others *Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the Rights of Persons with Disabilities? If not, what next?* (Essex Autonomy Project, University of Essex, 22 September 2014) at 16 -17.

<sup>626</sup> *PC v York City Council* [2013] above n 591. PC had previously been found to have capacity to marry but the question before the court was whether she had capacity to cohabit with her husband.

<sup>627</sup> Skowron, above n 205.

- 4.62 The s 2 diagnostic threshold was introduced as a device to limit the scope of MCA powers.<sup>628</sup> An argument in favour of the diagnostic threshold in the MCA's capacity test, concerning the functioning of the mind or brain, is that it serves a gate-keeping function to ensure that a person's actions, or ability to make a decision, are not being scrutinised on the basis of unwise decisions alone. Ironically, the requirement of a diagnosis is now seen as non-compliant with the CRPD as it specifically discriminates on the ground of disability. The legal complexity associated with removing the diagnostic test is the risk that the change required for CRPD compliance will in turn result in a violation of art 5 of the European Convention on Human Rights.<sup>629</sup> Unlike New Zealand, the United Kingdom finds itself in a difficult position of having to satisfy two international human rights requirements that pull in opposite directions.<sup>630</sup>

## Summary

- 4.63 The functional test in the MCA offers a simple and straightforward legal test for defining capacity, in contrast to the multiple tests for capacity in the PPPR Act, and in contrast to the lack of any definition of competence *at all* in the HDC Code. The functional test in the MCA codifies the common law and is similar to the existing tests in the PPPR Act. The MCA test has already been accepted implicitly in New Zealand case law,<sup>631</sup> and it has been adopted as part of a threshold test in a compulsory treatment Bill for addiction currently before the New Zealand Parliament.<sup>632</sup>
- 4.64 It is not necessary for New Zealand to adopt the diagnostic threshold in the MCA as part of a legal test, as that element is unnecessary and can be considered discriminatory towards people with disabilities under the CRPD.
- 4.65 In conjunction with a revised legal test, a Code of Practice with guidance for assessing capacity would be essential to avoid inconsistent and idiosyncratic interpretations of the legal test, and to ensure that the tenets of capacity – the presumption of capacity and the right to make unwise decisions – are applied.

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<sup>628</sup> *Winterwerp v The Netherlands*, above n 401 at 1. The reason for the diagnostic threshold was put in the definition of capacity was for compliance with art 5 of the ECHR and the requirement of "unsoundness of mind" requiring objective medical evidence.

<sup>629</sup> Szerletics, above n 209 at 44.

<sup>630</sup> The new Mental Capacity Bill in Northern Ireland has sought to qualify the "diagnostic" threshold to avoid discrimination on the ground of disability. See Chapter 1A Setting the Context.

<sup>631</sup> *Chief Executive of the Department of Corrections v Canterbury District Health Board and All Means All* [2014] NZHC 1433 at [17]. In an application by the Department of Corrections as to the lawfulness of not providing medical treatment to a serving prisoner on a hunger strike, Mr All Means All, Pankhurst J accepted the expert psychiatrist's evidence based on the MCA legal test that Mr All Means All had capacity to refuse medical treatment.

<sup>632</sup> Substance Addiction (Compulsory Assessment and Treatment) Bill, 2015. The four criteria for the compulsory treatment for substance addiction in clause cl 7(a)-(d) include the "capacity to make informed decisions" under clause 9, and adopts the functional test for "inability to make a decision" in section 3(1) of the MCA.

## RECOMMENDATION FOR A SINGLE TEST FOR CAPACITY

The definition of capacity in revised legislation should provide a single and unified legal test for capacity that mirrors Section 3(1) to (4) of the MCA, including:

1. Section 3 (1):

A person is unable to make a decision if they are unable -

- (a) To understand the information relevant to the decision;
- (b) To retain that information
- (c) To use of weigh that information as part of the process of making the decision, or
- (d) To communicate their decision.

2. Section 3(2) of the MCA:

A person is not to be regarded as unable to understand the information relevant to a decision if they are able to understand an explanation of it given to them in a way that is appropriate to their circumstances (using simple language, visual aids or other means).

3. Section 3 (3) of the MCA:

The fact that a person is able to retain information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.

4. Section 3(4) of the MCA:

The information relevant to a decision includes information about the reasonably foreseeable consequences of –

- (a) deciding one way or another; or
- (b) failing to make the decision.

# Chapter 5

## **Best Interests**

## Chapter 5: Best Interests – a Standard for Decision-making

Chapter 5 is in two sections:

- A. The absence of a “best interests” standard for decision-making in the PPPR Act and in the HDC Code.
- B. The evolution of the common law and codification of the best interests standard for decision-making under s 4 of the Mental Capacity Act (MCA).

### Introduction

- 5.1 The MCA has a statutory “best interests” standard. It applies where a person takes actions or decisions on behalf of another person who lacks capacity and is “unable to make a decision”, as defined in sections 2 and 3 of the MCA.<sup>633</sup> A “checklist” in s 4 provides a process for assessing the person’s best interests (the best interests assessment) and sets out matters that the substitute decision-maker (the decision-maker) must consider. These matters include the aim that the person with impaired capacity should participate in determining their best interests, recognising the person’s present and past wishes and feelings, and acknowledging the beliefs and values that would have likely influenced their decision if they had capacity.
- 5.2 Under the MCA, the concept of best interests therefore provides a framework for decision-making on behalf of people with impaired capacity. Previously, the law focused mainly on the autonomy of people *with* capacity, such as their right to refuse medical treatment, rather than on decision-making for people who could not make autonomous decisions.<sup>634</sup> As discussed in Chapter 2,<sup>635</sup> this best interests framework is compatible with supported decision-making because it requires participation by the person with impaired capacity where possible, and it is an appropriate approach to decision-making for people who cannot make decisions for themselves. This approach also recognises that, even if a person is unable to make a legally binding decision with support, their likely will and preferences remain central to the decision-making process: capacity is not an off-switch to a person’s rights and freedoms.<sup>636</sup>
- 5.3 Best interests guides substitute decision-making and is often contrasted to the notion of substituted judgment. While the former has traditionally been viewed as an objective standard, the latter is more subjective because it instructs the decision-maker to make the decision that the person would have wanted if they had capacity to do so. It has been preferred by courts in the United States.<sup>637</sup> It is considered to uphold the person’s autonomy to a greater degree. Both approaches have their challenges.<sup>638</sup> The statutory standard in the MCA can be

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<sup>633</sup> See Appendix C and Mental Capacity Act, s 4. Section 1(5) states that “an act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests”.

<sup>634</sup> Buchanan and Brock, above n 34 at 3.

<sup>635</sup> See Chapter 2 Supported decision-making.

<sup>636</sup> *Wye Valley NHS Trust v Mr B*, above n 171.

<sup>637</sup> Donnelly, above n 254 at 176.

<sup>638</sup> Donnelly, above n 254 at 177.

regarded as a hybrid approach, as a subjective element was introduced that was previously absent from the common law's approach to substitute decision-making.

- 5.4 New Zealand's legal framework provides no such comprehensive standard for decision-making where a person has impaired capacity. The PPPR Act refers to decisions being made in a person's "welfare and best interests", and, under Right 7(4) of the HDC Code, decisions can be made in a person's "best interests." However, best interests is not a primary principle of either piece of legislation and there is no guidance on how these best interests decisions are to be made in light of a person's "will, preferences and rights" under the United Nations Conventions on the Rights of Persons with Disabilities (CRPD).<sup>639</sup>
- 5.5 How best interests is assessed under the MCA, and the case law around it, is considered below. Recommendations are then made for revised legislation to provide a best interests standard in New Zealand based on s 4 of the MCA.

## 5A: BEST INTERESTS IN NEW ZEALAND LAW

### Best interests and the PPPR Act

- 5.6 Promoting the "best interests" of people with impaired capacity is not a primary objective of the PPPR Act, although it is often assumed that it is. It is not stated as a key statutory principle governing the exercise of the court's jurisdiction, nor as the basis for the appointment of a substitute decision-maker, such as a welfare guardian or an attorney under an EPOA. It is only once a substitute decision-maker has been appointed that the welfare and best interests of a person who lacks capacity becomes a paramount consideration in making decisions on that person's behalf.<sup>640</sup> There is also no clear direction that the court must make decisions in the person's best interests.<sup>641</sup> In practice, the concept of best interests is given considerable weight in judicial reasoning, but the Act provides no guidance as to what best interests means or how this would be operationalised.
- 5.7 In some sections of the PPPR Act best interests is given priority. For example, in s 18(3), regarding the exercise of a welfare guardian's powers, it is said:<sup>642</sup>

In exercising those powers, the first and paramount consideration of a welfare guardian should be the promotion and protection of the *welfare and best interests* of the person for whom the welfare guardian is acting, while seeking at all times to encourage the person to develop and exercise such capacity as that person has to understand the nature and foresee the consequences of decisions relating to the personal care and welfare of that person, and to communicate such decisions. [Emphasis added]

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<sup>639</sup> Article 12(4) of the CRPD uses the formulation 'rights, will and preferences'.

<sup>640</sup> The phrase "best interests" is used in 10 sections of the PPPR Act, primarily to highlight when the Court (or a trustee corporation) should or should not make an order or appoint a manager, for example, ss 30(1)(c), 31(5)(e), 32(3)(b), 105(1)(a) and 125(b). Best interests is not a criterion for personal orders under s 10 or the appointment of a welfare guardian under s 12.

<sup>641</sup> Personal and Property Rights Act 1988, ss 12(5)(b), 18(3), 97A(2) and 98A(2).

<sup>642</sup> This expression of paramountcy is reiterated in s 36(1) with regard to property managers and in ss 97A(2) and 98A(2) with regard to attorneys in promoting and protecting the welfare and best interests of the donor, whether in regard to use of the donor's property or personal care and welfare.



- 5.8 In the past, the “welfare and best interests” of the person has been referred to as “the welfare principle”.<sup>643</sup> The notion of “welfare” adds little to the concept. “Welfare and best interests” could be described as a triple tautology as ‘best’, ‘interests’ and ‘welfare’ all have the same purpose.<sup>644</sup> In philosophical literature, the notions of welfare and well-being are viewed as the same, whilst the term “best interests”, so important in legal thought, is little analysed.<sup>645</sup>
- 5.9 As with cases applying the English common law best interests test, a number of the early cases under the PPPR Act were concerned with sterilisation or orders to terminate a woman’s pregnancy.<sup>646</sup> In *KR v MR*,<sup>647</sup> where a personal order was sought to terminate the pregnancy of a disabled woman, Miller J considered the correct approach to the welfare principle:<sup>648</sup>
- The welfare principle is capable of being viewed from a range of perspectives. It is susceptible to prevailing social norms and the personal values of the decision-maker. It is not an objective test and its workability depends on informed fact finding and the wise exercise of discretion.... The principal objectives also quite plainly envisaged that there may be ‘secondary’ objectives, which are unspecified. Nonetheless, from the point of view of the person in respect of whom the decision is being made the principal objectives are a surer guide to the exercise of the decision-maker’s discretion than is a general appeal to the welfare principle.
- 5.10 The participatory model of the PPPR Act requires appointed welfare guardians and property managers to consult with the person subject to the order. It is only when exercising these powers, however, that the “first and paramount consideration” is said to be promoting and protecting the person’s welfare *and* best interests.<sup>649</sup> Importantly, this requirement that the welfare guardian or attorney must act in the person’s best interests only operates once incapacity has been established and the appointment of a substitute decision-maker made.
- 5.11 Despite this implied rather than expressed status of the best interests principle,<sup>650</sup> there is now considerable case law, particularly in respect of living arrangements for older adults, where the Court has accepted jurisdiction and made orders considered to be in the person’s best interests, albeit against their express wishes. In *Hutt Valley DHB v MJP*,<sup>651</sup> MJP, the person subject to the application, neither wanted nor had any support at home but was unable to look after herself. Personal orders for dementia level care and necessary medical treatment were made despite the express wishes of MJP to return to her own home. The Court held that for its jurisdiction to be governed solely by the least restrictive intervention principle –

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<sup>643</sup> *Re H* [1993] NZFLR 225, Judge Inglis.

<sup>644</sup> Interview with Dr Dominic Wilkinson, Director of Medical Ethics at the Oxford Uehiro Centre for Practical Ethics (A Douglass, Dunedin, 9 July 2015).

<sup>645</sup> Herring and Foster, above n 306 at 484.

<sup>646</sup> See for example *Re H*, above n 643, and the decisions based on the *parens patriae* jurisdiction at common law: *Re E v E* [1986] 2 SCR 388; *Re B (a minor, wardship: sterilisation)* [1987] 2 All ER 206; and *Secretary, Department of Health and Community Services v B (Marion’s case)* (1992) 175 CLR 218. Above n 52.

<sup>647</sup> *KR v MR*, above n 52 at [65]. Miller J noted that whilst the welfare principle is the first and paramount consideration may appear “...self-evident at first blush, this was not necessarily so as a matter of construction under s 10”.

<sup>648</sup> Personal and Property Rights Act 1988, ss 18(3) and (4) (welfare guardian) and s 98A(2) (attorney in relation to personal care and welfare).

<sup>649</sup> The implicit reliance upon best interests by the Court was noted in a review of the implementation of the PPPR Act for people with intellectual disabilities: A Bray and J Dawson *Who Benefits from Welfare Guardianship – A Study of New Zealand Law and People with Intellectual Disability* (Donald Beasley Institute, Dunedin, 2000).

<sup>650</sup> *Hutt Valley DHB v MJP* [2012] above n 42. See also, Atkin B and Skellern A “Adults with Incapacity: The Protection of Personal and Property Rights Act” in Dawson and Gledhill, above n 92, at 341.

which is explicit in the Act – would be to limit its application to the most compelling cases of incapacity. Judge Moss said a balancing approach was required:<sup>652</sup>

It is in this area of fine distinction that meaning must be found to find the difference between an intervention to the least extent possible, which will enable capacity, and what is in the best interests and welfare of the patient.

- 5.12 The best interests principle tends to be disguised by the court in such a balancing exercise, where, for example, a person's decision to refuse admission to residential care is called into question. This implicit reliance on best interests does not necessarily involve placing weight on the person's current or previous will or preferences, however, but rather goes to the degree of intervention likely to be imposed by the court order.
- 5.13 The High Court has previously cautioned against adopting an overly legalistic approach when applying the PPPR Act's express principles – to make the least restrictive intervention and maximise the person's participation – to ensure that the welfare and best interests of the person are also taken into account, even if this matter is not expressed as a guiding principle of the Act.<sup>653</sup> The precise role that best interests plays remains unclear, however, as it does not expressly apply to the initial finding that the person lacks capacity, nor is it the stated legal foundation for intervention against the person's express preferences.

### **Best interests – a different standard to child law**

- 5.14 In contrast to adult guardianship law under the PPPR Act, the Care of Children Act 2004 (COCA) places the welfare and best interests of the child as the first and paramount consideration.<sup>654</sup> The Act provides five principles to assist in this evaluation, with an emphasis on protecting child safety, and on parental and guardian responsibility.<sup>655</sup>
- 5.15 This difference between the PPPR Act and the COCA stems from fundamental policy differences between the two pieces of legislation. The purpose of the COCA is to promote children's welfare and best interests, with an overall purpose of protecting children. The COCA anticipates that children may be able to participate in decisions about their interests,<sup>656</sup> however, the threshold for state intervention is low.<sup>657</sup> In contrast, the primary objectives of the PPPR Act are to make the least restrictive intervention possible while enabling and encouraging the adult person to exercise and develop their capacity.<sup>658</sup> The aim of the PPPR Act is to "protect and promote" the interests of adults who are unable to manage their affairs. Although there is a protective function, there is a presumption of competence and recognition that intervention is only appropriate where an adult lacks capacity in law.

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<sup>652</sup> *Hutt Valley DHB v MJP* above n 42 at [16].

<sup>653</sup> *In the Matter of A* [1996] NZFLR 359 (HC) where there was a personal order in addition to a welfare guardian order. The welfare guardian powers were restricted so that the subject person was not to leave the primary care residence without further order of the Court.

<sup>654</sup> Care of Children Act 2004, s 4(1). "The welfare and best interests of a child in his or her particular circumstances must be the first and paramount consideration."

<sup>655</sup> In *B v K* [2010] NZCA 96 at [37] Arnold J explained how the principles in s 5 of the COCA are to be interpreted: "The answers to the question what is in the best interests of a particular child may differ as between judges. This is not because they involve discretionary decisions but because they involve evaluative assessments, which will not by their nature yield definitive answers".

<sup>656</sup> Care of Children Act 2004, s 16(1)(c) uses the term "helping the child to determine questions about important matters affecting the child".

<sup>657</sup> It is beyond the scope of this report to consider the competency of children in law to consent to medical treatment under the COCA, for example.

<sup>658</sup> Protection of Personal and Property Rights Act 1988, ss 8(1) and (2).

- 5.16 The ill-defined concept of “welfare and best interests”, applying to substitute decisions for adults under the PPPR Act, runs the risk of being confused with the necessarily more protective policy objectives for the care and protection of children under the COCA. What is important is that all welfare tests are subject to limitations, and failure to clearly delineate these limitations risks tipping the balance from welfare and best interests, to protective paternalism.<sup>659</sup>

## Best interests and the HDC Code

- 5.17 Healthcare decisions may be made in a person’s best interests under Right 7(4) of the HDC Code.<sup>660</sup> If a “consumer” (person) is “not competent” to make an informed choice or give informed consent and there is no substitute decision-maker, Right 7(4) of the HDC provides legal justification for providing health and disability services without consent. The healthcare provider must, however, take certain procedural steps and act in what they consider to be the person’s best interests.
- 5.18 The Right is based on the common law principle of necessity. As described by Lord Goff in *Re F*,<sup>661</sup> this principle is based on the “need” for the patient to receive treatment, in their own interests, when they are (temporarily or permanently) disabled from giving consent. Read in conjunction with Right 7(1), this Right has the effect of ensuring that the provision of treatment without consent will not infringe the HDC Code in the specified circumstances, whether or not some statutory or common law justification is also applicable.<sup>662</sup>
- 5.19 The procedural steps in Right 7(4) requires a provider to take reasonable steps to ascertain the views of the person and consider whether there are reasonable grounds to believe that the provision of services would be consistent with the informed choice the person would make if they were competent.<sup>663</sup> If the person’s views have not (or cannot) been ascertained, the provider should take into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise.<sup>664</sup>
- 5.20 There is no definition in Right 7(4) of “other suitable persons”. The range of possibilities could extend beyond family and next of kin to the patient’s GP (who may have admitted the patient to hospital), or caregivers and social workers who have some knowledge of the patient’s preferences and wishes, as well as an interest in their care and welfare. The provider of the services, for example a surgeon seeking consent from a patient for an operation, need only have a reasonable belief, based on their own judgement, as to the person’s best interests, to proceed. Right 7(4) may still be satisfied even where the views of other suitable persons cannot be obtained: for example, when it would be unreasonable to delay treatment, for example, and there is no-one available to consult in the timeframe available.
- 5.21 There is a substituted judgment element in Right 7(4) as the provider must reach a decision that is “consistent with” the informed choice that the person would make if they were

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<sup>659</sup> Email from Professor Mark Henaghan, Dean of Otago Law School to A Douglass (Dunedin, 3 May 2016).

<sup>660</sup> Right 7(4) of the HDC Code is also set out in full in Appendix C and is discussed in Chapter 3 regarding the common law doctrine of necessity upon which it is based.

<sup>661</sup> *F v West Berkshire Health Authority* [1991] UK HL 1 (17 July 1990) Lord Goff of Chieveley at 24. Also cited in *Re F (Mental Sterilisation)*, above n 125.

<sup>662</sup> Skegg, above n 109, at 300. There is also a defence available to providers under clause 3 of the HDC Code and they will not be in breach of the Rights in the Code in they take reasonable actions in relation to them.

<sup>663</sup> Right 7(4) (b) and (c)(i).

<sup>664</sup> Right 7(4)(c)(ii).

competent to do so. Similar principles apply under Right 6, the right to be fully informed. However, Right 7(4) stops short of requiring the provider to act on the “views” of the person, once reasonable efforts have been made to ascertain them. Nor does it specify what the provider should do where there are conflicting views, or views they disagree with, or how they should weigh the various views to reach a decision.<sup>665</sup>

- 5.22 Ultimately, Right 7(4)(a) suggests that the person’s best interests is the main factor in reaching a decision. Therefore, it seems, a provider could ascertain the views of the person and others but then decide that these views were contrary to the person’s best interests, and not follow them. For example, if a person has consistently said they do not wish to receive renal dialysis for their failing kidneys and their family supports this, then it seems the health practitioner, having ascertained their views, could still reach a legally (but not ethically) defensible decision to provide the treatment, based on what they consider to be in the person’s best interests.
- 5.23 Right 7(4) is a pragmatic response to the need for everyday healthcare decision-making for people unable to make decisions that are legally effective. The scope of its application is intended to be narrow. It relies largely upon the notion of “clinical” best interests as judged by the healthcare provider. As such, it provides an unsatisfactory standard for decision-making for people with impaired capacity in a wide range of circumstances. There is also considerable uncertainty about the extent to which Right 7(4) can be relied upon on a continuing basis, rather than in one-off situations or emergencies.<sup>666</sup>

## 5B: BEST INTERESTS AT COMMON LAW AND UNDER THE MENTAL CAPACITY ACT

### The evolution of best interests at common law

- 5.24 The power to make medical welfare decisions in the best interests of an incapacitated adult was first formally recognised by the courts in England in a 1990 case in the House of Lords. In *Re F*,<sup>667</sup> the issue was whether a profoundly mentally disabled young woman who was living in a hospital setting and having a sexual relationship with a man in circumstances where contraception was considered unsuitable, should have a hysterectomy to prevent her becoming pregnant and having a child. The House of Lords held that the common law doctrine of necessity allowed the medical treatment of adults who were unable to give consent. Treatment or care, which might otherwise be an assault upon a person who lacked capacity to agree to it, was lawful, provided it was in the best interests of the person concerned.

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<sup>665</sup> Right 6 provides: “Every consumer has the right to the information that a reasonable consumer, in that consumer’s circumstances, would expect to receive...”

<sup>666</sup> The issue of relying on the doctrine of necessity and Right 7(4) of the HDC Code to make decision that deprive a person of their liberty is discussed in Chapter 3 Liberty Safeguards.

<sup>667</sup> *Re F*, above n 125. There were a series of cases involving sterilisation of disabled women at that time, for example, *T v T* [1988] 1 All ER 613 at 625. There was further recognition of the declaratory jurisdiction in a Court of Appeal decision in *Re F (Adult: Court’s Jurisdiction)* [2001] Fam 38, Dame Butler-Sloss held that although an 18-year-old mentally handicapped woman did not come within the guardianship principles of the MHA 1983, and was too old for the court’s wardship jurisdiction, the court was entitled under the inherent jurisdiction and best interests doctrine to make declaratory judgments when there was risk of possible harm in respect of an adult who lacked capacity to make decisions.

- 5.25 This jurisdiction was first limited to declarations of lawfulness related to medical treatment<sup>668</sup> but later was extended to non-medical issues as well, such as a person's residence and contact with others. The resulting body of law is described by Fennell as one of the most dramatic manifestations of judicial creativity in recent years.<sup>669</sup> The COP recently expanded the declaratory jurisdiction to cover the withdrawal of life-sustaining treatment from someone who was in a minimally conscious state, not a permanent vegetative state.<sup>670</sup>
- 5.26 In *Re F*, the House of Lords, in the same judgment, adopted the *Bolam* test for medical negligence<sup>671</sup> as the standard governing health providers' determinations of best interests.<sup>672</sup> This meant that the task of determining a patient's best interests was effectively delegated to the medical profession, making the question a clinical one to be judged by a narrow "not negligent" test.<sup>673</sup> The adoption of this standard, referred to as the "Bolamisation" of medical law,<sup>674</sup> has been adopted in different areas of medical law besides negligence, including informed consent and when determining "Gillick" competence for consent from children.<sup>675</sup> More recently, the *Bolam* test has been put to rest with regard to the duty of a doctor to disclose information to the patient for the purpose of obtaining informed consent.<sup>676</sup>
- 5.27 The case law on necessity and best interests continued to evolve after *Re F* and many of these developments were codified in the MCA. The need to have a wider best interests criterion was recognised in English Law Commission reports, culminating in the enactment of s 4 of the MCA.<sup>677</sup> In modern parlance, when applying the MCA both doctors and lawyers refer to "clinical" best interests – that is, what a doctor might think best in the clinical circumstances of a person's case – as a distinct concept. It contributes to decisions about, but remains distinguishable from, a person's best interests as understood under the MCA.

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<sup>668</sup> The declaratory jurisdiction has also been exercised for the continuance of artificial nutrition and hydration: *Airedale NHS v Bland*, above n 165.

<sup>669</sup> P Fennell "Mental Capacity" in LO Gostin, P Bartlett, P Fennell and others (eds) *Principles of Mental Health Law and Policy* (Oxford University Press, Oxford, 2010) at 168.

<sup>670</sup> *M v Mrs N* [2015] EWCOP 76 (Fam) Hayden J. The Court had to consider whether the best interests of Mrs N, who suffered progressive and degenerative impact of multiple sclerosis to receive life sustaining treatment by means of clinically assisted nutrition and hydration (CANH) currently provided by a (PEG) tube.

<sup>671</sup> *Bolam v Friern Barnet Hospital Management Committee* [1957] 1 WLR 582. The *Bolam* test is as follows: A doctor is not guilty of negligence if he has acted in accordance with a practice accepted as proper by a responsible body of medical opinion.

<sup>672</sup> *Re F*, above n 125 at 78.

<sup>673</sup> M Donnelly "Best Interests, Patient Participation and the Mental Capacity Act 2005" (2009) 17 Med Law Rev 1 at 3.

<sup>674</sup> M Brazier and J Miola "Bye-bye Bolam: A Medical Litigation Revolution?" (2000) 8 Medical Law Review 85 at 90.

<sup>675</sup> *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112. See also, M Dunn, I Clare, A Holland and others "Constructing and reconstructing "Best Interests": an Interpretative Examination of Substitute decision-making under the Mental Capacity Act" (2007) J Soc Welf Fam Law 117.

<sup>676</sup> *Montgomery v Larnarkshire* [2015] UKSC 11. This case concerned a pregnant diabetic patient who was not warned by her consultant about the risk that her baby, being relatively large size in relation to the mother's pelvis, would have shoulder dystocia. The doctor thought the mother would opt for a caesarean section, which the doctor considered to not be in her best interests.

<sup>677</sup> Szerletics, above n 209.



## Best interests under the MCA

5.28 The MCA therefore now provides the framework for the application of the best interests test and the Court of Protection provides important guidance on its interpretation. Although a comprehensive definition of a person's "best interests" is deliberately not provided by the MCA, it sets out a number of rules which must be followed. These require that a decision-maker must consider all relevant circumstances, and in particular:<sup>678</sup>

- *Equal consideration and non-discrimination:* Determinations must not be made merely on the basis of the person's age or appearance, or on the basis of unjustified assumptions from the person's condition or behaviour;
- *Regain capacity:* Consider whether the person is likely to regain capacity and, if so when that is likely to occur;
- *Permitting and encouraging participation:* Encourage the person to participate as fully as possible in the decision before making it for the person;
- *Best interests decisions in relation to life-sustaining treatment:* These decisions must not be motivated by a desire to bring about the person's death;
- *Person's past and present wishes, feelings, beliefs and values:* This includes consideration of written statements, the person's beliefs and values, and any other factors that the person would be likely to consider if they were able; and
- *The views of other people:* Consult a number of people including carers, holders of lasting powers of attorney, deputies and anyone else named by the person.

## Constructing decisions

5.29 Assessing best interests (or "benefit" under Scottish law) is described by Adrian Ward, a Scottish lawyer, as a process of "constructing decisions" on behalf of the person who cannot make the decision themselves.<sup>679</sup> Neither the MCA nor its Code of Practice provides an indication of the relative weight to be given to the various factors.<sup>680</sup> For example, it is possible for two individuals conscientiously to apply the s 4 "checklist" and come to different views as to where the person's best interests lie, but both views could be "reasonable". Under s 5 of the MCA, both could then act on their beliefs to carry out routine acts of care and treatment safe in the knowledge that they were protected from liability.<sup>681</sup> The duty to consult the person

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<sup>678</sup> The factors listed here in s 4 of the MCA are set out in the Law Commission Report at 160. See Appendix C for s 4 of the MCA.

<sup>679</sup> The methodology for assessing benefit under the Adults with Incapacity Act (Scotland) is set out in A Ward above n 128 at Chapter 17 (A Douglass, Interview with Adrian Ward, Edinburgh, 29 May 2015).

<sup>680</sup> See, for example, *MCA Code of Practice*, above n 285 at 86 [5.5] to [5.7]. Note that the framework under the MCA creates the role of a best interests assessor. The design of the Act is that if a person is a decision-maker whether the person making the decision is acting as a family carer, a paid care worker, an attorney, a court appointed deputy or a health professional. As long as these acts or decisions are in the best interests of the person who lacks capacity to make the decision for themselves, or to consent to acts concerned with their care or treatment, then the decision-maker or carer will be protected from liability under ss 5 and 6.

<sup>681</sup> Example given in Ruck Keene and Butler-Cole, above n 201. In the *ZH v Commissioner of Police*, above n 415 at [40], the Court of Appeal emphasised that the defence afforded to health and social care



and others is wide. In *Winspear v City Hospitals Sunderland NHS Foundation Trust*,<sup>682</sup> the Court emphasised that, where the duty to consult under s 4(7) of the MCA has arisen and has not been complied with, there will be no defence available under s 5 of the MCA.<sup>683</sup> While the duty to consult is not absolute, the person carrying out an act in connection with care and treatment will not be able to proceed as if they had the consent of the individual lacking capacity.

- 5.30 In weighing the factors under s 4 of the MCA, the Courts have endorsed a “balance sheet” approach whereby the relevant benefits and burdens of a particular course of action are listed and, only where the “account” can be said to be in “significant credit” can a decision be said to be in a person’s best interests.<sup>684</sup> Although case law has confirmed that there is no hierarchy between these factors, in that the weight attached to each will vary in the circumstances of each case, certain factors can become “magnetic” and tilt the balance.<sup>685</sup>

### The person’s wishes, feelings, beliefs and values

- 5.31 Section 4(6) requires the decision-maker:

So far as is reasonably ascertainable to consider –

- (a) The person’s past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
- (b) The beliefs and values that would be likely to influence the decision if he had capacity, and
- (c) The other factors that he would be likely to consider if he were able to do so.

- 5.32 The practical effect of s 4(6) is to require the decision-maker to attempt to ascertain what the person’s subjective preferences would have been, had they been able to express them. This does not require the decision-maker to make a formal substitute judgement, by trying to put themselves in the shoes of the person, as the matters itemised in subsection (6) are merely considerations when deciding what the person would have wanted. Therefore, although there is an element of substituted judgement involved, the MCA represents a compromise between the objective and subjective approaches to decision-making for people with impaired capacity.

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professionals delivering routine acts of care and treatment is “pervaded by the concepts of reasonableness, practicality and appropriateness”.

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[2015] EWHC 3250 (QB).

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The provisions of MCA s 5 are based on the common law doctrine of necessity as set out in *Re F*, above n 125. See *MCA Code of Practice*, above n 285 at Chapter 6: “What protection does the Act offer for people providing care and treatment?” In addition, s 6 places clear limits on the use of force or restraint by only permitting restraint to be used for example, to transport the person to their new home, where this is necessary to protect the person from harm and is a proportionate response to the risk of harm. It is beyond the scope of this report to consider whether statutory protection for carers and health practitioners, as provided for in ss 5 and 6 of the MCA would be appropriate or necessary in New Zealand’s medico-legal environment under the no-fault treatment injury provisions of the Accident Compensation Act 2001.

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*Re A: (Mental Patient: Male Sterilisation)* [2000] 1 FCR 193 at 206, Thorpe LJ.

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*Re M* [2009] EWHC 2525 (FAM) At [35] Munby J lists the relevant factors, including: the degree of the person’s incapacity, for the nearer to the borderline the more weight should be attached to their wishes and feelings; the strength and consistency of the person’s view; and the extent to which P’s wishes and feelings, if given effect to, can properly be accommodated within the Court’s overall assessment.

- 5.33 Where the person's reliably identifiable wishes and feelings suggest a course of action that would be profoundly risky for them, the relative weight to be given to the person's wishes and feelings has been contentious,<sup>686</sup> as the statute does not set out a hierarchy of these considerations.<sup>687</sup>

### Conflict between past and present wishes and feelings

- 5.34 Nor does the MCA expressly indicate whether it is the *present* or the *past* wishes and feelings of a person that should be given priority, and neither are determinative. There may be situations where there is a conflict between the person's own views pre- and post-incapacity. A person's past preferences may not be relevant if their present circumstances have changed radically. Ward suggests that a person should "not be treated as irrevocably 'owned' by the past adult, and ... present wishes and feelings should prevail".<sup>688</sup> For example, under an advance directive,<sup>689</sup> a person, while capable, may express a strong preference that they would not wish to live with profound disabilities but when in that situation may appear to be contented.<sup>690</sup>
- 5.35 Such conflicts are an inevitable feature of the hybrid, participatory approach taken to best interests by the MCA and do not diminish the value of its approach.<sup>691</sup>

### Whose best interests?

- 5.36 Although there is a general obligation to consult certain people during the course of a best interests assessment, the overall aim is to have a better understanding of what would be in the individual's best interests.<sup>692</sup> The court has accepted, however, there are certain situations where the interests of others are inseparable from the interests of the protected person and therefore seem to carry moral relevance when making decisions on the person's behalf. In the case of *Re Y*,<sup>693</sup> a woman with severe disabilities was deemed to be the best suitable donor for her sister who suffered from a bone marrow disorder. The Court held that the required operations were in Y's best interests as she would tend to prolong her sister's life and Y would continue to receive emotional, psychological and social support from her sister in return.
- 5.37 There have also been cases of substituted "financial altruism". In *Re G (TJ)*,<sup>694</sup> Morgan J directed the court-appointed deputy of an elderly woman who lacked capacity, to make maintenance payments from her funds to her daughter on the basis that the payments were in the best interests of Mrs G. The approach taken in this case was a substituted judgment

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<sup>686</sup> A Ruck Keene and C Auckland "More presumptions please? Wishes, feelings and best interests decision-making" (2015) Eld LJ 293.

<sup>687</sup> *MCA Code of Practice*, above n 285 at 81 [5.38].

<sup>688</sup> A Ward *Greens Essential Legislation: Adults with Incapacity Legislation* (Thomson Reuters/W Green, London, 2008) at 15.

<sup>689</sup> The requirement to take account of the person's past wishes in s 4(6) of the MCA may be conflict with the advance refusal provisions provided for in ss 24-26 of the MCA.

<sup>690</sup> M Donnelly "Determining Best Interests under the Mental Capacity Act 2005" (2011) 19 Med Law Rev 304 at 311; *Re Martin* (1995) 538 N.W n.99.

<sup>691</sup> Donnelly, above n 673 at 2.

<sup>692</sup> Mental Capacity Act 2005, s 4(7).

<sup>693</sup> *Re Y (Mental Patient: Bone Marrow Donation)* [1997] Fam 110.

<sup>694</sup> *Re G (TJ)* [2010] EWHC 3005 (COP) Morgan J.

approach. Both the previously expressed wishes of Mrs G, as well as the hypothetical wishes and feelings that she would express if she were able, were considered.<sup>695</sup>

- 5.38 The impact of the best interests decision on others is considered relevant regarding the court's power to make gifts. In *David Ross v A*,<sup>696</sup> Senior Judge Lush authorised the payment of A's brother's school fees from A's clinical negligence award in circumstances where it was clear that A's well-being depended in large part upon the well-being of her family as a whole. A, who was severely disabled at birth, will never have the capacity to make or contribute to a decision of this kind and reliance was placed on the views of the professional deputy who managed her funds and knew her family well.

### Best interests and "the patient's point of view"

- 5.39 *Aintree University Hospital NHS Foundation Trust v James*<sup>697</sup> was the first decision of the Supreme Court of the United Kingdom under the MCA. It concerned a seriously ill man who lacked capacity to make decisions about his medical treatment. The hospital sought a declaration that it would be in the best interests of Mr James to withhold specified life-sustaining treatments should they be needed. His family opposed the application. The High Court declined the application and the Court of Appeal reversed that decision. Mr James died following a cardiac arrest but in view of the importance of the issues and the different approaches taken in the lower courts, the Supreme Court gave Mr James's widow leave to appeal. The Supreme Court was unanimous in rejecting the widow's appeal but disagreed with the Court of Appeal's reasoning, preferring the approach adopted by the High Court.

- 5.40 In *Aintree*, the Supreme Court addressed the question of how doctors and courts should decide when it is in the best interests of the person to be given, or not given, treatments necessary to sustain life. The Court held that the question for the Court is whether it is in the patient's best interests to receive the treatment, rather than in their best interests to have it withheld or withdrawn. Where there is complete agreement among clinicians that life-sustaining treatment should not be offered and their stance is confirmed by an independent expert who would also be unwilling to provide such treatment, there is, in effect, no best interests decision to be taken, as there is no treatment option available to the patient. Lady Hale corrected the Court of Appeal's suggestion that the test for considering a patient's wishes and feelings is an objective one of what a reasonable patient would think. As Lady Hale noted:<sup>698</sup>

The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his wishes were in the past, they may well have changed in light of the stresses and strains of the current predicament.

- 5.41 Lady Hale confirmed that "the preferences of the person concerned are an important component in deciding where his best interests lie." She went on to state:<sup>699</sup>

... in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical, but social

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<sup>695</sup> *Re G (TJ)*, above n 694, at [35].

<sup>696</sup> [2015] EWCOP 46.

<sup>697</sup> *Aintree*, above n 164.

<sup>698</sup> *Aintree*, above n 164 at 18 [45].

<sup>699</sup> *Aintree*, above n 164 at 15 [36].

and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; *they must try and put themselves in the place of the individual patient and ask what his attitude to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view on what his attitude would be.* [Emphasis added]

- 5.42 Some cases have suggested that, in certain circumstances, the person's wishes and feelings will be determinative. In *Re S*,<sup>700</sup> Hazel Marshall QC J accepted that the person's views are not ordinarily paramount, but went on to say that where a person's wish is not irrational (in the sense of being a wish that a person with full capacity might reasonably have), is not impracticable as far as its physical implementation is concerned, and is not irresponsible, having regard to the extent of the person's resources, then a presumption arises in favour of implementing their wishes, unless there would be some sufficiently detrimental consequence for the person to outweigh this.

## Best interests and proposed law reform under the MCA

- 5.43 It has been argued that the Supreme Court judgment in *Aintree* has given a new impetus to the centrality of the person at the heart of the best interests process.<sup>701</sup> However, the recent House of Lords' report on the operation of the MCA notes that one of the problems was that the wishes and feelings of the person lacking capacity were not routinely prioritised in best interests decision-making and, instead, "clinical judgements or resource-led decision-making predominate".<sup>702</sup>
- 5.44 Moreover, for pragmatic reasons, it will not be possible for every decision by a person lacking capacity to be the subject of a best interests determination under the MCA.<sup>703</sup> The House of Lords report found that "the best interests principle is widely praised but its implementation is problematic".<sup>704</sup> There have been a number of cases where insufficient recognition has been given to the person's wishes and feelings when making a best interests decision, as well as to the presumption that living or contact with family is in the person's best interests.<sup>705</sup>
- 5.45 The Law Commission has now proposed that the MCA should be aligned, as far as possible, with the CRPD. However, the UN Committee has effectively rejected best interests decision-making, saying national laws must ensure that the person's "rights, will and preferences" are respected, rather than decisions being based on an objective assessment of their best interests.<sup>706</sup> While the MCA refers to "wishes and feelings" in this context, the CRPD adopts the term "will and preferences".<sup>707</sup> The Law Commission did not consider that there was any substantial difference between these phrases, although they are deployed for different

<sup>700</sup> [2008] EWHC (16) FAM.

<sup>701</sup> House of Lords Select Committee, above n 3 at [99].

<sup>702</sup> House of Lords Select Committee, above n 3 at [104].

<sup>703</sup> *IM v LM*, above n 591 at [77].

<sup>704</sup> House of Lords Select Committee, above n 3 at [90].

<sup>705</sup> Cases include: *Hillingdon v Neary*, above n 462, (which was referred to extensively in the House of Lords report). In *G v E and others* [2010] EWHC 621, although a Local Authority's decision to remove a mentally incapacitated adult from a continuing placement with a person who had fostered him as a child breached his rights under Article 5 and 8 of the European Convention on Human Rights, it would be in his best interests to continue at the residential care unit to which he had been transferred until there was a final hearing to consider whether he might be returned to the foster carer.

<sup>706</sup> CRPD General Comment No. 1, above n 242 at [20]-[21].

<sup>707</sup> Article 12(4) of the CRPD uses the formulation 'rights, will and preferences'. The ALRC formulation follows the spectrum of decision-making based on the will and preferences of a person, through to a human rights focus in circumstances where the will and preferences of a person cannot be determined. See Chapter 2 Supported Decision-making.

purposes.<sup>708</sup> The Law Commission has recommended that there should be a presumption that the person's wishes and feelings will be followed, to make the best interests standard more compliant with the CRPD.<sup>709</sup> In *Wye v Mr B* Peter Jackson J defended the existing provision in the MCA and questioned this proposal:<sup>710</sup>

... my respectful view is that the Law Commission proposal would not lead to greater certainty, but to a debate about whether there was or was not "*good reason*" for a departure from the assumption. To elevate one important factor at the expense of others would certainly not have helped the parties, nor the court, in the present case. All that is needed to protect the rights of the individual is to properly apply the Act as it stands.

## Summary

- 5.46 In New Zealand, the phrase "best interests" is found in both the PPPR Act and in Right 7(4) of the HDC Code, but it cannot be regarded as a specified legal standard for decision-making of the kind codified in the MCA.<sup>711</sup> Nor does New Zealand law actively encourage supported decision-making as envisaged in the CRPD, and in the case law of the COP applying s 4 of the MCA.<sup>712</sup>
- 5.47 The UK Supreme Court decision of *Aintree*<sup>713</sup> provides some insights into how the best interests test might apply to end-of-life decision-making under the court's inherent jurisdiction in New Zealand.<sup>714</sup> However, withdrawal or withholding of treatment type cases rarely come before the High Court under the inherent jurisdiction in New Zealand. Most "best interests" decisions in respect of a person's care and welfare and property are made by those substitute decision-makers appointed under the PPPR Act or the Family Court under that jurisdiction. Or, they do not come before the courts at all, such as treatment and healthcare decisions that need to be made for people who lack capacity under Right 74) of the HDC Code. The net result is that the decision-making process for reaching "best interests" decisions – where the decisions are made by others – is largely invisible.
- 5.48 The scheme of the MCA and its Code of Practice is pragmatic as it allows the great majority of decisions to be made in the person's best interests by informal decision-makers, such as carers and family without recourse to the court or for the appointment of formal decision-makers at all.<sup>715</sup> It is also consistent with supported decision-making principles under the CRPD, to provide reasonable accommodation of support measures that are tailored to an individual's needs.<sup>716</sup> To this end, New Zealand should develop a decision-making standard that is similarly consonant with both human rights obligations and the need to ensure there is a clear and transparent process for decision-making that takes into account a person's will and preferences.

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<sup>708</sup> Law Commission, above n 199 at 165.

<sup>709</sup> Law Commission, above n 199 at 164.

<sup>710</sup> *Wye Valley v Mr B*, above n 172 at [17].

<sup>711</sup> There has been limited discussion about the meaning of "best interests" in the New Zealand context within the *parens patriae* jurisdiction, see *Re G* [1997] 2 NZLR (HC) and *Auckland Healthcare Services v L* [1998] NZFLR 998 (HC).

<sup>712</sup> See *Re M (Best Interests)* and *Wye Valley v Mr B*, case examples discussed in Chapter 2E Supported decision-making in practice and in English case law.

<sup>713</sup> Above n 164.

<sup>714</sup> N Peart "Withholding Treatment" [2014] NZLJ 117 at 119.

<sup>715</sup> Interview with Lady Brenda Hale, Deputy President, Supreme Court of the United Kingdom (A Douglass, London, 6 May 2015).

<sup>716</sup> B Hale, discussing discrimination on the grounds of not providing reasonable accommodation (Toulmin Lecture, Kings College London, 12 March 2015).

## RECOMMENDATIONS FOR BEST INTERESTS AS A STANDARD FOR DECISION-MAKING

1. Best interests should be codified as a standard for decision-making which should include:
  - a) taking into account the person's will and preferences, and all relevant circumstances, largely modelled on the best interests framework in s 4 of the MCA.
  - b) in determining what is in the person's best interests, the decision-maker would be required take a series of steps, including, so far as practicable, supporting the person to participate as fully as possible in the determination of what would be in their best interests.
  - c) consideration given to the establishment of a presumption in favour of the person's will and preferences in respect of a decision, where their preferences can be reasonably ascertained, unless there is compelling evidence that following their preferences would have serious adverse consequences for them.<sup>717</sup>
  - d) a general principle of proportionality should apply: the greater the departure from the person's reasonably ascertainable will and preferences, the more compelling must be the reasons for such a departure.
2. The best interests standard would have to be followed by those required to make decisions for others. It would apply across the operation of revised adult guardianship legislation (a reformed PPPR Act), as well as in the operation of Rights 5, 6 and 7 of the HDC Code, where a person lacks capacity to consent to, or refuse health or disability services.
3. Appointment of health and disability advocates to provide support to the person who lacks capacity to assist them to participate as fully as possible in any relevant decision. This would complement the consultative aspect of supported decision-making.<sup>718</sup>
4. An accompanying Code of Practice with guidance for decision-makers on the best interests standard, including how to assess a person's best interests in accordance with their rights, will and preferences, and how to support the person and their involvement in any decision that affects them.<sup>719</sup>

<sup>717</sup> *S v S (Protected Persons)* [2009] WTLR 315, Hazel Marshall QC presumption test and proposal by the English Law Commission (see Ruck Keene and Auckland, above n 686 at 295), currently under consultation. Amendments to the 2015 Northern Ireland Mental Capacity Bill were proposed by researchers associated with the Essex Autonomy Project (University of Essex, England), in conjunction with its ongoing "three jurisdictions" study of approaches to capacity legislation in England and Wales, Scotland and Northern Ireland. The amendments were prepared by W Martin (Director of the Essex Autonomy Project) and A Ruck Keene (Thirty Nine Essex Chambers).

<sup>718</sup> See for example, the Independent Mental Capacity Advocates (referred as "IMCAs") appointed under s 36 of the MCA and accompanying regulations. This would be an expansion of the current role of health and disability advocates under the Health and Disability Commissioner Act 1994.

<sup>719</sup> See for example, *MCA Code of Practice*, above n 285 at Chapter 3: How should people be helped to make their own decisions?





# Chapter 6

## **Research on People who Lack Capacity**

## Chapter 6: Research on People who Lack Capacity

Chapter 6 is in two sections:

- A. The problems encountered in New Zealand when health and disability research is intended to be carried out on people who lack capacity to consent (non-consensual studies) and the gap in the legal framework.
- B. International standards for research on people who lack capacity and the essential features of the statutory protections in ss 30 – 34 of the Mental Capacity Act.

### Introduction

- 6.1 This chapter considers the statutory safeguards provided in the Mental Capacity Act (MCA) for adults who lack capacity to consent to research.<sup>720</sup> While the discussion here aims to inform the proposed consultation by the Health and Disability Commissioner on Right 7(4) of the HDC Code (Right 7(4)),<sup>721</sup> the recommendation is for legislative authority to be established rather than simply making changes to the HDC Code, to address “the clearly unsatisfactory but remediable situation”<sup>722</sup> that currently exists in New Zealand. The MCA provisions provide a useful legal framework which New Zealand could use to establish its own statutory protections where none currently exist.
- 6.2 Sections 30 – 34 of the MCA provide lawful authority to carry out research on participants who lack capacity, where approved by a research ethics committee, as long as various safeguards are complied with.<sup>723</sup> These safeguards relate both to the characteristics of the research and to the participation of individuals in it. Among the numerous patient protections, the MCA provides that the research must have the potential to benefit the patient without imposing a burden that is disproportionate to that potential benefit, or the research must be of wider benefit for persons affected by the same or similar condition, and impose no more than negligible risk to the patient.
- 6.3 In New Zealand, it has been reported that since 2006 there have been 40 medical studies approved by ethics committees, in which some or all participants may not have had capacity to provide informed consent.<sup>724</sup> Right 7(4) of the HDC Code,<sup>725</sup> based on the common law doctrine of necessity, and the outdated provisions in the PPPR Act, substantially restrict the ability of researchers (investigators) to provide treatment without consent in the context of

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<sup>720</sup> Sections 30-34 of the MCA are set out in Appendix C. “Research” is intended to refer to health and disability research which falls under the current ethical review framework in New Zealand.

<sup>721</sup> In March 2015, Commissioner Hill announced that he would consult on whether Right 7(4) of the HDC Code should be amended in respect of research where participants lack capacity to consent. See A Hill (Commissioner) “20 Years Strong – The Commissioner, the Code and Informed Consumers” (A presentation at the Conference: “Improving the Consumer Experience”, Wellington, March 2015).

<sup>722</sup> J Manning “Non-consensual Clinical Research in New Zealand: Law Reform Urgently Needed” (2016) 23 JLM 516.

<sup>723</sup> Mental Capacity Act 2005, s 31.

<sup>724</sup> B Heather “Drugs Tested on Mentally Disabled” *Sunday Star Times* (13 July 2014) [www.stuff.co.nz/national/health/10261601/Drugs-tested-on-mentally-disabled](http://www.stuff.co.nz/national/health/10261601/Drugs-tested-on-mentally-disabled). Manning, above n 722 cites a number of examples at footnote 15.

<sup>725</sup> Right 7(4) of the HDC Code is colloquially referred to as “right seven-four”. See discussion of Right 7(4) in Chapter 5A Best Interests in New Zealand Law.

research (for non-consensual studies).<sup>726</sup> Deciding the legality of enrolling adults who lack capacity to consent in research that cannot reasonably be expected to provide benefit to them has been problematic and the current state of the law is a “legal near-vacuum”.<sup>727</sup>

- 6.4 Any changes made to the law in this sphere will need to be considered in conjunction with the governance arrangements for ethics committees and the standards they adhere to. In New Zealand, there is no overarching legal framework that expressly recognises the role and function of ethics committees to protect human participants in research and innovative practice.<sup>728</sup> Ethics committees have a dual function in this respect: not only to protect the interests of research participants, but also to allow ethically sound research that will secure benefits.
- 6.5 The problems that exist for non-consensual studies are, in part, indicative of the changes made to ethics committees in 2012 and the undermining of the ethics review system.<sup>729</sup> Although the government inquiry aimed to make New Zealand a more attractive place for innovative clinical trials,<sup>730</sup> the downgrading of protection for research participants and restructuring of ethics committees is not in line with international standards,<sup>731</sup> and the current ethics review system is “ad hoc, and fragmented and difficult to navigate”.<sup>732</sup>

## 6A: THE GAP IN NEW ZEALAND'S LEGAL FRAMEWORK

### Securing the benefits of research for people who lack capacity

- 6.6 There are three categories of adults who may lack capacity to consent to their participation in research: firstly, individuals whose diminished capacity is enduring due to a mental or physical

<sup>726</sup> The National Ethics Advisory Committee has issued guidelines for researchers on the ethical review of both intervention studies (clinical trials and medical experimentation which may or may not have therapeutic benefit to individuals participating), as well as “observational studies” (observational research which is not a “clinical trial”). National Ethics Advisory Committee (NEAC) *Ethical Guidelines for Intervention Studies: Revised edition* (Ministry of Health, Wellington, 2012).

<sup>727</sup> As described by the Scottish Law Commission who were reporting on the same problem over 20 years ago, prior to the enactment of the Adults with Incapacity (Scotland) Act 2000: Scottish Law Commission Report, 1995 [5.65], cited in Ward, above n 128.

<sup>728</sup> Health and Disability Ethics Committees are established under s 11 of the New Zealand Public Health and Disability Act 2000. The Act empowers the Minister of Health to create ministerial committees with functions as determined by the Minister of Health. Section 16 of the Act mandates the appointment of a national ethics advisory committee for health and disability services, including health research. Ironically, New Zealand has had specific legislation for the protection of animals in research since 1983 but not humans: Animals Protection Act (NZ), subsequently repealed and replaced with the Animal Welfare Act 1999. G Gillett, A Douglass “Ethics Committees in New Zealand” (2012) 20 JLM 266.

<sup>729</sup> The impact of the changes and gradual undermining of the independence of ethics review in New Zealand since the Cartwright Report in 1988 is discussed in: M Tolich and B Smith *The Politicisation of Ethics Review in New Zealand* (Dunmore Publishing Ltd, Auckland, 2015).

<sup>730</sup> New Zealand Health Committee *Inquiry into improving New Zealand's environment to support innovation through clinical trials* (House of Representatives 49<sup>th</sup> Parliament, Wellington, June 2011).

<sup>731</sup> The WHO Standards and Operational Guidance for Ethics Review of Health-related Research on Human Participants (2011) include: establishing a research ethics review system with an “adequate legal framework”, presumptive oversight of *all* research by ethics committees to avoid gaps, and scientific design and the conduct of the study as part of ethical review.

<sup>732</sup> NEAC “Cross-sectorial ethics arrangements for health and disability research: Submission summary” (14 July 2015) [www.neac.health.govt.nz](http://www.neac.health.govt.nz); see also New Zealand Law Society submission (26 February 2015) [www.lawsociety.org.nz/ data/assets/pdf file/0009/87597/I-NEAC-HD-Research-Ethics-26-2-15.pdf](http://www.lawsociety.org.nz/data/assets/pdf_file/0009/87597/I-NEAC-HD-Research-Ethics-26-2-15.pdf).

impairment; secondly, individuals who temporarily lack capacity, but whose capacity will return; and, thirdly, those with progressively deteriorating capacity.

- 6.7 Historically, people with intellectual disabilities have experienced disadvantage, over-protection and abuse where their right to give informed consent has been ignored.<sup>733</sup> Additionally, research involving temporarily unconscious patients may involve the use of an innovative practice or the evaluation of an established therapeutic treatment in emergency situations where it is not possible to obtain informed consent from the individual concerned.
- 6.8 As the New Zealand population ages, research on the aging process, and conditions and diseases that disproportionately affect older persons has become increasingly important. Social science research is essential for understanding the social phenomena of aging, such as the increase in residential care for older adults,<sup>734</sup> and through observation and understanding the experiences of adults who lack capacity and those who support them.<sup>735</sup>
- 6.9 Research participation can be direct, where the person is actively involved in a study and may receive a new treatment, or indirect, where the person's information or DNA samples are collected and analysed to better understand underlying causes of a particular disorder. This is especially true in biobanks where genetic research is focused on complex impairments such as psychiatric disorders or dementia.<sup>736</sup>
- 6.10 Research involving adults who lack capacity to consent can lead to innovations in healthcare that can substantially improve their health and quality of life and that of others with similar conditions. It is therefore important that these adults are given the opportunity to participate in such research.<sup>737</sup> To exclude them from any research would be discriminatory and would diminish their ability to participate as fully as possible in society.<sup>738</sup>

## Right 7(4) and legal justification for research without consent

- 6.11 Research involving unconscious patients or those with diminished capacity to consent or refuse participation in the research differs from standard research because participants are unable to give informed consent.
- 6.12 In general terms, an individual's ability to give valid consent or to refuse to participate in research will depend on the person's ability to understand what the research entails, provided they have been given sufficient information to make an informed decision. The degree of

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<sup>733</sup> A Bray *Research Involving People with Intellectual Disabilities: Issues of Informed Consent and Participation* (Donald Beasley Institute, Dunedin, 1998).

<sup>734</sup> There is growing literature internationally about ageing, death and dying. For example, Atul Gwande in his book, *Being Mortal: Medicine and What Matters in the End* (Henry Holt/Profile Books, New York and London, 2014) calls for a change in the philosophy of healthcare, explores the different models of social housing and care for older adults, recognising the process of older people losing their independence and ways to improve their well-being.

<sup>735</sup> In a qualitative assessment of how support workers caring for adults with intellectual disability perceived substitute decision-making under the MCA, Dunn and others found that the MCA extended this to all areas of personal care, not just to invasive and controversial medical treatment decisions. M Dunn, I Clare and A Holland "Living a Life Like Ours': Support Workers' Accounts of Substitute Decision-Making in Residential Care Homes for Adults with Intellectual Disabilities" (2010) 54 JIDR 144.

<sup>736</sup> E Togni, K Dierickx, C Porteri "Participation in biobanks for research by incapacitated adults: review and discussion of current guidelines" (2014) 29 Int J Geriatr Psychiatry 670.

<sup>737</sup> See for example, A Murray "The Mental Capacity Act Dementia Research" (2013) 25(3) Nurs Older People 14.

<sup>738</sup> Human Rights Act 1993, s 21(1)(h); United Nations Convention on the Rights of Persons with Disabilities, (CRPD) art 5.

detail required will vary according to the needs of the individual patient and the complexity of the procedures involved. In particular, assessment of risk (an important part of decision-making in all forms of healthcare) takes on greater significance in this sphere, since research can involve a degree of uncertainty of the risk involved.<sup>739</sup>

6.13 In New Zealand, the requirement of informed consent to any health research is codified in the HDC Code, and is affirmed in human rights instruments.<sup>740</sup> The Cartwright Report also intended that research participants should have access to the Health and Disability Commissioner process, to protect their rights.<sup>741</sup>

6.14 The rights in the HDC Code extend to health and disability research, although the extent to which the HDC Code protects the interests of research participants is unclear because “health research” or “disability research” are not defined in the HDC Code or Act.<sup>742</sup> Research in which participants are unable to consent is not expressly contemplated under Right 7(4). Right 9 states:

The rights in this Code extend to those occasions when a consumer is participating in, or it is proposed that a consumer participate in, teaching or research.

6.15 In addition, the HDC Code applies only to research involving provision of healthcare, so it does not apply to all relevant research, for example observational research, or non-therapeutic health and disability research carried out by people other than healthcare practitioners.<sup>743</sup>

6.16 Right 7(4) sets out the legal position concerning research involving the treatment of patients who do not have capacity to consent, where there is no legally authorised person available to give consent: it provides an exception to the usual requirement for informed consent and gives decision-making powers to the clinician-investigator so long as they have taken the steps set out in Right 7(4), to reach the conclusion that participation in the research will be in the patient’s “best interests”.<sup>744</sup> Right 7(4) can therefore be interpreted as authorising a decision

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<sup>739</sup> Letts, above n 282 at 142.

<sup>740</sup> HDC Code, Right 5 (right to effective communication), Right 6 (right to be fully informed) and Right 7 (right to make an informed choice and give informed consent). Section 10 of the New Zealand Bill of Rights Act 1990 also provides for the right not to be subject to medical or scientific experimentation without consent. Article 15 of the CRPD requires State Parties to have effective measures to prevent persons with disabilities, on an equal basis as others, from being subjected to torture or cruel or inhuman or degrading treatment or punishment and, in particular, “no one should be subjected without his or her free consent to medical or scientific experimentation.”

<sup>741</sup> S Cartwright *The Report of the Committee of Inquiry into allegations concerning the treatment of Cervical Cancer at National Women's Hospital and into other related matters* (Government Printing Office, Auckland, 1988).

<sup>742</sup> Health research “administered to or carried out in respect of any person” by a “healthcare provider” comes within the applicable definition of “healthcare procedure” and within the Code’s definition of “services”. Right 7(6) of the HDC Code, and the requirement that informed consent to a healthcare procedure (including participation in any research) must be in writing, contains important qualifications which reduce its impact in this context. Right 7(6) only applies to situations where consent “is required”. Therefore, written consent from those patients who are unable to consent (sometimes referred to as unconsentable) will not be required so long as the ethics committee is satisfied that the criteria in Right 7(4) are met.

<sup>743</sup> L Wadsworth “Rights and Research: An Examination of Research under New Zealand’s Code of Health and Disability Services Consumers’ Rights” (2013) 21 JLM 187.

<sup>744</sup> Right 7(4) requires either, reasonable steps have been taken to ascertain the views of the consumer, and if those views have been ascertained, the provider believes, on reasonable grounds, that the provision of services is consistent with the informed choice the consumer would make if he or she were competent: Right 7(4) (b) and (c)(i); or, if the consumer’s views have not been ascertained, the provider



to enrol a patient in research involving treatment, even though the consent of the patient or a substitute decision-maker has not been obtained. It provides a legal justification for research without consent, but only in some limited situations.

## The problems with Right 7(4) of the HDC Code

- 6.17 Right 7(4) sits within a list of protections for patients in Right 7, but it largely provides a defence to Code liability for researchers, rather than a safeguard for participants based on the common law doctrine of necessity.<sup>745</sup> There will be situations where it cannot be said that the research is in the individual's best interests, as often the point of research is not to benefit them but to benefit others in future who may be suffering from a similar condition.<sup>746</sup>
- 6.18 The National Ethics Advisory Committee Guidelines for Intervention Studies (NEAC Guidelines) place legal responsibility for non-consensual studies under Right 7(4) with the investigator, not the ethics committee, reflecting the position that ethics committees have no power to rule on the law.<sup>747</sup> The NEAC Guidelines stop short of stating that the law prohibits non-consensual studies.<sup>748</sup> Moreover, the status of the NEAC Guidelines and their interface with the Standard Operating Procedures (referred to as procedural, not ethical guidance), to which ethics committees are to adhere, is unclear, as is how they assist ethics committees when considering research that might be justified under Right 7(4).<sup>749</sup>
- 6.19 The problems with relying on Right 7(4) in the context of non-consensual health research came to a head in 2014. In a letter to ethics committees, the Chief Legal Advisor to the Ministry of Health advised that the NEAC Guidelines for non-consensual studies "are intended for application only to studies that are 'lawful'".<sup>750</sup> The effect of this directive has been to halt the process of ethics committees reviewing the ethics of a study, including risks and benefits, if participants are not able to give informed consent. Researchers are left in the invidious position of having to confirm the legality of the research based on their own assessment of what is in a person's individual best interests (and implicitly of the risks) under Right 7(4). As Manning says, "researchers are being forced to run the gauntlet of the law."<sup>751</sup>

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takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider: Right 7(4)(c)(ii).

<sup>745</sup> *Re F*, above n 124. Clause 3 of the HDC Code states that a provider is not in breach of the Code if the provider "has taken reasonable actions in the circumstances" to give effect to the rights, and comply with the duties, in the Code. Clause 3 specifically provides that in this context "the circumstances" means all the relevant circumstances, "including the consumer's clinical circumstances".

<sup>746</sup> Ashton, above n 25 at 272.

<sup>747</sup> NEAC *Guidelines*, above n 726 at 24 [6.27]. The NEAC Guidelines do not presume that participation in health research is limited to individuals who can give informed consent. They suggest that if there is a question as to the competence of a participant, the investigator should consider obtaining dual consent, from the participant and "the informed agreement of another person who is interested in, or has responsibilities for, that person's welfare".

<sup>748</sup> NEAC Guidelines, above n 726 at 24 [6.24] – [6.29].

<sup>749</sup> NEAC Guidelines are created under delegated legislation by the New Zealand Public Health and Disability Act 2000, ss 16(1) and (2). NEAC is charged with determining nationally consistent ethical standards and scrutinising health research and standards, for both interventional and observational health research studies. New Zealand Law Society submission to the National Ethics Advisory Committee (12 June 2012). [http://www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0020/53183/I-NEAC-ethical\\_guidelines\\_review-120612.pdf](http://www.lawsociety.org.nz/_data/assets/pdf_file/0020/53183/I-NEAC-ethical_guidelines_review-120612.pdf).

<sup>750</sup> Letter from P Knipe, Chief Legal Advisor, Ministry of Health to Health and Disability Ethics Committees regarding informed consent for ethics approval for trials (7 April 2014). The committees were reminded that they do not have authority to consent on behalf of participants who do not have capacity to consent (implying that this was in fact happening), and that in terms of Right 7(4), investigators must satisfy the committee that the proposed research is "lawful".

<sup>751</sup> J Manning, above n 722 at 517.

## The PPPR Act – limitation on powers of substitute decision-makers to consent

- 6.20 Where the person concerned is incapable of giving consent to healthcare, in the context of research, the first requirement of Right 7(4) is that a clinician-investigator attempt to obtain informed consent from someone entitled to give consent on the person's behalf, such as a welfare guardian appointed by the court or an attorney appointed under an EPOA, who has the authority to make health decisions on the person's behalf (a substitute decision-maker). The problem, however, is that section 18(1)(f) of the PPPR Act prevents such a substitute decision-maker from giving a legally effective consent to:<sup>752</sup>

any medical experiment other than one to be conducted for the purpose of saving that person's life or preventing serious damage to that person's health.

- 6.21 This rule prevents the substitute decision-maker consenting to research participation on behalf of the person for whom they act, except in very limited situations. The paramount consideration of a welfare guardian is the promotion and protection of the welfare and best interests of the person for whom they are acting.<sup>753</sup> It is not to authorise enrolment of the person in research for the purpose of benefiting other people in future. But Right 7(4) may permit them to give substitute consent to research on a person that is carried out in an emergency department or ICU within a hospital where the treatment or new drug being studied is considered the best treatment or option available.<sup>754</sup> This is because the treatment being trialled might save that person's life or prevent serious damage to their health, so providing substitute consent would not be prevented by section 18(1)(f).

- 6.22 These provisions on substitute consent to research under the PPPR Act are outdated. They do not take into account the broad range of health and disability research conducted beyond the clinical environment of emergency treatment, and they substantially limit the powers of others to consent to the inclusion in research of a person who lacks capacity to consent, in situations where their participation would be ethically justified. In the emergency setting, where the patient may be unconscious, there may also be difficulty in identifying whether the person has an appointed substitute decision-maker or not.<sup>755</sup>

## Individual best interests and societal benefit

- 6.23 If no substitute decision-maker is available, Right 7(4)(a) requires the clinician-investigator, having taken the steps to ascertain the views of the person or others required by Right 7(4), to reach the conclusion that participation in the research will be in the person's "best interests". This includes a clinical assessment by the clinician-investigator that there is a need for treatment to proceed, and, in the case of research, confirmation that the research is in the best interests of the individual concerned.

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<sup>752</sup> The same limitation of powers that apply to welfare guardians under s 18(1)(f) applies to attorneys appointed in relation to personal care and welfare (EPOAs) under s 98(4).

<sup>753</sup> Protection of Personal and Property Rights Act 1988, ss 18(3) and 98A(2).

<sup>754</sup> For a fuller discussion see Skegg, above n 580 at 227. Skegg states that if s 18(1)(f) precludes a welfare guardian from giving legally effective consent in such circumstances, the common law justification or "additionally or alternatively, for the purpose of Code liability under Right 7(4) of the Code of Rights", would suffice.

<sup>755</sup> An electronic register of EPOAs and court orders would potentially solve this particular problem. There are similar problems with identifying whether a person has a legally valid advance directive under Right 7(5) of the HDC Code.

- 6.24 The dual roles of the clinician-investigator can divert attention from the ethical conflict involved in both caring for the patient and potentially enrolling them in a study that may expose them to unacceptable risks.<sup>756</sup> Other than applying the “best interests” test to the proposed treatment, Right 7(4) does not give the investigator any guidance on how to address this conflict of roles and requires the investigator to make the decision whether or not to enrol the patient in the research in the absence of independent advice or oversight.
- 6.25 More often than not, it is not known in advance whether research will be in the best interests of the person, even though the research may subsequently prove to be beneficial and is not known to be harmful. In some research, there may be “clinical equipoise”, where there is genuine uncertainty in the expert medical community over whether a treatment will be beneficial.<sup>757</sup> An argument can also be made that there is an “inclusion benefit” in clinical trials: by simply participating in a trial, the participants get more attention and monitoring than similar patients being treated in the same institution who are not involved in research.<sup>758</sup>
- 6.26 There is an important distinction between research that is undertaken in a situation where a therapeutic intervention is needed (and the most promising treatment available is provided),<sup>759</sup> compared to research where the alternative treatment is less likely to benefit the patient (for example, receiving a placebo in a randomised clinical trial),<sup>760</sup> or where the new treatment being trialled is no more than equivalent to the standard treatment (“non-inferiority clinical trials”).<sup>761</sup> In the former situation, there is likelihood of direct benefit to the individual, whereas in the latter situations there may only be societal benefits resulting from the research. Such research may still be ethically justified, but it may not be in the best interests of the individual participating in the research, as required under Right 7(4).

## Some examples

*RE-VERSE-AD: Right 7(4) applied where the treatment being researched was in the individual's best interests, even though the investigator had both clinical and research roles*

- 6.27 This multi-centre clinical study was testing the efficacy and safety of a drug designed to reverse the blood-thinning effects of an anticoagulant drug to reduce the risk of bleeding. It received ethical approval on the basis that the research could be lawfully justified under Right

<sup>756</sup> TL Beauchamp and JF Childress *Principles of Biomedical Ethics* (5<sup>th</sup> ed, Oxford University Press, New York, 2001) at 319; A Jonsen, M Siegler and M Winslade *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine* (3<sup>rd</sup> ed, McGraw Hill, New York, 1992) at 147; F G Miller and D L Rosenstein, “The Therapeutic Orientation of Clinical Trials” (2003) 348 NEJM 1383 at 1384.

<sup>757</sup> B Freedman “Equipoise and the Ethics of Clinical Research” (1987) 317 NEJM 141. The “equipoise standard” is referred to in the NEAC Guidelines as the balancing of risks and benefits where there is a comparison of two or more interventions designed to meet the equipoise standard and there is usually use of a placebo or no intervention as a control.

<sup>758</sup> J Lantos “The Inclusion Benefit in Clinical Trials” (1999) 134 J Paeds 30 at 31; Miller and Rosenstein, above n 756 at 1383.

<sup>759</sup> For an example of a Phase 3 single arm study where the treatment was the best available see the RE-VERSE-AD study discussed below.

<sup>760</sup> For an example of a Phase 2 randomised controlled trial, see the CLEMATIS study discussed below.

<sup>761</sup> A non-inferiority clinical trial is one where the treatment or drug is said to be “as good as” or “not inferior to” standard treatment. For example, ASPECT: A double-blind study to assess the safety and efficacy of intravenous Ceftolozane/Tazobactam with that of Meropenem in ventilated nosocomial pneumonia. This was a Phase 3 trial to see whether a new antibiotic was as effective as an existing antibiotic, rather than superior. Conditional approval was granted on the basis that the researcher provide information that participation in the research would be in the patients’ best interests. (Northern A Health and Disability Ethics Committee Minutes, 11 March 2014, [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz)). For a fuller discussion of this study, considered at the same time as the CLEMATIS study, see Manning, above n 722 at 518.

7(4).<sup>762</sup> Prior to the study, patients on the anticoagulant had limited options available to control bleeding. Some of these patients were in a life-threatening emergency situation and required immediate surgical or medical intervention to manage their bleeding.<sup>763</sup> In the large majority of cases in this study, no substitute decision-maker was available for the investigator to consult under Right 7(4).<sup>764</sup> As there was potential to reverse a serious, life-threatening condition with the best treatment available, the principal investigator was able to confirm to the ethics committee that the research was in the best interests of individual participants, and so to proceed would meet the criteria under Right 7(4).

6.28 The study has been successful, with a significant number of “unconsentable” patients enrolled who had positive medical outcomes. In this way, New Zealand researchers have played a major role in globally demonstrating that the study drug is effective and safe.<sup>765</sup>

6.29 At the outset of this study, the principal investigator initiated the practice of seeking a second opinion from another doctor not directly involved in the study (a “disinterested colleague”) on the enrolment of a patient, when this would be justified under Right 7(4). The investigator explains the ethical conflict as follows:<sup>766</sup>

In cases where the decision as to whether treatment is in the patient’s interests rests predominantly on the clinician, the clinician’s judgement can be coloured by the wish to recruit patients to the trial. Even in cases where no bias is present, the possibility of perception of bias leading to an error of medical judgement cannot be excluded.

*CLEMATIS study: Randomised control trial, justified ethically by the societal benefit; exclusion of adults as research not in their best interests, but not children with parental consent*

6.30 When the benefits to an individual are less clear, or there is no imminent risk to health or safety that can be mitigated by the intervention, research participation is unlikely to be justified in terms of Right 7(4). The CLEMATIS study was a multi-centred clinical trial investigating a drug intended to enhance cognition and learning in people with Down syndrome. Approval for the study was initially declined, based on legal advice that it was not clear that the proposed research would be in the best interests of the participants.<sup>767</sup>

6.31 The application was resubmitted in July 2014 and was given approval for children whose parents could give consent for participation and for adults who had the capacity to give informed consent.<sup>768</sup> Ethical approval was declined for adults with Down syndrome who

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<sup>762</sup> Central Health and Disability Ethics Committee Minutes “Reversal of the Anticoagulant Effect of Dabigatran Using Idarucizumab” ethics ref. 14/CEN/58/AM03 (22 April 2014) [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz) at 8. The writer subsequently provided one of two legal opinions submitted to the ethics committee when amendments were made to the consent forms: (Central HDEC approval letter dated 1 May 2015).

<sup>763</sup> This is a Phase 3 single arm study and all patients enrolled in the study receive the study drug.

<sup>764</sup> Email communication from Dr Gordon Royle, Haematologist, Middlemore Hospital, New Zealand principal investigator for the RE-VERSE-AD study to Alison Douglass (29 February 2016).

<sup>765</sup> Email communication from Dr Gordon Royle, Haematologist, Middlemore Hospital, New Zealand principal investigator for the RE-VERSE-AD study to Alison Douglass (2 March 2016).

<sup>766</sup> Royle, above n 764. The ethics committee did not initially require a second opinion but subsequently approved the process for unconsentable participants as set out in the “Form for participants who are not able to give written informed consent”. The form also has a procedure should the patient subsequently regain capacity post-treatment.

<sup>767</sup> Northern A Health and Disability Ethics Committee “A Study of RG1662 in Adults and Adolescents with Down syndrome (CLEMATIS)” (8 April 2014) [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz) at 3. The study was a Phase 2 randomised clinical trial of the safety, efficacy and tolerability of a cognitive enhancing drug in people with Down Syndrome between the ages of 12 and 30.

<sup>768</sup> The Care of Children Act 2004 allows parents of children under 16 to give proxy consent for medical treatment.<sup>768</sup> Guidelines have extended this to include participation in research, N Peart and D

lacked capacity to consent, even though the drug could not effectively be tested in persons without Down syndrome.

- 6.32 The ‘necessity’ principle in research, as it applies to children, is that research should only be carried out on children if comparable research with adults could not answer the same question.<sup>769</sup> The decision to allow for substituted consent in one vulnerable population (children), but not to extend it to adults who lack capacity undermines this ethical principle and discriminates between two vulnerable groups.<sup>770</sup> Under Right 7(4) no account can be taken of wider societal benefits of the research, or of the fact that this particular study drug was aimed at providing treatment for people affected by Down syndrome, even though the study had been approved for adults in eight countries,<sup>771</sup> including meeting the standards of the Clinical Trial Regulations in the United Kingdom.<sup>772</sup>

### Proposal to amend Right 7(4) of the HDC Code

- 6.33 In the absence of clear legislative direction, these examples highlight the problematic terms of Right 7(4) when applied to research with participants unable to consent. Accordingly, in 2009, Commissioner Paterson recommended a change to Right 7(4) that might permit more research on unconscious or incompetent patients, provided the research was approved by an ethics committee.<sup>773</sup> The recommendation was that Right 7(4)(a) should be amended so as to justify healthcare proceeding where:

It is in the best interests of the consumer, or in the case of research, is not known to be contrary to the best interests of the consumer and has received the approval of an ethics committee.

- 6.34 This proposed amendment (introducing the “not known to be contrary to” formula) in effect sets a lower threshold for establishing what is in a patient’s best interests. The double negative formulation used does not guide ethics committees as to what factors they should take into account, however, in deciding what is not harmful (and not contrary) to the interests of research participants, or whether the assessment of best interests can consider benefits over and above direct benefits to an individual. It also continues to confuse the role of Right

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Holdaway “Legal and Ethical Issues of Health Research with Children” (1998) 2 Children’s Issues Centre 42 ([www.hrc.govt.nz](http://www.hrc.govt.nz)). The recently released report by the Nuffield Council on Bioethics *Children and Clinical Research: Ethical Issues* (2015) states that an understanding of a child’s longer-term welfare can include contributing to wider social goods, and parental consent to research should consider whether participation in the proposed research is *compatible* with their child’s immediate and longer-term interests (Chapter 4).

<sup>769</sup> See, for example the HRC’s *Guidelines for Health Research with Children* [www.hrc.govt.nz/sites/default/files/HRC%20Guidelines%20for%20Health%20Research%20with%20Children.pdf](http://www.hrc.govt.nz/sites/default/files/HRC%20Guidelines%20for%20Health%20Research%20with%20Children.pdf). The Guidelines are derived from the Guidelines of the Royal College of Paediatrics and Child Health 1999 and the European Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine 1996. The ‘necessity principle’ is discussed below under the MCA.

<sup>770</sup> J Lenagh-Glue “Resolving the Irreconcilable: Informed Consent and Participation in Medical Research for Adults with Intellectual Disability” (LLB (Hons) Dissertation, University of Otago, 2014).

<sup>771</sup> LuMind “Clinical Trials UPDATE: Roche Initiates RG1662 Phase II Clinical Trials for Individuals with Down syndrome” (19 May 2014) [www.plus15campaign.wordpress.com](http://www.plus15campaign.wordpress.com).

<sup>772</sup> *Clinical Trials Regulation* (UK) <http://www.ukctg.nihr.ac.uk/trials/trial-details/trial-details?trialNumber=NCT02024789>.

<sup>773</sup> In an earlier review of the HDC Code in 2004, Commissioner Paterson recommended the specific provision relating to research on unconscious or incompetent patients with appropriate safeguards rather than wholesale change to Right 7(4) to cover treatment of incompetent patients generally (not just research). See Health and Disability Commissioner *Report to the Minister of Health* (June 2009) at 14. <http://www.hdc.org.nz/media/21835/theact-review2004.pdf>.



7(4), a justification for proceeding with treatment in limited circumstances, with the need to have adequate safeguards in place for research participants.

- 6.35 In the 2014 review of the HDC Code, Commissioner Hill did not revisit the 2009 recommendation for changes to Right 7(4).<sup>774</sup> What is required is separate legislation that would provide similar protections for research participants who lack capacity as are found in the MCA, and in the Adults with Incapacity (Scotland) Act 2000.

## 6B: INTERNATIONAL STANDARDS AND THE MENTAL CAPACITY ACT

### International ethical standards for non-consensual studies

- 6.36 International ethical standards recognise that medical research involving subjects incapable of giving informed consent may be justified, such as research with unconscious patients, if the condition that prevents them from giving informed consent is a “necessary characteristic” of the research population. The World Medical Association’s Declaration of Helsinki<sup>775</sup> sets recognised ethical standards for the conduct of research. Its basic principles in relation to the involvement of an incapacitated adult include:

- Incompetent adults should not be included in research that is unlikely to benefit them personally, unless the research is necessary to promote the health of the population represented by the potential research subjects; this research cannot instead be performed on legally competent persons; and it involves only minimal risk and minimal burden to participants.
- Where an adult is incapable of giving consent, the responsible researcher must obtain informed consent from any legally authorised representative.
- Where an incompetent adult is capable of assenting to decisions about participation in research, this assent must be obtained, in addition to the consent of a legally authorised representative. Any dissent by the person should be respected.
- The research must be intended to provide knowledge relating to the condition or conditions that have contributed to the impairment of the individual’s incapacity.

- 6.37 The World Health Organisation (WHO), in collaboration with the Council for International Organizations of Medical Sciences (CIOMS), has issued international guidelines for ethical clinical research with human subjects.<sup>776</sup> Guideline 9 sets a “low-risk standard” for research involving individuals incapable of giving informed consent. This states:<sup>777</sup>

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<sup>774</sup> New Zealand Law Society submission on the Review of the Health and Disability Commissioner Act 1994 and the Code of Health and Disability Consumers’ Rights (17 February 2014)

<sup>775</sup> [www.lawsociety.org.nz/\\_data/assets/pdf\\_file/0012/75999/I-HDC-Act-and-Code-Review-17-02-14.pdf](http://www.lawsociety.org.nz/_data/assets/pdf_file/0012/75999/I-HDC-Act-and-Code-Review-17-02-14.pdf)

World Medical Association (1964) *Declaration of Helsinki*, Ethical Principles for Medical Research Involving Human Subjects, as subsequently amended most recently in 2008: see [www.wma.net](http://www.wma.net).

<sup>776</sup> CIOMS *International Ethical Guidelines for Biomedical Research Involving Human Subjects* (CIOMS, Geneva, 2002).

<sup>777</sup> CIOMS, above n 776 at 49.



The risk from research interventions that do not hold out the prospect of direct benefit for the individual subject should be no more likely and not greater than the risk attached to routine medical or psychological examination of such persons. Slight or minor increases above such risk may be permitted when there is an overriding scientific or medical rationale for such increases and when an ethical review committee has approved them.

- 6.38 Both the Declaration of Helsinki and the CIOMS guidelines affirm the need to have a legally authorised person, other than the investigator of the research, to give legally effective consent where a person lacks capacity to consent to research. If a participant with diminished capacity is capable of “assent” and there is no “dissent”, such assent is not legally effective on its own. The level of acceptable risk must be negligible or minimal even if there may be societal benefit over and above individual benefit, and an ethics committee must approve all research. None of these criteria in international standards are expressly articulated in New Zealand law.

## **Mental Capacity Act – law reform and research governance**

- 6.39 In 1995, the English Law Commission found a “striking degree of consensus over the factors which make non-therapeutic research ethical” and these are largely reflected in the MCA’s scheme.<sup>778</sup>
- 6.40 The initial draft Mental Incapacity Bill presented to the UK Parliament in June 2003 did not contain any provisions on research. The Joint Committee on the Bill concluded that there should be provision in the Bill to enable strictly controlled medical research to explore the causes and consequences of mental incapacity and to develop effective treatment for such conditions. It further recommended that these clauses should set out the key principles governing such research and the protections against exploitation or harm enshrined in the Helsinki Declaration of the World Medical Association of 1964.<sup>779</sup> Consideration was also given to the framework for research set out in s 51 of the Adults with Incapacity Act (Scotland) 2000.
- 6.41 The report acknowledged that if legal mechanisms prevented or deterred research for such people, then the development of treatments and the undertaking of treatment trials for disorders such as Alzheimer’s disease would be very problematic. The Joint Committee said:<sup>780</sup>

The range of medical research involving people with possible mental incapacity was considerable. Other examples include investigating why people with Down Syndrome are at such high risk for Alzheimer’s Disease, how best to treat the effects of acute brain injury, how to understand and manage problems such as self-injurious behaviour affecting people with autism, the causes of potentially very debilitating mental illness such as schizophrenia, or the best treatment of severe brain disorders such as in variant CJD. Research goes beyond the medical field and includes investigating factors influencing the quality of life of people with incapacitating disorders, or how they can be best helped to make decisions for themselves. In all of these examples, some of people involved will have the capacity to consent to research but others may not.

- 6.42 Medical research in England and Wales is governed by two distinct governance regimes. Clinical trials of investigational medicinal products are regulated under an EU Directive,<sup>781</sup>

<sup>778</sup> Hale, above n 194 at 220, citing Law Commission, above n 124 at [6.3(1)].  
<sup>779</sup> Joint Committee on the draft Mental Incapacity Bill First Report, Chapter 15  
[www.publications.parliament.uk/pa/jt200203/jtselect/jtdmi/189/18918.htm](http://www.publications.parliament.uk/pa/jt200203/jtselect/jtdmi/189/18918.htm).

<sup>780</sup> Mental Incapacity Bill, above n 779 at [279].

<sup>781</sup> European Union “Regulation of 16 April 2014” No. 536/2014 (2014) Official Eur Union. The Clinical Trials Regulations 2004 were updated in 2015. After almost two years of discussions, the EU Parliament

implemented by the Medicines for Human Use (Clinical Trials) Regulations 2004 (CT Regulations), with further amendments to come into effect in 2016.<sup>782</sup> All other medical research involving people who lack capacity (“intrusive research”), including clinical trials that do not relate to investigational medicinal products, falls under the MCA.

- 6.43 The Health Research Authority (like its predecessors prior to 2011) provides research and ethics committee governance in England and Wales, including an independent advisory panel available to assist ethics committees.<sup>783</sup>

## **Mental Capacity Act – sections 30–34**

- 6.44 Sections 30 – 34 of the MCA<sup>784</sup> provide lawful authority for “intrusive research” involving people without capacity where the research has been approved by an appropriate body.<sup>785</sup> Research is “intrusive” if it would legally require consent if it involved people with capacity.<sup>786</sup>
- 6.45 A broad approach has been taken to what constitutes “intrusive research” under the MCA. This concept is not limited to medical or biomedical research that is physically invasive. As a result, it can be difficult to decide whether some social science research, such as qualitative and observational studies, comes under the MCA, for example observational studies in care homes.<sup>787</sup>

## **Loss of capacity during the research project**

- 6.46 Some people who consent to long-term research studies may lose capacity before the study ends or experience diminishing and fluctuating capacity. The MCA follows the common law position that consent to participate in research does not survive the loss of capacity. This means that if a person has already consented to participate in research then loses capacity in the course of research, their continued participation would be unlawful unless the procedures applying to incapacitated participants were then followed.

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in April 2014 adopted a new regulation on clinical trials, which would replace the currently applicable 2001 Clinical Trials Directive in 2016.

<sup>782</sup> C Gennet, R Andorno and B Elgar “Does the New EU Regulation on Clinical Trials Protect Vulnerable Participants?” (2015) Health Policy <http://dx.doi.org/10.1016/j.healthpol.2015.04.007>.

<sup>783</sup> The Health Research Authority is an “arms-length” Non-Departmental Public Body (NDPB) that provides research governance for the National Health Service as well as social care research under the Care Act 2014. (Interview with Clive Collett, HRA Ethics Guidance and Strategy Manager, 5 June 2015, London) [www.hra.nhs.uk](http://www.hra.nhs.uk).

<sup>784</sup> Mental Capacity Act 2005, ss 30 – 34 are set out in full in Appendix C.

<sup>785</sup> Section 34 is a transitional provision relating to the loss of capacity in research that started before 1 October 2007 but has limited application under regulations: Mental Capacity Act 2005 (Loss of Capacity During Research Project) (England) Regulations 2007. The Regulations only apply to tissue and data collected before the loss of capacity from a person who gave consent and do not cover research involving direct intervention, for example, taking a further blood pressure reading or the taking of further tissue after loss of capacity. Where the Regulations do apply, research can only continue if the project has procedures to deal with people who lose capacity during the project and that has been approved by an ethics committee.

<sup>786</sup> Research may be unlawful for several different reasons, not only because it involves what would otherwise be an assault: for example, where use of the data or samples collected would breach confidentiality or data protection laws or the Human Tissue Act 2004. See *MCA Code of Practice*, above n 285 at Chapter 11.

<sup>787</sup> Interview with Martin Stevens, Chair of the Social Care Research Ethics (SCREC) (London, 10 June 2015).

- 6.47 A key difference under the CT Regulations is that consent survives the loss of capacity. If the person loses capacity during the research then a legal representative (who may be a professional) can consent on the person's behalf.<sup>788</sup>

### Ethics committee approval: key requirements

- 6.48 Under the MCA, an ethics committee, established as the "appropriate body", must approve any medical research project,<sup>789</sup> and can only approve a project that involves a person who lacks the capacity to consent to involvement if the following requirements are met:<sup>790</sup>

1. The research must be connected to an *impairing condition* affecting the person or his treatment.
2. There must be reasonable grounds for believing that *research of comparable effectiveness cannot be carried out* if the project has to be confined to, or only relate to, people who have capacity to consent to taking part.
3. The research must:
  - (a) have the *potential to benefit the person without imposing a burden that is disproportionate to the benefit*, or
  - (b) be intended to provide knowledge about the *causes of the impairing condition*, its treatment or about the care of people affected by the same or a similar condition, provided the research involves *negligible risk*.
4. Arrangements must be in place to comply with s 32 (*consultees*) and s 33 (*additional safeguards*).

### Impairing condition

- 6.49 An ethics committee may not approve a project unless it is connected with an "impairing condition" or its treatment.<sup>791</sup> Ensuring the research is related to the person's condition is described by Lewis as the "subject condition" requirement.<sup>792</sup>

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<sup>788</sup> The legal representative under the CT Regulations has legal authority to give consent or refusal. The differences between the two regimes regarding consultees can be confusing to researchers. In 2010 the NRES released an on-line toolkit offering practical advice on the confusing legal requirements and is explained in a video: <https://connect.le.ac.uk/alctoolkit/>

<sup>789</sup> Mental Capacity Act 2005, s 30(4).

<sup>790</sup> Mental Capacity Act 2005, ss 31(2)–(5).

<sup>791</sup> Mental Capacity Act 2005, ss 31(2) and 31(3). An impairing condition is one which is, or may be, either the cause or the effect of an impairment or disturbance in the functioning of the mind or brain or which contributes to it.

<sup>792</sup> Interview with Professor Penney Lewis, King's College London, London, 7 May 2015. See also P Lewis "Procedures that are Against the Medical Interests of Incompetent Adults" (2002) OJLS 575 at 602. This was also originally contemplated by the Law Commission, above n 125 at 98-100.

- 6.50 It is important that impairing conditions are linked to the condition that is being researched. For example, research that considers the increased incidence of falls in the elderly may justify enrolling people with dementia. However, enrolling people with dementia in genetic research to examine the genomes of a rare cancer unrelated to dementia should not, and did not, gain ethical approval.<sup>793</sup>

### The necessity condition

- 6.51 Section 31(4) of the MCA requires reasonable grounds for believing that if research were to be confined only to people who lacked capacity to consent, it would not be as effective. This condition is described by Lewis as the “necessity” requirement, because research of equal effectiveness could not be carried out if confined to participants with capacity.<sup>794</sup>

*Example: Observational study in an acute psychiatric-care setting where the necessity condition was not satisfied*

- 6.52 The Social Care Research Ethics Committee declined to approve a proposed study of acute psychiatric care in respect of people who lacked capacity. The researcher wanted to observe the mental health assessment process, including both the mental health practitioner and the service user.<sup>795</sup> The study raised the issue of the consent mechanism at a time when people lack capacity to consent because of a critical illness, but may regain capacity. The necessity condition was not met because research could have been carried out equally well by only including assessments of psychiatric patients who had the capacity to consent to taking part. The ethics committee noted that the research was of no personal benefit to the individuals and there were “non-negligible” risks involved given the intrusive nature of the assessment process. In addition, having a personal consultee,<sup>796</sup> such as a family member, give consent could potentially cause a conflict of interest and would place more stress on the participants.
- 6.53 A similar study was approved which aimed to include participants who had sufficient capacity to agree to the researcher being present at the assessment (assent and no dissent). Consent for the data collected at the time of the assessment to be included in the research was sought if and when the person regained capacity. If the person did not regain capacity, or refused to allow their data to be used in the research, it would be discarded.<sup>797</sup>

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<sup>793</sup> As was the case in a large longitudinal study, the “100,000 Genomes” project. Interview with Nigel Wellman, Chair of the Oxford C Ethics Committee, (Oxford, 2 June 2015). The project will sequence 100,000 genomes from around 70,000 people. Participants are NHS patients with a rare disease, plus their families, and patients with cancer [www.genomicsengland.co.uk/the-100000-genomes-project](http://www.genomicsengland.co.uk/the-100000-genomes-project).

<sup>794</sup> Lewis (2002), above n 792.

<sup>795</sup> “Exploring AMHP decision-making during mental health assessments”, Extracts of anonymised minutes released by the National Social Care Research Ethics Committee, 12 June 2015.

<sup>796</sup> Personal consultees are discussed below.

<sup>797</sup> Stevens, above n 787.

## Balancing the benefit and burden of research

- 6.54 Where the research meets the requirement of being connected to the person's impairing condition but does not have the potential to benefit the person without imposing a burden that is disproportionate to that benefit,<sup>798</sup> the MCA imposes a number of additional requirements. There must be reasonable grounds for believing that:<sup>799</sup>
- The risk to the research subject is likely to be negligible [minimal];<sup>800</sup>
  - Anything done to, or in relation to, the research subject will not interfere with the person's privacy or freedom of action in a significant way;
  - Anything done, to or in relation to, the research subject will not be unduly invasive or restrictive.
- 6.55 The research should have the potential to benefit the person without imposing a burden that is disproportionate to that benefit. Therefore, if participants stand to benefit personally from the research, a greater level of risk or inconvenience may be acceptable.<sup>801</sup>
- 6.56 The Scottish and English legal frameworks adopt similar approaches to the benefit and risk thresholds, but with nuanced differences. The Scottish legislation says that where the research entails "no foreseeable risk, or only a minimal foreseeable risk",<sup>802</sup> the research must be "likely to produce real and direct benefit" to the adult.<sup>803</sup>
- 6.57 Manning argues that the Scottish model is clearer and more protective of subjects because it only allows minimal risk, regardless of the potential to benefit the adult, whereas the MCA does not define what an acceptable risk might be.<sup>804</sup> At the time the MCA Bill was before the UK Parliament there was a misapprehension that the Scottish wording "real and direct benefit" was too restrictive and that it meant that there would *definitely* have to be benefit to the individual research participant.<sup>805</sup> The approach taken in the MCA was also justified as

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<sup>798</sup> Mental Capacity Act 2005, s 31(4). Examples of possible benefits to participants include developing more effective ways of treating them or managing their condition, improving the quality of their care, discovering the cause of this would be helpful to them, and reducing the risk of harm or disadvantage. *MCA Code of Practice*, above n 285 at [11.14]. Examples of useful general knowledge might be to see whether a particular way of helping people with congenital learning disabilities might also help people with disabilities caused by head injuries *MCA Code of Practice* at [11.17].

<sup>799</sup> Mental Capacity Act 2005, s 31(6).

<sup>800</sup> The Government committee considering the MCA Bill considered that "negligible" was synonymous with "minimal". Joint Committee On Human Rights Fourth Report (on HL Bill 13) (24 January 2005) <http://www.parliament.the-stationery-office.co.uk/pa/jt200405/jtselect/jtrights/26/2607.htm>, at [4.67].

<sup>801</sup> This kind of research is sometimes referred to as "therapeutic" research. However the distinction between therapeutic and non-therapeutic research can be difficult. Under the NEAC guidelines, "intervention studies" refers to research that includes therapeutic interventions as well as preventative and diagnostic interventions, above n 726.

<sup>802</sup> Adults with Incapacity (Scotland) Act 2000, s 51(3)(d).

<sup>803</sup> Adults with Incapacity (Scotland) Act 2000, s 51(3)(a). If it is not of real and direct benefit, it must be likely to benefit others with the same incapacity through 'significant improvement in the scientific understanding of the adult's incapacity to the attainment of real and direct benefit to the adult or to other persons having the same incapacity', s 51(4). Therefore, the necessity and condition requirements of both laws are similar.

<sup>804</sup> Manning, above n 722 at 527.

<sup>805</sup> Joint Committee On Human Rights Fourth Report, above n 779 at [4.63].

covering the broad range of research possible under the Bill (“intrusive research”), rather than only direct medical interventions.<sup>806</sup>

- 6.58 The Scottish model does not address the principle of proportionality when taking into account the relative risks and benefits of participating in research.<sup>807</sup> By comparison, the MCA recognises a greater risk (burden) is justified where there is potential to benefit the individual concerned.<sup>808</sup>

## Consultees

- 6.59 Section 32 of the MCA requires researchers to have adequate arrangements in place for consulting designated persons (“consultees”) about whether a person lacking capacity should take part in the research. Reasonable steps must be taken to identify a “personal consultee”. This should be someone who knows the individual who lacks capacity in a personal capacity and is able to advise the researcher about the person’s wishes and feelings in relation to the research.<sup>809</sup> This will ordinarily be a family member or someone close to the person, or it could be someone acting under a lasting power of attorney (LPA) or appointed by the court.
- 6.60 If no appropriate person can be identified who is willing to act as a personal consultee, the researcher may consult a “nominated consultee”, that is, someone appointed by the researcher who has some connection with the participant (often a paid care worker or professional) and is independent of the research. Researchers have sometimes shown a reluctance to have a nominated consultee where a personal consultee is not available, or more rarely, where there is a conflict of interest.<sup>810</sup>
- 6.61 The consultee gives advice rather than consent.<sup>811</sup> They must be given information about the project and advise on what the participant’s wishes and feelings would be about taking part, similar to the approach taken when assessing a person’s best interests under s 4 of the MCA. A key difference in the CT Regulations is that it gives the legal authority to enrol a person in research to someone else (other than the researcher),<sup>812</sup> whereas, under the MCA, it is the researcher who makes the decision about participation, provided the process has been approved by an ethics committee.

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<sup>806</sup> Joint Committee On Human Rights Fourth Report, above n 779 at [4.55].

<sup>807</sup> Mental Capacity Act 2005, s 31(5)(a).

<sup>808</sup> The omission of the principle of proportionality in the Scottish legislation in respect of research was noted by the Joint Committee on Human Rights, above n 779. The general principles in Part I of the Scottish legislation include the “least restrictive” principle and that there should be “no intervention in the affairs of an adult unless the person responsible for authorising or effecting the intervention is satisfied that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without intervention,” s 1(2).

<sup>809</sup> Mental Capacity Act 2005, s 32(2).

<sup>810</sup> Stevens, above n 786. For example, Independent Mental Capacity Advocates (IMCAs) appointed under the MCA could be a nominated consultee, but are not currently appointed for this purpose (Interview with Dr Michael Dunn, Ethox Centre, Oxford University and member of the Social Care Research Ethics Committee, Oxford, June 2015).

<sup>811</sup> Mental Capacity Act 2005, s 32(4). Guidance on nominating a consultee for research involving adults who lack capacity to consent issued under s 32(3) of the MCA, Department of Health, 2008.

<sup>812</sup> The legal representative can either be personal or professional and the latter can include the patient’s own doctor unless connected to the research study: Clinical Trials regulations, above n 772 at Part 5.



- 6.62 The consultee provisions in the MCA are stronger than the steps required under Right 7(4) in New Zealand and are tantamount to a power of veto over participation in the research. The researcher must take heed of any advice from the consultee that enrolment or continued involvement in the study would be contrary to the wishes of the person who lacks capacity.<sup>813</sup> Even if a person with capacity had originally consented to join the research project, if they later lose their capacity they must be withdrawn if this approval process has not been completed, unless withdrawal of the treatment would involve significant risk to their health.<sup>814</sup>

### Additional safeguards

- 6.63 The consultee provisions in s 32 also need to be read in light of additional safeguards in s 33 which include “dissent” during the course of the research.<sup>815</sup> These provisions mean that the research cannot proceed if the person appears to object, unless it would protect them from harm or reduce their pain or discomfort.<sup>816</sup> Nor can anything be done which is contrary to an advance decision, or any other form of statement by the participant, of which the researcher is aware.<sup>817</sup>

### Emergency care research

- 6.64 Where treatment is to be provided urgently, the MCA allows by exception for a person lacking capacity to be entered into research prior to a consultee being consulted, subject to strict conditions. The researcher must either have the agreement of a doctor who is not involved in the research, or, if this is not practicable, comply with some other procedure laid down by the ethics committee when the research was approved.<sup>818</sup> Once the urgency has passed, the research must not continue on this basis.<sup>819</sup>
- 6.65 The CT Regulations were amended in 2006 to allow unconscious patients in emergency situations to be enrolled in clinical trials without prior consent, provided an appropriate research ethics committee has approved the research.<sup>820</sup>

### *Example: PARAMEDIC-2: The adrenaline trial*

- 6.66 The PARAMEDIC-2 study is a large clinical trial that will involve 8000 patients and is looking at whether the use of adrenaline is safe and effective in the treatment of cardiac arrest.<sup>821</sup> The ethics committee approved the study under the CT emergency regulations. As all

<sup>813</sup> Mental Capacity Act 2005, ss 32(4) and 32(5).

<sup>814</sup> The consultee provisions are similar in some respects to human tissue legislation in England (Human Tissue Act 2004) and New Zealand (Human Tissue Act 2008) but there is no hierarchy of persons who can consent or object. See an explanation of the informed consent and objection provisions in the Human Tissue Act: A Douglass “The New Human Tissue Act” (2008) NZLJ 377.

<sup>815</sup> There is also a curious and slightly contradictory provision in s 33(3) of the MCA which states: “In conducting the research, the interests of the participant must always be assumed to outweigh those of science and society.” This principle is in compliance with international standards (Declaration of Helsinki, General Principle 8).

<sup>816</sup> Mental Capacity Act 2005, s 33(2)(a).

<sup>817</sup> Mental Capacity Act 2005, s 33(2)(b).

<sup>818</sup> Mental Capacity Act 2005, ss 32(8) and (9).

<sup>819</sup> Mental Capacity Act 2005, s 32(10).

<sup>820</sup> Medicines for Human Use (Clinical Trials) Amendment (No 2) Regulations 2006.

<sup>821</sup> The PARAMEDIC-2 trial was reviewed and approved by the South Central Oxford C Research Ethics Committee [14/SC/0137]. This clinical trial is a double blind, randomised placebo controlled trial of the use of adrenaline in cardiac arrest in hospital, commenced in December 2014 and runs to 2018. As at 11 February 2016, 2000 paramedics are now trained in the trial procedures and 1500 patients were recruited. <http://www2.warwick.ac.uk/fac/med/research/hscience/ctu/trials/critical/paramedic2/>

patients undergoing treatment for cardiac arrest will lack capacity to consent to their participation, there was an agreed procedure for the investigators to recruit participants to the study.

- 6.67 Adrenaline is routinely used to treat a cardiac arrest. Analysis of international evidence available has shown that while use of adrenaline may improve the return of spontaneous circulation and short-term survival, there is insufficient evidence to suggest that it improves long-term survival and neurological outcome.<sup>822</sup> International consensus demonstrated the need for a randomised, placebo-controlled trial of adrenaline. Therefore there is genuine clinical equipoise concerning the two treatment approaches involved in this study.
- 6.68 The ethics committee had to consider two main ethical issues; firstly, whether to deny patients adrenaline, which has been standard care for 50 years despite the growing evidence against its use; and, secondly, whether relatives of participants who die should be told that their family member was in the study, in view of the low (1 in 10) survival rates in out-of-hospital cardiac arrests.<sup>823</sup>
- 6.69 Following a public information campaign and consultation about the study, the ethics committee agreed to an “opt out” process for consent. Members of the public who do not wish to take part, in the event that they have a cardiac event, can request a steel “no study” bracelet. In respect of whether to inform families, it was decided the burden of actively informing the family outweighed the potential benefit, unless families initiated contact; then they can meet with the ambulance team. Although there was some public opposition,<sup>824</sup> the ethics review process allowed this large and important study to proceed.

## Innovative treatment

- 6.70 Although the MCA covers the involvement of incapacitated adults in research, it does not make specific mention of innovative treatment, which is sometimes difficult to distinguish from research. Innovative treatment is often an extension of usual treatment but may expose the patient to a greater degree of risk than established procedures.
- 6.71 In *Simms v Simms*,<sup>825</sup> use of an experimental treatment, not provided during research, was authorised by the Family Division of the High Court when it had not been tested on human beings. Its use was approved for two young patients (16-and18-years-old) who were thought to be suffering from variant Creutzfeldt Jakob disease (vCJD).<sup>826</sup> Dame Elizabeth Butler-

<sup>822</sup> The International Liaison Committee for Resuscitation synthesised available evidence in 2010 with a re-assessment in 2012 (see the Adrenaline Trial Protocol, 3 March 2014, Oxford C REC: 14/SC/0157). The circumstances are similar to those of the CRASH trial (corticosteroid randomisation after significant head injury): steroids that had for years been given in head injury were actually doing harm. P Edwards, M Arango, L Balica and others “Final results of MRC CRASH, a randomised placebo controlled trial of intravenous corticosteroid in adults with head injury—outcomes at 6 months” (2005) 365 *Lancet* 1957.

<sup>823</sup> Interview with Nigel Wellman, Chair of the Oxford C Ethics Committee (Oxford, 2 June 2014).

<sup>824</sup> M McCartney “Adrenaline in cardiac arrest: it’s unethical for patients not to know” (2014) 349 *BMJ* g5258 (22 August 2014). In the news media it was reported that, for people to be able to opt out, “there needs to be an information storm so that all potential participants will see some information about the trial. [Only] then is it legitimate to say that anyone who has not opted out has consented to participate.” The author of the *BMJ* article then asked, “But where is the consent from the thousands of other people who have cardiac arrests but do not know that the adrenaline that they receive may harm them?”

<sup>825</sup> *Simms v Simms*, *PA v JA* [2003] 1 All ER 669, [2002] EWHC 2734 (FAM).

<sup>826</sup> There are no reported cases regarding research in the Court of Protection under the MCA. Although this decision was made before the MCA came into force, it is likely that the Court of Protection would reach a similar decision, given that the innovative treatment was deemed to have been in the best interests of the person lacking capacity to consent: Letts, above n 282 at 149.

Sloss accepted that, although the patients would not recover, the treatment offered the only hope for them in slowing down the decline in their condition. The concept of “benefit” in this context would encompass:<sup>827</sup>

An improvement from the present state of illness, or a continuation of the existing state of illness without deterioration for a longer period than might otherwise have occurred, or for the prolongation of life for a longer period that might otherwise have occurred.

- 6.72 The current standards in New Zealand<sup>828</sup> have reduced the scope of ethical review, which no longer covers “innovative practice”, or what was referred to as “innovative treatment” in earlier standards,<sup>829</sup> and as “new or unorthodox treatment” in the Cartwright Report.<sup>830</sup> People receiving such treatments who are unable to consent through their incapacity are just as vulnerable, however, as patients involved in research. They may be just as unaware that they may be exposed to unnecessary or unacceptable risks. This was the case with the patients whose treatment was investigated in the Cartwright inquiry. Any review of the regulatory framework for ethics review should therefore put innovative treatment back into the scope of ethical review, as originally recommended by the Cartwright Report.<sup>831</sup>

## Summary

- 6.73 There is a wide range of circumstances in which people who lack capacity to consent to research could, and should, share in the benefits and burdens of research. The key question is how to protect vulnerable research participants from harm and exploitation without excluding the populations to which they belong from the benefits of research.
- 6.74 Right 7(4) of the HDC Code is an inadequate legal basis for allowing participation in research by adults incapable of giving informed consent. In addition, the outdated provisions of the PPPR Act do not allow their participation in a sufficient range of research, or support people with diminished capacity to participate in worthwhile research that may benefit them.
- 6.75 Within a cohesive regulatory framework, where the risks are minimal, the law should permit research on people who lack capacity that has potential to benefit either them or other people with a similar condition, provided there are clear statutory safeguards to protect the interests of such vulnerable research participants.

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<sup>827</sup> *Simms v Simms*, above n 825 at [57].

<sup>828</sup> Ministry of Health *Standard Operating Procedures for Health and Disability Ethics Committees* (MOH, Wellington, 2014) [www.ethics.health.govt.nz](http://www.ethics.health.govt.nz).

<sup>829</sup> Ministry of Health *Operation Standards for Ethics Committees* (Updated ed, MOH, Wellington, 2006).

<sup>830</sup> The “unfortunate experiment” was concerned with a situation where withholding of standard treatment of the time from women with pre-invasive cervical cancer was not thought by the researcher to expose them to harm. The women concerned did not give informed consent to participation in research and were unaware they were participating in medical experimentation. Cartwright report, above n 740.

<sup>831</sup> New Zealand Law Society submission to NEAC (16 February 2012).

## RECOMMENDATIONS FOR RESEARCH ON PEOPLE WHO LACK CAPACITY

1. The recommendation is to adopt the main features of sections 30 – 34 of the MCA so that research may only be undertaken on people who lack capacity provided the following conditions are satisfied:
  - a) The research is approved by an *ethics committee*.
  - b) *An Impairing condition*: the research must be connected with the cause or treatment of the condition affecting the potential research participant.<sup>832</sup>
  - c) *The necessity condition*: research of a similar nature cannot be carried out with comparable effectiveness on an adult who is capable of consenting to participate.<sup>833</sup>
  - d) *Balancing the benefits and burdens of research*: the research must have either (a) the potential to benefit the person without imposing a disproportionate burden, or (b) is intended to provide knowledge of the causes or treatment of, or care of persons affected by, the same or similar conditions.<sup>834</sup>
  - e) There is *minimal risk*: If the research falls into category (b) above, there must be reasonable grounds for believing that both the risks to the person from taking part in the project are likely to be negligible, and it will be minimally invasive or restrictive.<sup>835</sup>
  - f) *Consultees*: researchers must take reasonable steps to identify an appropriate person who is interested in the participant's welfare and can advise the researcher of the participant's likely wishes and feelings – if they had capacity – about taking part, and their continued involvement in the research; as well as the ability to appoint independent advocates.<sup>836</sup>
  - g) *Additional safeguards for "dissent"*: nothing may be done to the person in relation to research to which the person appears to object, or which is contrary to any effective prior statement.
  - h) *Emergency care research*: an opinion from an independent doctor, or, if this is not practicable, following an agreed process with an ethics committee.
  - i) *Innovative treatment and practice*: is included within the scope of ethical review.

<sup>832</sup> Mental Capacity Act 2005, s 31(2).

<sup>833</sup> Mental Capacity Act 2005, s 31(4).

<sup>834</sup> Mental Capacity Act 2005, s 31(5).

<sup>835</sup> Mental Capacity Act 2005, s 31(6).

<sup>836</sup> Mental Capacity Act 2005, ss 32(2) and (4).



# Chapter 7

## **Code of Practice**



## Chapter 7: Code of Practice

Chapter 7 is in three sections:

- A. A description of the English Code of Practice under the Mental Capacity Act.
- B. The case for a Code of Practice in New Zealand.
- C. Discussion of current guidance and scopes of practice for health practitioners undertaking capacity assessments in New Zealand; a survey undertaken of doctors concerning such assessments; and first steps towards establishing nationally consistent guidance, with the development of a Toolkit for Assessing Capacity.

### Introduction

- 7.1 In New Zealand, there is no nationally accepted Code of Practice or statutory guidance on capacity law and practice for health practitioners, lawyers or others involved with people with impaired capacity. Understanding the law and applying it is an inherently interdisciplinary exercise combining law, healthcare and ethics. It involves health practitioners (doctors, nurses and psychologists) making the capacity assessment and lawyers and judges applying that assessment to the legal tests. Social workers, healthcare providers and families often initiate the legal process and provide valuable information about a person's preferences.
- 7.2 If there is to be a wider review of the PPPR Act, and its interface with the HDC Code, then it would be premature to draft a complete Code of Practice at present, when the law may change. The revised law should provide simple and concise legislation with an accompanying Code of Practice that would aid its implementation.<sup>837</sup> The MCA Code of Practice has been pivotal in implementing the English legislation. It provides an excellent model from which to develop a New Zealand Code of Practice.

### 7A: THE MENTAL CAPACITY ACT (MCA) CODE OF PRACTICE

#### Legal effect

- 7.3 A central feature of the Mental Capacity Act (MCA) is authorising the issue of more detailed statutory guidance in the form of a Code of Practice that sets standards for the guidance of people using the Act's provisions. The policy intent of the MCA recognised that complex legislation of this sort requires an accompanying Code of Practice for the practical guidance of health professionals, lawyers and a range of people involved with adult incapacity and those affected by its provisions.<sup>838</sup> The MCA Code of Practice (Code of Practice) was formally

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<sup>837</sup> See discussion in Chapter 1B, Overview of New Zealand Law and Chapter 4 Defining Capacity.  
<sup>838</sup> Provision for statutory guidance is made in the Act under s 42 of the MCA 2005. House of Lords, House of Commons *Draft Mental Incapacity Bill*, above n 779 at 64 [229].

issued in April 2007 and came into effect on 1 October 2007 as the statutory guidance for the entire MCA 2005 as originally enacted.<sup>839</sup> By comparison, in Singapore where the English MCA was adopted nearly in its entirety, a Code of Practice was drafted, and put in place by the Office of the Public Guardian, at the same the new legislation was passed.<sup>840</sup> Both of these Codes of Practice provide guidance to anyone who is working with or caring for adults who may lack capacity to make particular decisions. They explain the key concepts of capacity and best interests and how the law operates on a day-to-day basis. Examples of best practice are set out for carers and a wide range of professionals involved, reflecting a multi-disciplinary approach to applying the law.

- 7.4 The English Code of Practice is issued under the statute, which means that certain categories of people have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves.<sup>841</sup> These people include: an attorney under a lasting power of attorney (LPA), a deputy appointed by the Court of Protection (COP), healthcare professionals, researchers, independent mental capacity advocates (IMCAs) and paid workers acting on behalf of the person who lacks capacity.
- 7.5 The Act and the Code of Practice are constructed on the assumption that the vast majority of decisions concerning adults who lack capacity are taken informally and collaboratively by individuals or groups of people consulting and working together, rather than by one individual who is given special legal status to make decisions. For most day-to-day actions the “decision-maker” is the carer most directly involved with the person at the time. Where the decision involves the provision of medical treatment, the doctor or other clinician responsible for administering the treatment or carrying out the procedure is the decision-maker, and in some cases the Court of Protection is involved.<sup>842</sup>
- 7.6 The Code of Practice also aims to provide help and guidance to the wide range of less formal carers, such as close family and friends, who have important relationships with the person lacking capacity and are able to support them. It also emphasises that there are specific decisions that can never be made or actions that can never be carried out under the Act, whether by family members, carers, professionals, attorneys or the Court of Protection, because they are so personal to the individual concerned,<sup>843</sup> or governed by other legislation.<sup>844</sup>

## Sanctions for non-compliance

- 7.7 The Code of Practice is viewed as guidance, rather than instruction.<sup>845</sup> It requires that certain cases to be brought before the court, but no legal liability arises from a breach of the Code

<sup>839</sup> *MCA Code of Practice*, above n 164. A supplement to the Code has since been issued separately to deal with the deprivation of liberty provisions inserted into MCA by the Mental Health Act 2007, which came into effect in April 2009. The Department of Health and the Office of the Public Guardian have also produced complementary materials to the MCA Code of Practice.

<sup>840</sup> Mental Capacity Act 2008 (Singapore); Office of the Public Guardian *Code of Practice: Mental Capacity Act (Chapter 177A)* (3<sup>rd</sup> ed, OPG, Singapore, 2015). The Code of Practice is also much shorter, 100, not 300 pages long, as with the MCA Code of Practice. Interview with Sumytra Menon, lawyer involved with drafting the Singapore MCA Code of Practice, Senior Assistant Director, Centre for Biomedical Ethics, National University of Singapore, 31 March 2015, Singapore.

<sup>841</sup> Mental Capacity Act 2005, s 42(4) and (5).

<sup>842</sup> *MCA Code of Practice*, above n 163 at 5.8.

<sup>843</sup> For example, decisions concerning family relationships such as consenting to marriage or a civil partnership: Mental Capacity Act 2005, s 27.

<sup>844</sup> For example, treatment for mental disorder under Part 4 of the Mental Health Act 1983: Mental Capacity Act 2005, s 28, or s 29 – voting rights.

<sup>845</sup> *MCA Code of Practice*, above n 164 at 1.

itself. Nevertheless, a failure on the part of a health professional to comply with the Code's guidance would be taken into account in any relevant proceedings in a court or tribunal. It would, for example, be relevant to an assessment of a doctor's fitness to practice before the General Medical Council.<sup>846</sup>

- 7.8 Compliance with the Code of Practice is relevant to the application of the statutory defences that are available to health professionals under the MCA. Section 5 of the MCA, for instance, provides certain statutory protection to carers and healthcare professionals who provide care and treatment that is necessary and in the best interests of a person who lacks capacity to consent.<sup>847</sup> In the law reform process that produced the MCA, the legal position of informal carers, such as family members, was carefully considered. It was recognised that it was essential that family members and carers comply with their legal responsibilities, and understand the seriousness of their actions and the need to be accountable for them. However, it was considered inappropriate to impose on them a strict requirement to act in accordance with the Code of Practice.<sup>848</sup> Although not under a legal duty, informal carers still have an obligation to act in accordance with the principles of the MCA and the best interests of a person lacking capacity.<sup>849</sup>

## Tool for interpretation of the MCA

- 7.9 Judges frequently use the Code of Practice to interpret and apply the law.<sup>850</sup> In *G v E*,<sup>851</sup> for instance, Mr Justice Baker explained how the Code of Practice applied in a decision not to appoint a sister and a former carer as personal welfare deputies for E, a 20-year-old man who suffered from severe disabilities. While the Code of Practice gives examples where it can be impracticable to insist on decisions being taken by the court rather than by the appointment of a deputy, the scheme of the MCA is to only appoint deputies under s 16(4) in exceptional circumstances, and they were not found in this case.<sup>852</sup>
- 7.10 The Code of Practice can be used as evidence in a court or a tribunal. In *Aintree University Hospitals NHS Foundation Trust v James*,<sup>853</sup> the first decision of the Supreme Court under the MCA, the Court addressed the question of how doctors and courts should decide when it is in the best interests of a person who lacks capacity to be given, or not given, treatment necessary to sustain life. In a unanimous decision, Lady Hale accepted the statements in the

<sup>846</sup> Brazier and Cave, above n 295.

<sup>847</sup> Mental Capacity Act 2005, s 5. The provisions of section 5 are based on the common law doctrine of necessity as set out in *Re F*, above n 125. In addition, s 6 places clear limits on the use of force or restraint by only permitting restraint where this is necessary to protect the person from harm and is a proportionate response to the risk of harm. It is beyond the scope of this report to consider whether statutory protection for carers and health practitioners, as provided for in ss 5 and 6 of the MCA would be appropriate or necessary in New Zealand's medico-legal environment under the no-fault treatment injury provisions of the Accident Compensation Act 2001.

<sup>848</sup> Ashton, above n 26 at 85.

<sup>849</sup> *MCA Code of Practice*, above n 164 at 2.

<sup>850</sup> Interview with Judge Elizabeth Batten, District Judge of the Court of Protection (A Douglass, 16 April 2015, Court of Protection, London).

<sup>851</sup> Above n 158.

<sup>852</sup> In the Code of Practice examples under MCA, s 16(4) include situations that involve a series of decisions about medical procedures or where the assets of an incapacitated adult are of a magnitude that requires regular management: *MCA Code of Practice*, above n 163 at [8.38] and [8.39]. At [59], Mr. Justice Baker interpreted these paragraphs to mean that, "Common sense suggests that the second of these examples is likely to arise more frequently than the first, that the appointment of deputies is more likely to be more common for property and affairs than for personal welfare".

<sup>853</sup> *Aintree*, above n 164.

Code of Practice, regarding withholding treatment that can be futile, or overly burdensome to the patient, or where there is no prospect of recovery, as an accurate statement of the law.<sup>854</sup>

## MCA – problems with implementation

- 7.11 The overall finding by the post-legislative scrutiny report of the House of Lords was that the MCA was a very significant and progressive piece of legislation, with the potential to transform lives.<sup>855</sup> However, the key problem with implementation was that there was no provision in the MCA to monitor compliance with the Code of Practice, or with the Act more generally.<sup>856</sup> This point was made with some force in the House of Lords' report:<sup>857</sup>

While we recognise that the application of the Act is very wide and a complete picture would be hard to achieve, the absence of any monitoring is indefensible, if the benefits of this legislation are to be delivered.

- 7.12 In practice, the vast majority of cases before the COP concern property, rather than welfare decisions. The experience of Senior Judge Lush of the COP is that attorneys and deputies show a distinct lack of knowledge of the Code of Practice, which can lead to financial abuse.<sup>858</sup> Most attorneys and deputies are unaware of the existence of the Code of Practice. Very few have a copy of it, or have downloaded it from the internet and, even if they do have a copy, fewer still have read it or applied it in practice. Senior Judge Lush says:<sup>859</sup>

More than any other feature of the Mental Capacity Act, the Code of Practice has potential to revolutionise the way we treat members of society who are unable to make their decisions. Over time, the standards laid down in the Code should permeate and influence good practice. However, the Code will only be a success if people know about it and read, mark, learn and inwardly digest it and this simply isn't happening.

- 7.13 In order to address the failure to embed the Act in everyday practice, the House of Lords recommended responsibility for oversight of the Act's implementation should be given to a single independent body. The intention was not to remove ultimate responsibility for the MCA

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<sup>854</sup> *Aintree*, above n 164 at [28] and [29] - Lady Hale: "Paragraph 5.31 (of the Code of Practice) gives useful guidance, derived from previous case law, as to when life-sustaining treatment may not be in the patient's best interests. Both the judge and the Court of Appeal accepted them as an accurate statement of the law and so would I. However, they differed as to the meaning of the words in italics. The Code is no statute and should not be construed as one but it is necessary for us to consider which of them was closer to the correct approach."

<sup>855</sup> House of Lords Select Committee on the Mental Capacity Act 2005 *Mental Capacity Act 2005: post-legislative scrutiny* (TSO, London, 2014), above n 3 at [12] - [20]. The most significant exception to the Act being considered a good piece of legislation was criticism of the poor drafting and implementation of the Deprivation of Liberty Safeguards. See Chapter 1C Problems with implementation of the MCA.

<sup>856</sup> While a number of the witnesses to the House of Lords Select Committee emphasised the importance of focusing more on supported decision-making in order to enhance compliance with the CRPD, the House of Lords Report did not review the compatibility of the MCA with the CRPD. However they received evidence of how the use of the Act in practice could be better aligned with the UN Convention: House of Lords, above n 855 at [51]-[53].

<sup>857</sup> House of Lords, above n 855 at [35]. A mechanism for the review of the MCA Code of Practice was not regarded as an answer to poor implementation.

<sup>858</sup> Under the MCA, professionals may be employed to carry out the role of deputies and some solicitors specialise as professional deputies. The Court may require a deputy to give a bond (security) for the discharge of their functions and submit reports to the Public Guardian.

<sup>859</sup> D Lush "Financial Crime Committed Against the Elderly and Infirm: A Review of its Increasing Prevalence and how Effective Practitioners, Public Bodies and the Courts are Tackling it" (paper presented at a joint seminar STEP London Central Branch and ACTAPS, London, 10 December 2014) at 13.

from government ministers, but to locate ownership of the Act in one place, so as to provide a clear form of accountability, and a focus for enhanced activity.<sup>860</sup>

## Quality of capacity assessments

7.14 Evidence before the House of Lords' Select Committee gave a bleak picture of the quality of capacity assessments. The implementation of the presumption of capacity<sup>861</sup> – the idea that capacity must be assumed until proven otherwise – was described as “patchy, at best”.<sup>862</sup> The reasons given included: a tendency among health and social care staff to make assumptions based on impairment; the failure to conduct assessments when necessary; poor quality of assessments generally; and the failure to take into account the impact of specific conditions on assessment. Disconcertingly, there was evidence of the presumption of capacity being used to support non-intervention by service providers. The Law Society referred to the presumption of capacity principle being applied “perversely”, to avoid assessing capacity and to justify lack of provision of services.<sup>863</sup>

7.15 Many of the criticisms raised were about the way in which capacity assessments were being carried out by professionals who were not closely involved with the care of the person affected.<sup>864</sup> A group of lawyers who jointly submitted evidence to the Select Committee found that:<sup>865</sup>

The best capacity assessments are by people who know P (the person who lacks capacity), and who have experience and training in communicating with people with disabilities, and who see their task as assisting P to make a decision, not testing P's knowledge.

7.16 The English experience to date has demonstrated that even the most up-to-date law that has a clear explanation of its core principles is difficult to embed. It requires participation from the professionals and appointed decision-makers who must implement the law. A consistent theme in the evidence before the House of Lords was the tension between the empowerment that the Act was designed to deliver and the tendency of professionals to use the Act in an overly protective way.<sup>866</sup> Prevailing professional cultures of risk aversion and paternalism have inhibited the aspiration of empowerment for people with impaired capacity from being realised.<sup>867</sup>

7.17 One of the recommendations in the House of Lords' report is that the English Government work with professional regulators and the medical Royal Colleges to ensure that the MCA is given a higher profile. It specifically recommended training for medical students and general practitioners (GPs) to embed and enhance their understanding of the MCA in view of the vital role that GPs play in providing healthcare in the community.<sup>868</sup>

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<sup>860</sup> House of Lords, above n 855 at 6, [35], [36], [39]. In the event, the independent body was not established.

<sup>861</sup> Mental Capacity Act 2005, s 1(2): “A person must be assumed to have capacity unless it is established that he lacks capacity.”

<sup>862</sup> House of Lords, above n 855 at [56].

<sup>863</sup> House of Lords, above n 855 at [63].

<sup>864</sup> The experience of Mark Neary, father to Steven Neary, a young man in his early 20s with autism and a severe learning disability, who was involved with a high profile case, was that the supported process had turned into an adversarial one: House of Lords, above n 854 at [68]. In *Hillingdon v Neary*, above n 461, the COP held that Steven Neary had been unlawfully detained, against his own and his father's wishes by the London Borough of Hillingdon in 2010.

<sup>865</sup> House of Lords, above n 855 at [69].

<sup>866</sup> See Chapter 4A Unwise decisions and the protection imperative.

<sup>867</sup> House of Lords, above n 855 at [15].



## 7B: DEVELOPMENT OF A CODE OF PRACTICE FOR NEW ZEALAND

### Best practice standards

- 7.18 The New Zealand health and disability sector is very familiar with professional standards, guidelines and Codes of Practice, and with the general use of subordinate or secondary legislation.<sup>869</sup> A significant segment of New Zealand public law has evolved from subordinate legislation and the consideration of its legal effect.<sup>870</sup> Although there can be confusing terminology, many secondary sources of “subordinate legislation”, such as “guidelines”,<sup>871</sup> are more concerned with establishing best practice standards than definitive rules or regulations.
- 7.19 Nevertheless, the HDC Code is itself subordinate legislation, as it is a regulation issued under the Health and Disability Commissioner Act 1994.<sup>872</sup> Non-compliance with practice standards in the health and disability sector may result in a provider of services (whether an individual or an institution) being found in breach of Right 4(2) of the HDC Code for failing to provide services that comply with “legal, professional, ethical, and other relevant standards”.<sup>873</sup>
- 7.20 The HDC Code only applies to “providers” of health and disability services and does not cover the wide range of people, including some professionals, who may be involved with people with impaired capacity, such as paid carers, social workers, appointed substitute decision-makers under an EPOA or welfare guardian, and lawyers. Therefore, a Code of Practice based on the English MCA model would need to have much wider application than standards for health practitioners under the current HDC Code.<sup>874</sup>

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<sup>868</sup> House of Lords, above n 854 at [18].

<sup>869</sup> For example, the Human Assisted Reproductive Technology Act 2004 requires the Advisory Committee to the Minister of Health (ACART) to promulgate advice and guidelines under the framework of that Act and for providers of fertility services to adhere to these, including ethical review by the ethics committee of the assisted reproductive procedures that fall within the guidelines.

<sup>870</sup> The Parliament’s Regulations Review Committee may draw attention to delegated legislation, including legislative instruments and disallowable instruments to the House under Standing Order 319. See R Carter, J McHerron and R Malone *Subordinate Legislation in New Zealand* (LexisNexis NZ Limited, Wellington, 2013) at 171. “Instrument” as defined under the Legislation Act 2012, s 48 (a) means “any instrument (whether called regulations, rules, an Order in Council, a notice, bylaws, a code, a framework, or by any other name) that has legislative effect and that is authorised by an enactment.”

<sup>871</sup> For example, the *Guidelines to the Mental Health (Compulsory Assessment and Treatment) Act 1992* (Ministry of Health, Wellington, 2012) provide guidance intended to support the effective and lawful use of the Act and recognise that the Act is not a comprehensive framework for mental health treatment. The introduction to these guidelines states that “no piece of legislation can be framed in such a way that all circumstances that can possibly arise are precisely covered. If there is uncertainty as to the “correct” interpretation, any action should be taken in good faith, be consistent with the spirit and intent of the Act, and reflect best clinical practice.”

<sup>872</sup> As noted above there is no guidance in the HDC Code about the concept of capacity – referred to as “competence” or how to assess whether the person has capacity for the purpose of giving or refusing informed consent under Right 7 of the HDC Code. Sanctions for a finding by the Commissioner that a health practitioners is in breach of the HDC Code can result in a referral to the Health Practitioners Disciplinary Tribunal or to the Director of Proceedings with potential for a compensation claim in the Human Rights Review Tribunal.

<sup>873</sup> For example, a GP’s failure to assess the competence of a woman with Huntington’s disease was found to be in breach of Right 4(2) of the HDC Code: HDC *Opinion 11 HDC00647 – GP, Dr C* (10 June 2013). See Chapter 1B.



## Social workers

- 7.21 In England, social workers are actively involved with the operation of the MCA, including assessing capacity as well as best interests, for the purpose of meeting the requirements under the Act, including the authorisation of Deprivation of Liberty Safeguards (DoLS) and reporting to the COP.<sup>875</sup> The Code of Practice sets out case studies and gives examples of how to implement the law in situations that can be ethically complex and challenging. Social workers are very familiar with managing a conflict between the person with impaired capacity and their family, or disputes between family members over the care and living arrangements for their relative.
- 7.22 In some instances, the COP has preferred the opinion of an independent social worker on the issue of a person's capacity over a medical expert on the basis that the social worker had greater knowledge of the person's environment and their potential to achieve capacity for decision-making. In *X v K*<sup>876</sup> a young man, L, with mild mental disability and some learning difficulties, had previously been assessed as lacking capacity regarding his living arrangements and contact with others. When deciding an application by the local authority to place L in his own supported accommodation, Mrs Justice Theis preferred the evidence of an independent social worker over the report of the psychiatrist who had not provided a "compliant" assessment of L's capacity. The psychiatrist had not revisited L or considered the use of drawings or pictures, even though this communication method was used on a daily basis as support for L. The Court found that the psychiatrist's assessment was not in keeping with the provision of support required under Article 12(3) of the CRPD.<sup>877</sup>
- 7.23 In New Zealand, hospital social workers have traditionally been familiar with the procedural requirements of the PPPR Act and their role is pivotal in assisting families and coordinating applications to the Family Court under that Act. Social workers now practise in diverse environments, from private practice, to statutory roles, and non-governmental and not-for-profit agencies. In response to the need to navigate the complexities of working with families under the PPPR Act, they have developed their own voluntary practice guidance.<sup>878</sup> This requires that when a client's capacity is being questioned, "Social workers will be competent to have conversations about issues of client capacity with others involved in the client's care," and this includes understanding capacity assessments required for activation of an EPOA.<sup>879</sup>

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<sup>874</sup> For example, the current HDC Code does not apply to informal carers, lawyers, social workers, appointed substitute decision-makers, e.g. a welfare guardian or an attorney appointed under an EPOA.

<sup>875</sup> A "best interests assessment" is often carried out by social workers under s 4 of the MCA. There is a system of accreditation and specific regulations for the role of a "best interests assessor". See Guidance note: Ruck Keene and Butler-Cole, above n 201.

<sup>876</sup> *X v K* [2013] EWHC 3230 (Fam).

<sup>877</sup> *X v K*, at [51]. The Court specifically referred to [4.16] of the Code of Practice which states: "It is important not to assess someone's understanding before they have been given relevant information about a decision. Every effort must be made to provide information in a way which is most appropriate to help the person understand". The social worker had in fact carried out a best interests assessment (not a capacity assessment). However, this evidence was preferred by the Court to the capacity assessment undertaken by the psychiatrist, resulting in the Court requesting a further capacity assessment to revisit the issue of L's capacity.

<sup>878</sup> Australian New Zealand Association of Social Workers (ANZASW) Social Work and Protection of Personal and Property Rights Act Working Group "An ANZASW Practice Note for Social Workers Working with the Protection of Personal and Property Rights Act 1988" (2015). The practice note is to accompany the Code of Ethics of Aotearoa New Zealand Social Work Association. <http://anzasw.nz/wp-content/uploads/Practice-Note-for-SW-working-with-PPPR-Act-Sept-2015.pdf>.

- 7.24 The next step would be for greater formal recognition to occur in New Zealand of the role of social workers and all allied healthcare professionals, such as speech therapists and occupational therapists, in working with people with impaired capacity and their families. Based on the experience in England, a Code of Practice could provide valuable guidance to them, including informing them on what the court requires from them in court proceedings.

## Guidance for lawyers

- 7.25 There are guidelines issued by the Family Court for the lawyer appointed to represent a person subject to an application under the PPPR Act, but these guidelines are specific to the representation and that lawyer's reporting to the court.<sup>880</sup>
- 7.26 There is a lack of guidance for lawyers generally on issues surrounding mental capacity and how to assess or assist clients who lack capacity.<sup>881</sup> Property solicitors, for example, are often faced with questions from a family over their relative's capacity to make an EPOA or a will. In circumstances where a client's capacity is in doubt, it is often desirable, and a matter of good practice, for lawyers to obtain a medical or expert opinion, especially regarding complex or serious decisions. Lawyers need to know what kind of doctor or other health practitioner they should request an opinion from, how to clarify the relevant legal tests, how to provide the relevant information, and how to explain the particular areas of capacity the lawyer wishes the doctor to report on. Individuals may retain capacity to make decisions in some areas of functioning but not in others. They might, for example, be able to understand the issues involved in appointing an enduring attorney to deal with their finances but lack the capacity to make specific financial decisions themselves.<sup>882</sup> A lawyer may need to explain these complexities to the health professionals concerned.
- 7.27 The statutory framework under the PPPR Act does not codify all the common law tests of capacity recognised in case law, such as the test for capacity to make a will, capacity to marry, capacity to make a gift, capacity to contract, capacity to litigate, and so on. A Code of Practice would recognise that there are both common law and statutory tests of mental capacity, and would explain the different capacity tests that apply when the client may lack capacity to give instructions or make their own legal decisions.

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<sup>879</sup> ANZASW, above n 878 at [2.2] – [2.4].

<sup>880</sup> Judge PF Boshier, Principal Family Court Judge, *Guidelines for counsel for subject person appointed under the Protection of and Property Rights Act 1988*, March 2011, <http://www.justice.govt.nz/family-justice/about-us/info-for-providers/documents/guidelines-counsel-for-subject-person-pppra.pdf>.

As discussed in Chapter 1B, these guidelines present their own set of challenges for the lawyer appointed to represent the subject person where the person's will and preferences are contrary to the views of others about their welfare and best interests.

<sup>881</sup> The Law Society of New South Wales, Australia has published a practical guidance for lawyers which gives guidance to a lawyer's role in a capacity assessment, principles applicable, and techniques available to lawyers. Law Society of New South Wales *A Practical Guide for Solicitors: When a client's capacity is in doubt* (LSNSW, Sydney, 2009). See also legal toolkits available state by state in Australia, e.g. NSW Toolkit: <http://capacityaustralia.org.au/wp-content/uploads/2013/10/NSW-Legal-kit-8pp-sept-2013-version-.pdf>.

<sup>882</sup> Letts, above n 282 at 175.

## Compliance with the CRPD

- 7.28 There are considerable advantages in developing a Code of Practice concurrently with reform of the legislation to bring the law and practice in line with the new human rights framework under the CRPD. A Code of Practice would have greater impact if recognised in revised and well-drafted legislation, and enable better understanding of the law. It would explain the law, provide public education, and establish a framework for professionals involved with people with impaired capacity to make decisions. In doing so, it could reduce the need for State intervention and court proceedings to resolve some issues.
- 7.29 A Code of Practice would be an “appropriate measure” through which New Zealand could implement supported decision-making in practice and would give effect to New Zealand’s commitment to Article 12(3) of the CRPD.<sup>883</sup>

## 7C: THE FIRST STEP – A TOOLKIT FOR ASSESSING CAPACITY

### Who should undertake capacity assessments?

- 7.30 There is no restriction in New Zealand on the range of professionals who may perform capacity assessments, or the scope of practice required of those who do so<sup>884</sup> (although an EPOA may specify who must conduct the assessment concerning its coming into effect).<sup>885</sup> Only “certificates of mental incapacity” for activating EPOAs (not “de-activating” them when someone regains capacity) have a prescribed form.<sup>886</sup> In the Guidelines to the PPPR Act Regulations,<sup>887</sup> the form for health practitioners completing a certificate of mental incapacity for an EPOA states: “Although there is no prescribed method of assessing incapacity for the purposes of this certificate, it is important that the practitioner records the reasons for his or her opinion in case it is challenged”.<sup>888</sup> The certificate must be completed by a “relevant health practitioner whose scope of practice enables him or her to assess a person’s mental capacity and is competent to undertake an assessment of that kind.”<sup>889</sup>

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<sup>883</sup> United Nations Convention on the Rights of Persons with Disabilities, art 12(3).

<sup>884</sup> Protection of Personal and Property Rights Act 1988, s 94(4). The PPPR Act allows the court to request a “medical, psychiatric or psychological or other report”, Protection of Personal and Property Rights Act 1988, s 76(1)(a).

<sup>885</sup> Protection of Personal and Property Rights Act 1988, s 99D(2). The donor may specify in an enduring power of attorney that the assessment of his or her mental capacity for the purposes of this Part be undertaken by a health practitioner with a specified scope of practice, but only if the scope of practice specified includes the assessment of a person’s mental capacity.

<sup>886</sup> There is no prescribed form for court applications under the PPPR Act. A form that was originally developed by the late Mr Keith Matthews, partner of the law firm, Tripe Matthews and Feist, for the Wellington Family Court, appears on the Ministry of Justice website: <http://www.justice.govt.nz/family-justice/other-court-matters/power-to-act/getting-an-order-reviewed/forms-fees-and-cost>.

<sup>887</sup> Protection of Personal and Property Rights Act (Enduring Powers of Attorney Forms) Regulations 2008.

<sup>888</sup> A social worker is not a “health practitioner” for completing the certificate but, nurses, occupational therapists and psychologists (in addition to doctors) are health practitioners under the Health Practitioners Competence Assurance Act 2003.

<sup>889</sup> Protection of Personal and Property Rights Act 1988, s 99D. There is currently a proposed amendment to s 99D to replace the requirement that there is a prescribed form of certificate of the donor’s mental incapacity to the requirement for “prescribed information”: Statutes Amendment Bill, Part 21 Amendments to the Protection of Personal and Property Rights Act 1988, Clause 78. In its submission on the Bill, the New Zealand Law Society opposed this change as regulations should not be left to define “prescribed information”, unless the relevant test for mental incapacity is clearly defined in the PPPR

- 7.31 The Medical Council of New Zealand has advised that all doctors should be able to assess capacity.<sup>890</sup> The Medical Council lists 36 vocational scopes of practice, none of which include a specific criterion for assessing mental (in)capacity.<sup>891</sup> A “scope of practice” is not, however, intended to describe or prescribe how practice is undertaken but rather the areas of medicine in which a doctor is permitted to practise.<sup>892</sup> The expected “competence” of doctors to undertake capacity assessments is underpinned more by the training required to be a member of the relevant medical Colleges. Nurses could also be expected to undertake capacity assessments, but there is similarly no indication that assessing capacity is within the competencies required of nurses or within their scope of practice.<sup>893</sup>
- 7.32 Typically, a general practitioner in the primary care setting who has knowledge of the person and the family may be approached to complete a capacity assessment. Where cases are complicated by existing medical or psychiatric conditions, a psychiatrist, geriatrician, or psychogeriatrician may become involved. Increasingly, clinical psychologists undertake capacity assessments, not only in their more traditional spheres of intellectual disability and brain injury, but also in the elder care setting.<sup>894</sup>
- 7.33 Neuropsychologists can have a more specialised role where a person’s incapacity is borderline and requires more in-depth assessment. These assessments are based on how best to identify a person’s cognitive strengths and weaknesses for specific tasks, rather than on a “one size fits all” approach.<sup>895</sup> Psychological testing includes assessing executive functioning in intellectual disability and assessing impairment in a person’s ability to “weigh up” information as part of the reasoning process.<sup>896</sup> These matters can be very relevant to assessing the extent to which a person’s decision-making is unduly influenced by others, via

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Act. The Law Society noted that what constitutes mental incapacity is an area of difficulty under the PPPR Act that is in need of legislative clarification: New Zealand Law Society “Statutes Amendment Bill” (29 January 2016).

[http://www.lawsociety.org.nz/data/assets/pdf\\_file/0008/98207/Statutes-Amendment-Bill,-Part-21-29-1-16.pdf](http://www.lawsociety.org.nz/data/assets/pdf_file/0008/98207/Statutes-Amendment-Bill,-Part-21-29-1-16.pdf) at 4.

<sup>890</sup> *Report of the Minister for Senior Citizens on the review of the amendments to the Protection of Personal and Property Rights Act 1988 made by the Protection of Personal and Property Rights Amendment Act 2007* (Ministry of Social Development, Wellington, 2014), above n 73 at 13; see also Skegg and Paterson, above n 580 at 231.

<sup>891</sup> Medical Council of New Zealand  
<https://www.mcnz.org.nz/get-registered/scopes-of-practice/vocational-registration/types-of-vocational-scope/>. “Scope of practice” means any health service that forms part of a health profession and that is for the time being described under section 11”, Health Practitioners Competence Assurance Act 2003, s 5. Psychiatrists are expected to be able to perform mental capacity evaluations and have the option of completing a Certificate of Advanced Training in Psychiatry of Old Age, which includes a standard on capacity assessments for testamentary capacity and EPOAs.  
<https://www.ranzcp.org/Files/PreFellowship/2012-Fellowship-Program/Psychiatry-of-Old-Age-Certificate/Old-age-Certificate-requirements.aspx>.

<sup>892</sup> Email communication from David Dunbar, (Registrar, Medical Council of New Zealand) on scope of practice (16 March 2016).

<sup>893</sup> The New Zealand Council: <http://www.nursingcouncil.org.nz/Nurses/Scopes-of-practice>.

<sup>894</sup> There has been a submission to the Psychologists Board by neuropsychologists for capacity assessments to be included as a competency within their scope of practice (Email communication from K Cunningham (neuropsychologist), (29 May 2016).

<sup>895</sup> KL Cunningham “Neuropsychological Assessment of Medico-Legal Capacity in the New Zealand Context” in JAB Macniven (ed) *Neuropsychological Formulation: a clinical casebook* (Springer, New York, 2016) at 114.

<sup>896</sup> Psychologists use a variety of tests, for example, ABAS-II (Adaptive Behaviour Assessment System-Second Edition), whereby adaptive functioning scales can be filled out by the person and a reliable informant (family member and/or health professional). This test gives information of the person’s actual daily functioning skills without support or assistance. Cunningham, above n 895 at 94.

emotional or sexual manipulation, for example, and to whether a person has capacity if they decline good support offered to them.

- 7.34 Members of the different health professions may have different approaches to assessing capacity, depending on the assessment methods to which they adhere.<sup>897</sup> Where possible, it is best to have a health practitioner who knows the person conduct the assessment. In many instances, practice nurses, social workers and occupational therapists may be part of a multi-disciplinary team that contributes to that assessment.

## Existing guidance for assessing capacity

- 7.35 In New Zealand, Young,<sup>898</sup> and more recently Astell,<sup>899</sup> have described approaches to capacity assessment for doctors. However, in contrast to the developments under the MCA and similar laws, no specific guidance has been established in New Zealand that takes into account the provisions of both the PPPR Act and the HDC Code, human rights developments under the CRPD, and the need to recognise tikanga Māori and cultural diversity within clinical practice.
- 7.36 Traditionally, clinicians<sup>900</sup> have used intuitive or unstructured methods of capacity assessment – sometimes referred to as “clinical judgement”. This approach is not accurate enough and will not withstand legal scrutiny, for example when assessing a person’s capacity to make a will or gift significant assets. There is often a misconception that tools for assessing cognitive impairment, such as the Mini-Mental State Examinations that produce a scored measure of cognitive function, are sufficient. However, these tools are not specific tests of decision-making capacity.<sup>901</sup> Furthermore, the correlation between decision-making capacity and cognitive ability is not reliable in a legal setting, especially in the earlier stages of dementia.
- 7.37 A variety of methods of capacity assessment have been published internationally but these mainly relate to other jurisdictions.<sup>902</sup> The MacArthur Competence Assessment Tool for Treatment (MacCAT-T)<sup>903</sup> has provided the basis for a clinical tool now used widely to assess capacity. It is internationally regarded as a “gold standard” of assessment, but requires some familiarity and training to use correctly. It has been used in the United States to assess decision-making capacity in relation to treatment decisions in many different clinical contexts,

<sup>897</sup> K Sullivan “Neuropsychological assessment of mental capacity” (2004) 13 Neuropsych Rev 131.

<sup>898</sup> G Young “How to Assess a Patient’s Competence” (2004) Feb New Eth J 41. This seminal article was the first New Zealand specific method developed for GPs to assess capacity under the PPPR Act using a mnemonic for remembering the assessment procedure (“Play SOCCUR Excellently”).

<sup>899</sup> H Astell, J Hyun-Lee and S Sankran “Review of capacity assessments and recommendations for examining capacity” (2013) 126 NZMJ 1383). Drs Astell and colleagues in the Community Geriatrics Department at Middlemore Hospital, Counties and Manukau DHB, identified the need to train specialist nurses and GPs to perform capacity assessments and developed a resource kit for this purpose.

<sup>900</sup> The term ‘clinician’ is used to refer to health practitioners and can include, doctors, nurses and psychologists.

<sup>901</sup> M Folstein, SE Folstein and PR McHugh “‘Mini-Mental State’ – A Practical Method for Grading the Cognitive State of Patients for the Clinician” (1975) 12 J Psychiatr Res 189.

<sup>902</sup> Examples internationally: T Grisso and P Appelbaum *Competence Assessment Tool for Treatment (MacCAT-T)* (Professional Resources Press, Sarasota, FL, 1998) (USA); Mental Capacity Act 2005 Code of Practice Chapter 4, A Ruck Keene (ed) *Assessment of mental capacity: a practical guide for doctors and lawyers* (4<sup>th</sup> ed, British Medical Society and the Law Society, London, 2015) (UK); Attorney General *Capacity Toolkit* (New South Wales, 2008) and Capacity Australia “Mini-legal Kits” [www.capacityaustralia.org.au/resources/mini-legal-kits](http://www.capacityaustralia.org.au/resources/mini-legal-kits) (Australia);

Ontario Ministry of the Attorney General “Guidelines for Conducting Assessments of Capacity” (2005) <http://www.attorneygeneral.jus.gov.on.ca> (Canada).

<sup>903</sup> Grisso and Appelbaum, above n 902, refer to capacity assessments for research participation.



including research.<sup>904</sup> This clinical tool provides a semi-structured interview that enables the assessor to evaluate capacity in terms of four abilities closely resembling the criteria in the MCA test<sup>905</sup> (and the legal tests in the PPPR Act). A semi-structured interview approach is one which provides a framework for questioning, but which allows the clinician to insert details that are relevant to the issue and to the person being assessed. This approach can assist the clinician to ensure that the assessment is systematic and complete but is also sufficiently flexible and specific to the decision and circumstances.

- 7.38 Major problems faced in the development and implementation of standards for assessing decision-making capacity are inter-rater reliability and the extent to which standards can be objective.<sup>906</sup> Assessment of capacity will incorporate elements of value and rationality and the question is how to apply this in a clinical setting,<sup>907</sup> particularly where the person has a severe psychiatric disorder. A particular difficulty that can arise for the clinician is whether the person's ability to manipulate the information (that is, "foresee the consequences" or "use or weigh" the information) meets the standard of capacity. The assessment should focus on the process used in coming to a decision, not the content of the decision itself. However, assessing how a person weighs up the consequences is particularly subject to normative bias, based on the clinician's own value judgements about how the patient "ought to" use the information.<sup>908</sup> This may extend to cultural bias when assessing Māori, and generally there is a risk of failing to recognise the diverse cultural contexts within which capacity assessments are carried out.<sup>909</sup>

## A survey of doctors in New Zealand

- 7.39 In December 2015, as part of this research project, a survey entitled, "What do you know about assessing capacity, and what would help you do it better?" was sent to all doctors working at both Hutt Valley and Wellington hospitals.<sup>910</sup> Information and a link to the survey were also published in three national newsletters widely read by GPs.<sup>911</sup> The aim of this survey was three-fold: to increase awareness of the role of capacity assessments; to determine what doctors already know about the principles of capacity assessment; and to determine what their educational needs and preferences might be.

<sup>904</sup> P Appelbaum "Assessment of patients' competence to consent to treatment" (2007) 357 New Eng J Med 1834. Note the legal test is slightly different – refer to Chapter 4 on Defining Capacity.

<sup>905</sup> G Richardson "Mental Capacity at the Margin: the Interface between Two Acts" (2010) Med Law R 63.

<sup>906</sup> See Chapter 4A Defining Capacity.

<sup>907</sup> LC Charland "Mental Competence and Value: the Problem of Normativity in the Assessment of Decision-making Capacity" (2001) 8 Psychiat Psychol L 135.

<sup>908</sup> Banner, above n 547.

<sup>909</sup> See Chapter 2E Supported decision-making in practice and in English case law.

<sup>910</sup> The survey was a collaboration by the writer with a number of doctors, led by Dr Greg Young, psychiatrist, Capital & Coast DHB. The collaboration involved Dr Crawford Duncan (psychiatrist), Dr Lorraine Davison (psychiatry registrar), Capital & Coast DHB; Dr Ben Gray, (Academic GP, Wellington School of Medicine, University of Otago); and Professor John McMillan (Director of the Bioethics Centre, University of Otago). A pilot survey was carried out at Hawkes Bay DHB in collaboration with Drs Lucy Fergus, Ian Hosford and Elaine Plesner. The survey received ethical approval from the Otago University Human Research Ethics Committee, (D15/213) and the institutional ethics committees of the Hawkes Bay and Capital & Coast DHBs. Statistical advice for the analysis of the survey was provided by Ellen Hewitt.

<sup>911</sup> The Royal College of New Zealand General Practitioners (RCNZGP) circulated the survey on its electronic newsletter, ePulse and it was reported in New Zealand Doctor, "Closer look at GPs tricky job of judging mental capacity", NZ Doctor.co.nz, 16 December 2015 [www.nzdoctor.co.nz/.../2015/.../2015/.../closer-look-taken-at-gps'-tricky-](http://www.nzdoctor.co.nz/.../2015/.../2015/.../closer-look-taken-at-gps'-tricky-)



- 7.40 This was a mixed-methods, cross-sectional survey consisting of four parts, using convenience sampling.<sup>912</sup> Part 1 collected demographic information, including the doctor's seniority, specialty, and frequency of experience with patients who may lack capacity. Part 2 asked doctors about the characteristics of a patient lacking capacity who they had encountered in the past year. Part 3 consisted of 13 questions testing the doctor's knowledge about the principles of capacity assessment. Part 4 asked whether the doctor had received any postgraduate training on capacity assessment, whether they felt confident enough to defend their decisions in court, whether they considered assessing capacity to be within their scope of practice, and how they might like to receive educational material in the future. The final question asked doctors to describe what they considered to be the main difficulties they faced when assessing capacity.
- 7.41 A total of 74 GPs and 153 hospital doctors responded, the majority of whom were medical consultants. In view of the number of doctors invited to participate, the results are of limited generalisability to all New Zealand doctors. However, valuable information was obtained, as the results showed that the doctors responding lacked knowledge regarding capacity assessments. A significant portion of GPs (24.3%) and hospital doctors (30.1%) did not consider capacity assessments to be within their scope of practice. Hospital doctors were sometimes confused as to whose job it was to assess capacity: i.e. whether they should take responsibility for the assessment of their patient or whether to refer them to a specialist, such as a psychiatrist or geriatrician. The median score on the multiple-choice questions in Part 3 was 17/26 for GPs and 18/26 for hospital doctors. Many doctors appeared not to realise that capacity assessment was decision-specific, and many incorrectly believed that a patient's next of kin (without possession of a power of attorney) could give legal consent on that patient's behalf.
- 7.42 The vast majority of respondents had not had any formal training in capacity assessment. Those doctors who had training scored slightly higher than their peers. Doctors gave various reasons why they had difficulty with assessments, including lack of knowledge and confidence, time pressures, and lack of understanding of the relevant law. GPs also identified having to involve patients' families as an area of difficulty. The reasons given were: resulting pressure from relatives for the GP to do a "grey area" assessment; family having "preconceived ideas"; family not understanding end-of-life care issues; family giving conflicting information to that received from the patient; and conflict between relatives.
- 7.43 It is clear that most doctors sampled would benefit from structured, formal training in assessing capacity that would impart both clinical and legal knowledge. The survey showed that medical education in this area is particularly urgent, given that most respondents indicated that greater than 20 percent of their patients were aged 65 years or more, and that they had fairly frequently (6 – 12 times per year) been concerned about a patient's capacity, or had to do a capacity assessment. Many respondents were enthusiastic about the prospect of learning how to better assess capacity, choosing various options for receiving educational material, and provided positive feedback to the authors for undertaking this research.

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<sup>912</sup> The survey was based on work by Ganzini and colleagues that examined a number of misconceptions and uncertainties about capacity assessment in a group of old-age psychiatrists, physicians and psychologists in the United States: L Ganzini, L Volicer, W Nelson and others "Pitfalls in Assessment of Decision-Making Capacity"(2003) 44 *Psychosom* 237.

## A toolkit for assessing capacity

- 7.44 The survey clearly identified the need for professional education of doctors on how to assess capacity and on the legal framework. The authors have therefore developed guidance, in the form of a toolkit, using the results of the survey and their combined experience of teaching how to assess capacity to doctors, medical students and other clinicians.<sup>913</sup> This toolkit was circulated widely in draft among doctors (and some lawyers) and was presented at a workshop attended by mainly hospital doctors and social workers.<sup>914</sup> Detailed written feedback was received from over 30 respondents, including GPs and hospital doctors.
- 7.45 The toolkit is intended to assist doctors and other health practitioners, including psychologists, nurses, occupational therapists (clinicians) and social workers who may be involved in assessing capacity. Guidance or standards for health practitioners need to be clear, appropriate and practically useful to clinicians.<sup>915</sup> A key factor in developing the toolkit has been to ensure it provides the right balance of legal and clinical knowledge for clinicians using it. The toolkit recognises the need for culturally responsive practice when undertaking capacity assessments, especially if the person undergoing the assessment is from a different culture to the clinician. Tikanga Māori has been included by making whakawhanaungatanga, and the process of engagement and establishing connections between people, a platform for supported decision-making.<sup>916</sup> The toolkit is therefore the first step towards providing a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting.
- 7.46 The toolkit for assessing capacity is annexed to this report.<sup>917</sup>

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<sup>913</sup> A Douglass, G Young and J McMillan “A Toolkit for Assessing Capacity” (2016) [www.lawfoundation.org.nz](http://www.lawfoundation.org.nz); Appendix D.

<sup>914</sup> “Elder Law in the Health Sector for Bright Star Training, Capacity assessments of older patients” (Crowne Plaza, Auckland, 24 February 2016). The Royal New Zealand College of General Practitioners (RCNZGPs) circulated the draft toolkit to a special interest group and various doctors were targeted through the network of doctors who supported the project.

<sup>915</sup> L Anderson “Writing a new code of ethics for sports physicians: principles and challenges” (2009) 0 Br J Sports Med 1.

<sup>916</sup> See Chapter 2D The Cultural Dimension. Advice on tikanga Māori was received from Dr Jo Baxter, Associate Dean of Māori, University of Otago.

<sup>917</sup> Douglass, Young and McMillan, above 913, Appendix D.

## RECOMMENDATIONS FOR A NEW ZEALAND CODE OF PRACTICE

The recommendations in relation to a Code of Practice for New Zealand are:

1. Revised incapacity legislation should provide for a Code of Practice to be developed by the government agency responsible for the legislation, in consultation with the health and disability, social development and justice sectors, with enabling provisions in the legislation modelled on those of the MCA.
2. There should be a statutory requirement for public consultation and input by the health and disability, social development and justice sectors, in formulating the Code, and in subsequent reviews, as with the HDC Code.<sup>918</sup>
3. The Code of Practice should provide guidance on the interface between the revised legislation and the notion of capacity or “competence” as used in the statement of Rights in the Code of Health and Disability Services Consumers’ Rights (the HDC Code).
4. The Code of Practice should explain, and make provision for, supported decision-making as a form of best practice, in keeping with the United Nations Convention on the Rights of Persons with Disabilities (CRPD) and tikanga Māori, as identified in this report.
5. An independent statutory body should be given responsibility for implementation of the new legislation and for monitoring implementation of the Code of Practice.
6. That independent body should promote professional education and involvement of the relevant health practitioner registration authorities, Colleges and allied social work organisations, in this task.
7. The development of the Code of Practice should commence concurrently with a review of the PPPR Act, so it can be in place on commencement of revised legislation.

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Health and Disability Commissioner Act 1994, s 21.

# Chapter 8

## **Conclusion – A Checklist for Reform**

## Chapter 8: Conclusion – A Checklist for Reform

Chapter 8 is in four sections:

- A. A summary of the useful provisions in the Mental Capacity Act that could be adopted with some modifications into revised New Zealand legislation.
- B. Major gaps in current New Zealand law that need to be filled.
- C. A Code of Practice to assist with implementation of the law.
- D. Further features of the Mental Capacity Act in the checklist for reform.

### Conclusion

- 8.1 The PPPR Act has provided New Zealand with a progressive model for adult guardianship law underpinned by sound human rights principles. The Act reflects the need to strike a balance between promoting autonomy and providing necessary intervention to safeguard the interests of people with impaired capacity in a range of circumstances. However, the legislation's weakness lies in its unnecessary complexity and lack of clarity about two essential concepts. These are firstly, capacity – the bright legal line determining whether intervention is permitted in people's lives; and secondly, best interests – the standard upon which others should make decisions when a person is unable to make decisions for themselves, taking into account the will and preferences of the person concerned.
- 8.2 Importantly, the PPPR Act lacks an adequate mechanism for oversight of its implementation in keeping with the principles underpinning it. There has never been a public body that champions it and educates the public, and professionals working within the health and disability sector, about it. For the legal framework to have more integrity, a clear and precise law is needed that is accessible to all. Otherwise it runs the risk of being largely ignored, or being considered ineffective in safeguarding and promoting the rights of people with impaired capacity.
- 8.3 This report has identified useful provisions of the Mental Capacity Act 2005 (for England and Wales) that could be adopted, with some changes, into revised New Zealand legislation. The MCA has codified decades of judge-made law, and English case law is relied upon for interpreting our law when it is similar to the MCA. The MCA provides for the specialised jurisdiction of the Court of Protection, which develops corresponding expertise and case law. It also provides for a Code of Practice. This has led to greater transparency (of both the standards and the process) concerning decision-making for people who lack capacity, under a single piece of legislation that has codified much of the common law. English law under the MCA has also embraced the growing role of human rights instruments – such as the European Convention on Human Rights (ECHR) and the United Nations Convention on the Rights for Persons with Disabilities (CRPD) – in developing its principles. New Zealand should draw on this English experience, using these positive features of the MCA in the revision of our law.

- 8.4 The CRPD offers new ways of thinking about capacity, particularly in its emphasis on supported decision-making and recognition of universal legal capacity. New Zealand lags behind comparable jurisdictions in its commitment to implement the CRPD. Much of the international discussion has been on the positive rights in the CRPD, plus access to decision-making support under Article 12(3) for people with impaired capacity for decision-making. There has been less discussion about how to provide the corresponding safeguards concerned, not only in respect for the “rights, will and preferences” of the person, but also safeguards from undue influence and dealing with conflicts of interest, under Article 12(4).<sup>919</sup> A finding of this report is that supported decision-making and substitute decision-making – as currently understood in adult guardianship law – are not mutually exclusive concepts. For a workable law, there is a need for a more integrated approach for these two models of decision-making for them to co-exist.
- 8.5 Implementing the concept of supported decision-making as understood in the CRPD presents challenges as well as opportunities for policy- and law-makers. New Zealand has a history of adding an innovative cultural dimension to its law and policy. We should develop a law that fits our population size, and our social and cultural expectations. There needs to be flexibility in the legal framework to reflect the fact that a wide range of people with impaired capacity and circumstances may be affected by it: people with learning disabilities, older adults with dementia, those with acquired brain injuries, and those whose capacity is affected by mental illness.
- 8.6 The law’s approach to autonomy is often regarded as too individualistic. There is now greater recognition of the importance of relationships, as our autonomy is strongly influenced by our social and cultural context. The positive obligation to recognise support relationships in the CRPD has synergies with tikanga Māori, where values of individual autonomy and collective decision-making work alongside each other.
- 8.7 This report has put forward a number of recommendations for reform of the PPPR Act. These recommendations fall into four categories. Firstly, certain provisions of the MCA are identified that could easily be inserted (with some modifications) into the PPPR Act to give greater integrity to its legal framework and to assist with the interpretation of the HDC Code. Secondly, there are some major gaps identified in New Zealand law that need to be filled. Thirdly, the MCA Code of Practice is commended as an excellent model for implementing mental capacity law from which New Zealand could learn by introducing a similar Code with a statutory imprimatur. Fourthly, other useful aspects of the MCA are identified which this report has not covered in detail due to the scope of this research project but should form part of a wider review of the law.

<sup>919</sup>

A recent report released by the Essex Autonomy Project on legal reform across the UK on the rights of persons with disabilities provides informed discussion on legal reform of mental capacity legislation and the necessary safeguards contemplated by art 12(4) of the CRPD across the three jurisdictions in the UK: W Martin, S Michalowski, J Stavert and others *The Essex Autonomy Project Three Jurisdictions Report: Towards Compliance with the CRPD Art.12 in Capacity Incapacity Legislation Across the UK* (Essex Autonomy Project, University of Essex, 6 June 2016).



## 8A: PROVISIONS OF THE MCA THAT COULD BE INSERTED INTO THE PPPR ACT

8.8 The PPPR Act is in need of review and the HDC Code is silent on the definition of the capacity or “competence” that a person requires to make an informed healthcare decisions. The recommendations below aim to inject more clarity into the key concepts governing decision-making for those with impaired capacity, notably, into the concepts of supported decision-making; capacity itself; and the notion of best interests as a standard governing decision-making for others. These recommendations concern:

- *Supported decision-making – a legal principle, taking into account tikanga Māori.* The CRPD provides an opportunity to enhance and improve New Zealand’s adult guardianship law by giving priority to supported decision-making as a legal principle, including incorporation of tikanga Māori. There is a need for clear statutory guidance about who bears the responsibility, and when, to provide support to people whose decision-making ability is impaired, to enable them to make their own decisions whenever possible.
- *Defining capacity – a single test.* As capacity or incapacity is the “brightline” for deciding whether the law permits intervention in people’s lives, it is essential that there is a clear test for it. There are currently several tests for incapacity in the PPPR Act and no definition of incapacity in the HDC Code for the purposes of determining whether a person can give informed consent or refusal to healthcare. Section 3 of the MCA provides a single legal test, whereby a person lacks capacity if they are unable to make a decision due to an inability to: understand information relevant to the decision, retain that information, use or weigh the information, or communicate the decision. This test is recommended for adoption in New Zealand.
- *Best interests – a standard for decision-making.* The “best interests” standard recognises that where supported decision-making options have been exhausted, decisions by others need to be made. It can provide a transparent basis for decision-making when a person is unable to fully exercise their legal capacity. It is an essential complement to a supported decision-making framework: capacity is not an off-switch to a person’s rights and freedoms. In New Zealand the phrase “best interests” is found in both the PPPR Act and in Right 7(4) of the HDC Code, but it cannot be regarded as a specified legal standard for decision-making of the kind codified in the MCA. Section 4 of the MCA provides a checklist setting out a series of matters that must be considered when best interests decisions are made on behalf of a person by a substitute decision-maker. These include: the person with impaired capacity should participate as much as possible in the process of determining their best interests; their present and past wishes and feelings (or will and preferences) should be recognised; and so should the beliefs and values that would likely have influenced their decisions if they had capacity.

## 8B: MAJOR GAPS IN CURRENT NEW ZEALAND LAW

8.9 The second category of reform concerns major gaps in New Zealand legislation where English law provides models from which New Zealand could learn and adapt into New Zealand law. From a New Zealand perspective, the most significant development in English law has been the realisation that the doctrine of necessity under the common law – the principle that necessary treatment and care can be provided to a person in their best interests – which is

expressed in New Zealand through Right 7(4) of the HDC Code, provides inadequate legal safeguards for people who lack capacity and who are unable to consent or object to their healthcare, their living arrangements, or their participation in research. This report's recommendations for New Zealand law therefore include:

- Liberty safeguards:* Liberty and freedom of movement are values of fundamental importance in our society, yet currently in New Zealand, for some people who lack capacity, there is no legal process governing their loss of liberty. In a broad range of settings, people who lack capacity are detained, and under the continuous supervision and control of those caring for them, and not free to leave. Yet, in many cases – such as where they are not under the authority of the mental health legislation (MH(CAT) Act) or an order made under the PPPR Act – no process is automatically triggered to review the lawfulness or appropriateness of their detention. This is the so-called “Bournewood gap” that has led to major developments in England under the MCA and in the European Court of Human Rights, including the establishment of the “Deprivation of Liberty Safeguards” (DoLS) to fill the gap. In New Zealand, courts (and the Mental Health Review Tribunal) review the position of people detained in psychiatric facilities under the MH(CAT) Act, and some orders for secure residential placement are made under the PPPR Act by the Family Court. In most cases, however, the PPPR Act does not provide an ongoing process for reviewing the detention of people who lack capacity. It is not designed to perform continuing review functions of this kind. Revised legislation should therefore provide what might be called “liberty safeguards”, including: a process to identify, authorise and monitor deprivations of liberty; procedural rules regulating such deprivations of liberty; a code of practice to guide providers and facilities when the safeguards apply; a clear and speedy authorisation process; and the powers and procedures of an independent monitoring body.
- Research on people who lack capacity:* Right 7(4) of the HDC Code, based on the common law doctrine of necessity, is also an inadequate legal basis for allowing participation in research by adults incapable of giving informed consent. Here too the MCA provides a useful legal model upon which New Zealand could base its own statutory protections where none currently exist. Sections 30 – 34 of the MCA provide lawful authority to carry out research on participants who lack capacity, where approved by a research ethics committee, as long as various safeguards are complied with. These safeguards relate both to the characteristics of the research and the participation of individuals in it. Among the numerous protections, the MCA provides that the research must have the potential to benefit the patient without imposing a burden that is disproportionate to that benefit, or be of wider benefit for persons affected by the same or a similar condition, and must impose no more than negligible risk to the patient.

## 8C: IMPLEMENTATION OF THE LAW IN PRACTICE

- 8.10 The MCA Code of Practice has been pivotal in making English law accessible. New Zealand should establish a Code of Practice concurrently with reform of the legislation. New Zealand is too small a country to have everyone “reinventing the wheel” by forming their own standards for best practice; greater-cross sectoral leadership is needed. The English experience shows it is vital that the professionals, as well as informal carers, know what the law is and how to implement it.

- *Code of Practice*: Revised legislation should provide for a Code of Practice to be developed by a government agency responsible for the legislation. The enabling provisions should be based on those in the MCA. The Code should be developed after consultation with the health and disability sector. It should recognise the legal interface with the rights under the HDC Code and give guidance on how supported decision-making can operate in keeping with tikanga Māori.
- *A Toolkit for Assessing Capacity*. The toolkit included in Appendix D is a practical legal and clinical guide to assist health practitioners in carrying out capacity assessments. It is a first step towards providing a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting.

## 8D: FURTHER FEATURES OF THE MENTAL CAPACITY ACT

8.11 In addition, there are a number of areas that have been touched on in this report but require closer scrutiny in a future review of the law.

- *Register for enduring powers of attorney (EPOAs)*: There is no transparent mechanism in New Zealand to ensure oversight of attorneys appointed under an enduring power of attorney (EPOA). The 2007 amendments, which purported to address ongoing problems of misuses and abuse of EPOAs in New Zealand, have failed to provide a solution. A key factor promoting the success of the English model is the fact that there is a national register of enduring powers of attorney (referred to as LPAs), supported by a public agency, with the objective of ensuring more effective supervision of attorneys acting under EPOAs. It is now recognised in the UK that measures under existing mental capacity legislation, such as EPOAs and advance directives, should be utilised for their potential as instruments of support for the exercise of legal agency as contemplated by art 12(3), with accompanying safeguards under art 12(4), of the CRPD.<sup>920</sup> The establishment of a register to facilitate these measures, and associated safeguards that would accompany it, is an essential reform for New Zealand. It could be cost-effective, self-funded, and efficient through the use of an electronic register.
- *Advance directives*: As with EPOAs, advance directives are an important expression of a person's prior autonomy – as they are an advance direction made when a person is still capable, to refuse specified medical treatment for a time in the future when they may lack capacity to consent to or refuse treatment. In New Zealand, there is no mandated form for an advance directive. Right 7(5) of the HDC Code provides: "Every consumer may use an advance directive in accordance with the common law," but it does not tell us what the common law rules are. Under the PPPR Act, there is a confused relationship between EPOAs and advance directives. Where an attorney has been appointed under the PPPR Act, they must consult the person for whom they act. However, the paramount consideration for the attorney in these circumstances is to act in the person's best interests, and the attorney might, on occasion, consider this requires them to act contrary to the person's own prior instructions contained in an advance directive.<sup>921</sup> New Zealand law gives no clear indication as to whose views

<sup>920</sup> Martin, Michalowski, Stavert and others, above n 919.

<sup>921</sup> Protection of Personal and Property Rights Act 1988, s 99A(2). There are limits on the powers of an attorney, (as with welfare guardians under s 18) including preventing the attorney from refusing consent

should prevail. The MCA, in contrast, has a clearly mandated framework for creating valid and applicable advance directives which state the circumstances in which a specified treatment either should, or should not, be carried out.<sup>922</sup> This clarifies the circumstances in which the advance directive is to prevail. These developments could encourage people to make advance directives for when they lose capacity for decision-making for a range of decisions. All advance directives and EPOAs could be included on one electronic register, so they can be readily known.<sup>923</sup>

- *Oversight and monitoring by a public body:* In England, the MCA established the Office of the Public Guardian (OPG). This is an executive agency of the Ministry of Justice. Its aim is to help make sure that adults who lack capacity to make decisions for themselves are protected from abuse. The functions of the Public Guardian fall into three categories: establishing and maintaining a register of LPAs (EPOAs); supervising deputies (welfare guardians or property managers) appointed by the court; and investigations – referred to as “safeguarding referrals”. The Public Guardian’s office can also provide a professional deputy (the equivalent of a welfare guardian) who can be appointed by the Court under the MCA. This kind of arrangement would go some way to assist with the shortage of independent welfare guardians available in New Zealand. Such a public body could also provide oversight of the legislation and its proposed Code of Practice.
- *Independent advocates:* New Zealand currently has no provision for the appointment of an independent advocate for adults with impaired capacity when serious medical treatment decisions need to be made or when they are deprived of their liberty. While there are health and disability advocates, they are largely concerned with complaints under the HDC Code. In England, the MCA has created an independent mental capacity advocate service (IMCA). This service is designed to help vulnerable people who lack the capacity to make such important decisions and who have no family or friends that it would be appropriate to consult. Recent law reform reports in the UK have emphasised that compliance with the CRPD requires that statutory advocacy services should be funded at a level that ensures genuine and effective access to independent advocates by persons with disabilities in any matter that impact upon their ability to exercise legal capacity.<sup>924</sup>

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for standard medical treatment or procedures intended to save that person’s life or prevent serious damage to that person’s health: Protection of Personal and Property Rights Act 1988, s 18(1)(c).

<sup>922</sup>

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Mental Capacity Act, ss 23-26.

The establishment of an electronic “health directive register” for EPOAs and advance directives could also include organ donations. See recent health policy consultation document about the need to increase organ donation in New Zealand. The proposal is that the Ministry of Health should establish a consistent mechanism whereby health professionals around New Zealand can obtain independent assurance that new practices and processes are ethically acceptable: Ministry of Health *Increasing Rates of Deceased Organ Donation: Consultation document*. Ministry of Health, Wellington, June 2016). It is important to note that the Human Tissue Act 2008 would not need to be amended to establish a register. The Act already has enabling provisions to establish regulations for a national organ and tissue donor “opt-on” register: Human Tissue Act, s 78. See A Douglass, “The new Human Tissue Act” (2008) NZMJ 377.

<sup>924</sup>

Martin, Michalowski, Stavert and others, above n 919 at 79; Law Commission interim statement (2016) above n 224.

- 8.12 It is said that the measure of a society is how well the most vulnerable are treated.<sup>925</sup> The PPPR Act is overdue for revision in line with contemporary thinking about the law for protecting and promoting the rights of people with impaired capacity for decision-making. The mental capacity law landscape in New Zealand is fragmented. A review of the law will require a coordinated approach across the social, health and legal policy sectors. It will create the opportunity for New Zealand to show a firm commitment to human rights principles in its construction of capacity as a legal concept, and the chance to develop the law from New Zealand's own cultural perspective. Such reform is urgently needed. It is likely to get full support from those working within the health and disability sector who want to make positive changes that will benefit people with impaired capacity for decision-making.

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<sup>925</sup> Mahatma Ghandi, "A nation's greatness is measured by how it treats its weakest members"; also: Pearl S Buck civil rights/Nobel prize author of "The Good Earth"; James Earl "Jimmy" Carter Jr, former US President; and Pope John Paul II – among others.

# Appendices





# Appendix A

## A Review of Selected PPPR Act Cases

### Introduction

1. This is a review of Family Court (and to a limited extent, High Court) judgments (cases) that directly consider the criteria used to find that a person lacks capacity for the purpose of establishing the Court's jurisdiction to make an order under the Protection of Personal and Property Rights Act 1988 (PPPR Act).<sup>1</sup> It provides an analysis of reported cases dating from 1988, and unreported cases from 2010 to 2015, where jurisdiction was either contested or discussed in the court judgment.<sup>2</sup>
2. The PPPR Act provides no single test for incapacity, which makes it complex legislation to follow and apply.<sup>3</sup> In general terms, the Act says a person lacks capacity if they do not understand the nature or cannot foresee the consequences of decisions, or are unable to communicate them.<sup>4</sup> The extent of incapacity required to appoint a welfare guardian<sup>5</sup> is greater than is needed to make a personal order,<sup>6</sup> a property order,<sup>7</sup> or an administration order.<sup>8</sup> There are separate tests for activating an enduring power of attorney (EPOA), however there is no statutory test for the purpose of making an EPOA.<sup>9</sup>
3. A fundamental principle of the Act is the presumption of competence: a person must be presumed to have capacity unless proved otherwise.<sup>10</sup> Moreover, people are entitled to make imprudent or unwise decisions so long as they have the capacity to do so.<sup>11</sup> The Family Court can only intervene by making an order where a person lacks capacity based on the legal test that is specific to the making of the order.<sup>12</sup> Once jurisdiction has been established, the Court can then determine what intervention, if any, should occur, given the principles of the least restrictive intervention and the need to enable the person to exercise their capacity to the greatest extent possible.<sup>13</sup>

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<sup>1</sup> Research assistance for this review was provided by Jessie Lenagh-Glue.

<sup>2</sup> Some of the PPPR Act cases have already been mentioned or discussed in Chapters 1 and 5 of this report.

<sup>3</sup> Protection of Personal and Property Rights Act 1988, ss 12(5)(b), 18(3), 97A(2) and 98A(2).

<sup>4</sup> Protection of Personal and Property Rights Act 1988, s6 (personal – care and welfare orders).

<sup>5</sup> Protection of Personal and Property Rights Act 1988, ss 6 and 12.

<sup>6</sup> Protection of Personal and Property Rights Act 1988, ss 6 and 10.

<sup>7</sup> Protection of Personal and Property Rights Act 1988, s 25 (2)(b). A further aspect of property orders is that in determining jurisdiction the Court can take into account the degree to which a person may be subject to undue influence: s 25(4).

<sup>8</sup> Protection of Personal and Property Rights Act 1988, s 11.

<sup>9</sup> A presumption of donor competence was introduced in the 2007 amendments to the Protection of Personal and Property Rights Act 1988, s 93B.

<sup>10</sup> Protection of Personal and Property Rights Act 1988, s 5.

<sup>11</sup> Protection of Personal and Property Rights Act 1988, s 8(3).

<sup>12</sup> See Chapter 4 Defining Capacity for an analysis of the different legal tests.

<sup>13</sup> Where jurisdiction is established, the Court also has the power to make recommendations, rather than a personal order, under s 13. See, for example, *TBH v JIB* FAM-2012-054-378, [2013] NZFC 763 (unrep) at [18], where the Court made a recommendation under s 13 with the proviso that should the matter come back before the Court, orders would be made under s 10. Recommendations are non-binding and this section is rarely used.

4. Despite the multiple tests for incapacity in the Act, in only a few cases has the Court explicitly worked through the legal tests to determine whether, and to what extent, a person lacks capacity with respect to a specific decision or decisions. Even when capacity has been carefully considered, rarely has there been a comparison of the relative difference, if any, between what it means to “partly” and “wholly” lack capacity for the purposes of establishing jurisdiction.
5. These cases can be divided into two groups. Firstly, in the early years of the Act, the Court often considered making protective orders for younger people learning disabilities who were being deinstitutionalised. Families or the social services were looking to the Family Court to make orders to help protect these individuals as they transitioned into living in the community.<sup>14</sup> Secondly, the more recent cases are mainly concerned with older adults with dementia where the opposite social phenomena is occurring, that is, the appointment of a welfare guardian is proposed or, property or personal orders are made to protect assets or to decide the living arrangements of the person concerned away from their family home.<sup>15</sup>

## Method

6. The review consists of two parts. Part 1 considers published Family Court and High Court judgments from 1988 through 2015. The keywords “capacity” and “jurisdiction” and “Protection of Personal and Property Rights Act 1988” were entered in the search engines Westlaw NZ and LexisNexis. This yielded 160 results in LexisNexis, and 215 results in Westlaw NZ. Those results were then scanned using the terms “welfare guardian” or “personal order” or “property management” to ascertain which judgments specifically addressed the issue whether jurisdiction was established under the criteria of s 6 of the Act, and also whether the making of an order was the ‘least restrictive intervention’ as required under s 8. This produced 41 cases of interest for this review.
7. Part 2 considers unreported judgments of the Family Court from 2010 to 2015.<sup>16</sup> The Ministry of Justice keeps a database of unreported judgments, the Judicial Decisions Interface (JDI).<sup>17</sup> The JDI was searched using the keywords “PPPR”, “capacity” and “jurisdiction”, and was cross-checked using “family jurisdiction” and “PPPR”. This search yielded 138 cases. Each case was then scanned to see whether the application was for a personal order;<sup>18</sup> appointing a welfare guardian;<sup>19</sup> an order for property management<sup>20</sup> or property administration;<sup>21</sup> or pertained to the making or revocation of an enduring power of attorney,<sup>22</sup> or a court-ordered will.<sup>23</sup> A total of 94 cases matching these criteria were identified. The cases were

<sup>14</sup> *Re E* [1992] 9 FRNZ 393 Judge Inglis; *Re A and Others* [1993] 10 FRNZ 537 Judge Inglis; *Re G (PPPR: Jurisdiction)* [1994] 11 FRNZ 643, Judge Inglis.

<sup>15</sup> Examples include: *Hutt Valley DHB v MJP* (2011) FAM-2011-032-623 Judge Moss; *Re CCKS* [2011] NZFLR 603, Judge Hikaka; *Loli v MWY* FAM-2009-004-001877 Judge Adams; *Auckland DHB v Temples* [2014] NZFC 8932, Judge Druce.

<sup>16</sup> Cases prior to 2010 have not been digitalised and were not able to be scanned.

<sup>17</sup> Personal communication with Zoë Lawton, Research Counsel to the Principal Family Court Judge of New Zealand, 28 October 2015.

<sup>18</sup> Protection of Personal and Property Rights Act 1988, s 10.

<sup>19</sup> Protection of Personal and Property Rights Act 1988, s 12.

<sup>20</sup> Protection of Personal and Property Rights Act 1988, s 31.

<sup>21</sup> Protection of Personal and Property Rights Act 1988, s 11.

<sup>22</sup> Protection of Personal and Property Rights Act 1988, ss 100 – 106.

<sup>23</sup> Protection of Personal and Property Rights Act 1988, s 55.

analysed to identify those in which the issue of capacity was contested and/or subject to a defended hearing.<sup>24</sup> In addition, it was noted whether or not additional expert medical opinion was obtained in relation to capacity.

## Limitations

8. This review is not a comprehensive evaluation of PPPR Act judgments since the Act came into force. The limitations of this review are considerable. Many of the judgments are not in any electronic database, and the criteria for determining which judgments will be published are currently under review.<sup>25</sup>
9. Currently, defended hearing judgments are uploaded to the JDI and each week approximately 10 cases across all Family Court jurisdictions are identified as being of either unique interest to the public, or clearly elucidating the law in a particular area for a lay person. These cases are then anonymised for publication. The decision to upload a case to the database may be on the basis of a recommendation from the judge, or by the individuals working on the JDI. There are 600-700 judgments delivered monthly to the Ministry of Justice, with fewer than five percent published. While the process to check and publish cases is becoming more transparent, many cases do not appear on the electronic database. Thus, there are no complete 'hard data' that can be statistically evaluated.

## Results

### Part 1- reported cases 1988 to 2015

10. Part 1 involved a search of reported cases on the legal databases Westlaw and LexisNexis, which yielded 41 cases from 1988 to 2015, (of which six were High Court decisions), where the issue of jurisdiction for making a court order was explicitly addressed.<sup>26</sup>

### Impact of the early decisions

11. Many of these cases were early decisions of Judge Inglis,<sup>27</sup> which were seminal in clarifying how the different tests of capacity in the Act were to be interpreted, and how they interact with one another. In *Re L*,<sup>28</sup> where there was an application for

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<sup>24</sup> Cases that had already been identified under Part 1 were not analysed further.

<sup>25</sup> Personal communication with Aroha Fletcher (Research Assistant to the Principal Family Court Judge, Ministry of Justice, 1 February 2016).

<sup>26</sup> A list of these cases is presented at the back of this Appendix.

<sup>27</sup> Twelve cases in total: *Re "Joe"* [1990] NZFLR 260; *Re "Tony"* [1990] 5 NZFLR 609; *Re E* [1992] 9 FRNZ 119; *Re K (A protected person)* (1992) 9 FRNZ 119; *Re Carroll (A protected person)* [1992] 9 FRNZ 126; *Re Z* (1992) 9 FRNZ 397; *Re RMS (PPPR)* (1993) 10 FRNZ 387; *Re A and Others* (1993) 10 FRNZ 537; *Re L (PPPR)* (1993) 11 FRNZ 114; *Re G* (1994) NZFLR 445; *Re V (Personal Order: Birth Procedure)* [1997] NZFLR 718; *Re H & H (PPPR)* (1999) 18 FRNZ 297.

<sup>28</sup> *Re L (PPPR)* (1993) 11 FRNZ 114. See also *Re G* (1994) NZFLR 445, where Judge Inglis stated that it is not "necessary to show that the subject is in a vegetable state, completely lacking any power of cognition or rational thought. It is sufficient to show that the subject's capacity to understand the nature and to foresee the consequences of alternatives or options available for choice is so limited by intellectual disability or by mental illness or both that any choice between such alternatives or options which the subject may make cannot responsibly be recognised as effective".

the appointment of joint welfare guardians (L's parents) for a young man with Down Syndrome, Judge Inglis expressed reservations about the wording of the criteria in s 12:<sup>29</sup>

It is of course clear from the medical evidence that, when the full range of decisions relating to personal care and welfare is considered, L is far from "wholly lacking in capacity". However that is a far wider test than the rather *unhappily worded* s 12(2) requires. What the provision requires is a focus on particular respects in which the person concerned lacks capacity, so that a welfare guardian's appointment is required not to manage the person's whole life but only to make up whatever shortfall in capacity there may be. (emphasis added)

12. Judge Inglis' decisions are still applied today. *Re "Tony"*<sup>30</sup> was referred to in *BAH v JFE*,<sup>31</sup> as holding that capacity for appointing an enduring power of attorney was dependent on whether a person understood the nature and consequence of the decision at the time it was made, and that incapacity in one area did not mean incapacity for all decision-making.
13. *In the Matter of A*<sup>32</sup> (where jurisdiction was not contested) is an influential High Court decision of the full bench, and is still cited today as authority for the Court to treat a person's welfare and best interests as the first and paramount consideration in the decision to make a personal or welfare guardianship order.

#### Data on jurisdiction cases

14. Of the 41 jurisdiction cases found in this search, approximately half (19) were made prior to 2000, and only one was a High Court decision.<sup>33</sup> Only six of these 19 decisions were defended hearings where capacity was contested.<sup>34</sup> Jurisdiction was established in 13 decisions.<sup>35</sup> Nine cases were applications for the appointment of a welfare guardian under s 12,<sup>36</sup> and in five of these it was determined that the person wholly lacked capacity, as required for jurisdiction to be established.

<sup>29</sup> *Re L (PPPR)* (1993) 11 FRNZ 114 at 115.

<sup>30</sup> [1990] 5 NZFLR 609.

<sup>31</sup> FAM-2013-091-000549, [2014] NZFC 10178 (unrep) at [24].

<sup>32</sup> *In the Matter of A* [1996] NZFLR 359 (HC), North, Ellis, Doogue JJ.

<sup>33</sup> *In the Matter of A* [1996] NZFLR 359 (HC).

<sup>34</sup> *Re Long* [1988] 5 NZFLR 545; *Re LM (A Protected Person)* (1992) 9 FRNZ 555; *Re E* (1992) 9 FRNZ 119; *Re RMS (PPPR)* (1993) 10 FRNZ 387; *Re G* [1994] NZFLR 445; *Re L (PPPR)* (1994) 11 FRNZ 114.

<sup>35</sup> *Re Long* [1988] 5 NZFLR 545; *Re LM (A Protected Person)* (1992) 9 FRNZ 555; *Re S (Shock Treatment)* [1992] NZFLR 208; *Re Barbara (aka R v C)* (1991) 8 FRNZ 169; *Re K (A protected person)* (1992) 9 FRNZ 119; *Re Carroll (A protected person)* (1992) 9 FRNZ 126; *Re A and others* (1993) 10 FRNZ 537; *Re G* [1994] NZFLR 445; *B v DR* [1994] NZFLR 898; *Re L (PPPR)* (1994) 11 FRNZ 114; *In the Matter of A* [1996] NZFLR 359 (HC); *Re V (Personal Order: Birth Procedure)* [1997] NZFLR 718; *Re H & H (PPPR)* (1999) 18 FRNZ 297.

<sup>36</sup> *Re "Joe"* [1990] NZFLR 260; *Re "Tony"* [1990] 5 NZFLR 609; *Re LM (A Protected Person)* (1992) 9 FRNZ 555; *Re Z* [1993] 10 FRNZ 387; *Re A and others* [1993] 10 FRNZ 537; *Re G* [1994] NZFLR 445; *In the Matter of M* [1994] NZFLR 164; *Re L (PPPR)* (1993) 11 FRNZ 114; *In the Matter of A* [1996] NZFLR 359 (HC).

15. From 2001 to 2015, there were another 10 reported cases under s 12 where jurisdiction was expressly discussed in the judgment.<sup>37</sup> The Court determined that jurisdiction had not been established in two cases.<sup>38</sup> In *FJR v EMR*,<sup>39</sup> there was medical evidence of partial and complete lack of capacity in several areas. The Court held however, that a welfare guardian order was not the only satisfactory way to ensure appropriate decisions would be made regarding the person's care and living arrangements. Instead, a personal order was made under s 10.
16. The Part 1 review also examined whether the judgment considered s 8 and whether the intervention proposed was the least restrictive given the circumstances. This principle was expressly discussed in 27 of the 41 cases, often in conjunction with discussion of the two-step procedure, first establishing that jurisdiction existed under s 6, and only then determining the degree of intervention, if any, required.<sup>40</sup> In *Re S (Shock Treatment)*, the Court held:<sup>41</sup>

... it is clear that the test to be applied is not a 'welfare' or 'best interests' test. Instead the enquiry must be as follows: (a) what is the degree of Mr M's incapacity; (b) having regard to the degree of his incapacity, what is the least restrictive intervention possible; ... (c) what course of action will enable Mr M to exercise such capacity as he has to the greatest extent possible?

## Part 2 – unreported cases from 2010 to 2015

17. Part 2 of this review analysed 138 unreported judgments from the Ministry of Justice database, JDI. Of these, 35 cases were deemed not relevant,<sup>42</sup> and nine cases were judgments that had been reported elsewhere and were included in Part

<sup>37</sup> *Y v X (Mental Health: sterilisation)* [2004] 23 FRNZ 493; *X v Y (Mental health: sterilisation)* [2004] 23 FRNZ 475 (HC) (this was an appeal from Judge Fraser's decision to not make a decision concerning capacity in deciding whether to grant a welfare guardian's request that X be sterilised, as her lack of capacity had already been decided by the decision in 2003 to make a s 12 order. Miller J granted X's appeal, stating that the Court cannot utilise s 12 for the purpose of authorising non-routine treatment under s 18(2) unless it is satisfied that the subject person wholly lacks capacity. He opined that: "The question of capacity to make the decision that is the subject of the application is a threshold question that must be considered in every case"; *Dawson v Keesing* [2004] 23 FRNZ 952 (HC); *KBC v JEC* [2005] 25 FRNZ 505; *Re N* (2006) FAM-2005-019-926; *B v W* (2006) FAM-2005-069-305; *M v H* (2006) FAM-2006-063-52; *FJR v EMR* (2006) FAM-2005-085-716; *DW v JPW* (2009) FAM-2009-092-001787; *Re RVR* (2010) FAM-2007-054-000472; *Re CCCKS* [2011] NZFLR 603.

<sup>38</sup> *DW v JPW* (2009) FAM-2009-092-001787; *Ellery v Hampton* [2014] NZFC 8225 (in this case, an application to extend proceedings had first been filed in 2012 and a report had been ordered in November 2013 to address whether the person met the criteria under the Act to establish jurisdiction. The person refused to engage with the psychiatrist, and there was no evidence that the situation would change).

<sup>39</sup> (2006) FAM-2005-085-716, Judge Mill.

<sup>40</sup> See *Re Barbara* [1991] 8 FRNZ 169; *Re V (Personal Order: Birth Procedure)* [1997] NZFLR 718; *Re H & H (PPPR)* [1999] 18 FRNZ 297; *Public Trust v CMS* (HC) [2008] 27 FRNZ 184; *DW v JPW* (2009) FAM-2009-092-001787.

<sup>41</sup> *Re S (Shock Treatment)* [1992] NZFLR 208 at 213.

<sup>42</sup> Reasons for eliminating cases as not relevant included cases which were final confirmation of interim orders with no detailed reasoning; cases involving legislation other than the PPPR Act; cases where the subject person was deceased and the issue was the propriety of decisions made by attorneys or property managers; or cases where a property manager was requesting guidance from the Court on a specific issue, such as gifting, or an undisputed testamentary disposition.



1. In only one of the remaining 94 cases did the Court make an outright finding that jurisdiction was *not* established.<sup>43</sup>

18. In a further 15 cases the Court either determined that the evidence demonstrated only partial lack of capacity,<sup>44</sup> or the Court directed further evidence was required and ordered a medical report under s 76.<sup>45</sup> In one case, the Court held that although jurisdiction was established, in view of the least restrictive intervention principle, it was not necessary to make a s 11 property administration order.<sup>46</sup>

## Participation in the hearing

19. The PPPR Act clearly states that the person about whom the application is made should be present at any hearing.<sup>47</sup> There is a procedure for excusing them under certain circumstances<sup>48</sup> and the subject person is represented by the court-appointed lawyer. In 15 of the 94 cases, the judge expressly excused the person from participating in the hearing. Of the remaining 79 cases, in only 24 was there evidence that the person actively participated in the hearing.<sup>49</sup>
20. There were 25 cases where the person clearly objected to the orders being made, and a further 10 where it was unclear whether there was an objection or not. In the 14 cases where the person objected, they clearly participated in a defended hearing. In a further nine cases the person objected, but did not participate in the hearing. There were a further two cases where older adults were excused from attendance despite their objection to the orders being made in their absence.<sup>50</sup> In only nine cases did the person participate in the hearing when they were not formally objecting to the application.

<sup>43</sup> *LCA v RJG* (2011) FAM-2010-004-00701 (unrep). This was an application for a property management order under s 25. The Court found that the evidence from both a neuropsychologist and a psychogeriatrician contradicted DHB specialist reports that the subject person had a delusional psychosis and that the subject person had a reasonable overall understanding of financial management. The application was dismissed.

<sup>44</sup> *RCD & DAD v VED* (2009) FAM-2009-024-000061; *CP v VEH* (2011) FAM-2010-021-000185; *VJW v KLM* (2012) FAM-2010-042-000730, [2012] NZFC 3164; *SPH, TJC v MM, BGC & JC* (2013) FAM-2013-004-001295, [2013] NZFC 7913; *SJW v MJW* (2013) FAM-2011-077-000032; *MTL v MTB* (2014) FAM-2014-070-000437, [2014] NZFC 4306 (all unrep). In these 6 cases, the Judge granted either a personal order under s 10, or an administration order (s 11) or property management order(s 25) instead of a s 12 welfare guardianship order.

<sup>45</sup> *KMA v FJR* (2012) FAM-202-019-000851, [2012] NZFC 4358; *JAH v DAP* (2010) FAM-2010-088-000350; *HBP v AGB* FAM-2011-043-000649; *BGM v CPF* (2012) FAM-2012-043-000428, [2012] NZFC 7047; *Public Trust v AVA* (2012) FAM-2005-044-000559, [2012] NZFC 7056; *TJM & EMR v DSP* (2014) FAM-2013-004-001961, [2014] NZFC 2805; *JAH v DAP* (2010) FAM-2010-088-000350; *CMM v RWL* (2014) FAM-2010-043-000891, [2014] NZFC 6520; *TJM & EMR v DSP* (2014) FAM-2013-004-001961 (all unrep).

<sup>46</sup> *GH v RMT* (2011) FAM-2003-043-000502 (unrep).

<sup>47</sup> Protection of Personal and Property Rights Act 1988, s 74(1).

<sup>48</sup> Protection of Personal and Property Rights Act 1988, ss 74(2)-(4).

<sup>49</sup> In six judgments it was unclear whether the person participated in the hearing or not.

<sup>50</sup> In *AJI v LF* [2012] NZFC 9152 (unrep), a welfare guardian was appointed and a personal order granted that the person reside in a secure dementia unit for six months; in *PKM v HJF* [2013] NZFC 8381 (unrep) a welfare guardian and a property manager was appointed.

## Family Court statistics 2006-2007

21. The latest published statistics of Family Court cases cover the period 2006-2007. They show that over 40 percent of the PPPR Act cases were for people over the age of 60, whereas only 17 percent of the general population was in this age bracket.<sup>51</sup> This review of jurisdiction cases reflected the trend of these statistics. Of the 94 cases identified, almost 60 percent (55/94) involved people over 60 years of age. Table A-1 illustrates the types of orders applied for by the age category of the subject person.

**Table A-1**<sup>52</sup>

|            | Welfare Guardian (s 12) | Property Mgmt/Admin (ss 25/11) | Personal Order (s 10) | Validity of EPOA | Court ordered Will (ss 54,55) |
|------------|-------------------------|--------------------------------|-----------------------|------------------|-------------------------------|
| > 60 years | 34                      | 38                             | 11                    | 7                | 6                             |
| < 60 years | 25                      | 20                             | 9                     | 0                | 0                             |
| Unknown    | 1                       | 2                              | 1                     | 0                | 0                             |

22. The majority of applications were for the appointment of a welfare guardian, often accompanied by an application for a property order.<sup>53</sup> Of the 60 welfare guardian applications, 46 were made, with another two granted on an interim basis. In the vast majority of these decisions, reference was made to medical or specialist reports confirming that the person wholly lacked capacity.

## Jurisdiction issues and case examples

23. The key issues which arose regarding jurisdiction in both parts of this review, discussed below, are:
- whether the presumption of capacity has been displaced by the medical and other evidence;
  - the importance of independent medical evidence where capacity is contested;
  - the meaning of “wholly” lacking capacity, regarding s 12 welfare guardian applications;
  - the meaning of “partly” lacking capacity, regarding s 10 personal orders, and whether a distinction between “wholly” and “partly” lack capacity was made; and
  - whether a donor lacked capacity to enter into, or revoke, an Enduring Power of Attorney (EPOA).

<sup>51</sup> Ministry of Justice *Family Court Statistics in New Zealand in 2006 and 2007* (Ministry of Justice, Wellington, 2009) at 57.

<sup>52</sup> The numbers do not reflect the number of judgments, as in many cases there were multiple applications for the same person in a judgment.

<sup>53</sup> Protection of Personal and Property Rights Act 1988, s 25.

#### a) The presumption of capacity not displaced

24. There are few decisions of the Family Court where the person subject to an application directly challenges the Court's jurisdiction to make orders on the basis that they do not meet the incapacity threshold. This review identified 41 cases (30% of the overall total) where the subject person participated in a defended hearing, and another two where the presiding judge spoke with the subject person on an unsworn basis. Of these, there were 19 cases where the subject person objected to the application and gave evidence disputing that the presumption of capacity had been displaced.
25. In *Re RMS*,<sup>54</sup> the question for the court was whether the threshold for making a personal order or a welfare guardian order had been met in the case of an 86-year-old woman suffering from cancer. She was not able to manage her own care and she had been subject to an interim order to live in a rest-home. RMS objected to the order and wanted to return to her own home. Judge Inglis held that RMS was on the "borderline" of jurisdiction, and:<sup>55</sup>

... in her evidence Mrs Smith demonstrated powers of marshalling argument and presentation of her viewpoint superior to that of many witnesses half her age and in normal health. Mrs Smith is far from the stereotype of an elderly rest-home patient well advanced into senility, and indeed she expressed impatience at being obliged to be in the company of such people at Beechworth.

26. In finding that jurisdiction had not been established, Judge Inglis stressed it was important to remember that:<sup>56</sup>

Total or partial lack of capacity ... is not necessarily indicated merely because those decisions appear to others to be decisions which a person in Mrs Smith's circumstances exercising ordinary prudence would not make.

#### b) The importance of independent medical evidence where capacity is contested

27. In *VJM v MH*,<sup>57</sup> there was an application for a personal order under s 10 in respect of MH, who had been admitted to hospital following a fall. There were serious medical concerns about her frailty, her poor nutrition, and the failure of previous attempts to support her in her own home. It had been recommended that MH be discharged to a supported care facility. MH was adamantly opposed to the concept and wished to return to her own home. The DHB, in its application, had filed numerous reports from health professionals, occupational therapists and a social worker. During the hearing, a court-appointed psychiatrist, who had examined Mrs H over two days, opined that MH suffered from early stage dementia which affected her reasoning, insight and judgment, leading to significant functional impairment in

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<sup>54</sup> *Re RMS (PPPR)* (1993) FRNZ 387, Judge Inglis.

<sup>55</sup> *Re RMS (PPPR)* (1993) FRNZ 387, 390.

<sup>56</sup> *Re RMS (PPPR)* (1993) FRNZ 387, 393.

<sup>57</sup> *VJM on behalf of the Hawke's Bay District Health Board v MH* (2011) FAM-2011-041-516, Judge Callinicos (unrep).

matters of personal care.<sup>58</sup> In differentiating between lack of wisdom and lack of competence, the psychiatrist stated:<sup>59</sup>

The point at which the decision becomes one which lacks competence, rather than simply lacks wisdom, is the point at which the person fails to recognise certain things that are generally regarded as factual, for example the issue of what the caregiver is required to do, the incontinence issues, the real risks that may confront her, the inability to differentiate between the risk of something extremely unlikely, for example a UFO attack, and something that is perfectly plausible in an older person such as a fall and failing to manage at home, and the failure to be able to discuss contingency plans or engage in that discussion at all.

28. Having established jurisdiction, the Court made s 10 interim orders specifying that MH enter a rest home, emphasising this was the least restrictive approach available, having regard to MH's frail state of health. Judge Callinicos emphasised the following matters which had been presented in the medical report: the medical assessor was appointed by the Court and therefore neutral; MH was examined on two separate occasions for the report; the diagnosis was of dementia, and provided a medical cause for the incapacity and the reason for its non-reversibility; MH had impaired executive functioning which reduced her insight into the seriousness of the situation, and impaired her ability to consider the possible consequences of her choices, or consider, even hypothetically, the possibility of a future adverse event; plus MH's frail state of health and the serious risk of further decline if the advice of the multidisciplinary team was not followed. Judge Callinicos concluded that MH's rigid refusal to follow the advice given was "the result of a lack of competence rather than a failure to exercise ordinary prudence" as envisaged by the 'caveat' in s 6(3).
29. In this case, the Court tested the evidence provided in the medical report by suggesting a trial situation with fixed contingency arrangements, and permitted a reasonable adjournment to allow counsel to attempt to obtain MH's agreement with the proposal. Despite this, MH did not shift in her "rigid view" and would not accept assistance that she did not believe she required. The Court was satisfied that MH's inability to make reasoned decisions about the arrangements for her discharge from hospital was a "tipping point", and that the Court had jurisdiction as required by s 6 of the PPPR Act.

### c) The legal test of "wholly" lacking capacity

30. In the context of the whole review, there were 82 cases that included an application for the appointment, or the renewal of appointment, of a welfare guardian. Twenty-nine of these cases included a comprehensive discussion of the evidence and whether the person "wholly" lacked capacity, thereby establishing jurisdiction for the Court to make an order.
31. In the early cases, Judge Inglis (and others) examined the issue of how the concept of "wholly" lacking capacity should be interpreted. *Re "Joe"*,<sup>60</sup> concerned an elderly gentleman who had been living in a "state of profound self-neglect" and refusing all support services, but was adamant that he wished to be left alone and believed he

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<sup>58</sup> *VJM v MH*, at [27].

<sup>59</sup> *VJM v MH*, at [32].

<sup>60</sup> *Re "Joe"* [1990] NZFLR 260.

would be ‘hopelessly unhappy’ in a rest home. Judge Inglis directed the matter for a hearing on jurisdiction, noting that there was doubt that Joe *wholly* lacked capacity and, when “the person himself positively wants to be left alone, force-fed help may amount to an act of unkindness, no less devastating to the subject because it is well intentioned”.<sup>61</sup>

32. *Re Z*<sup>62</sup> involved a woman who had capacity to make and communicate decisions, but wholly lacked the capacity to execute them physically due to the lack of cooperation by her caregiver. Judge Inglis found this lack of capacity was “not a shortfall of the kind recognised by the PPPR [Act]” and any such gap in the Act was a matter for Parliament to address. He declined the daughter’s application to be appointed a welfare guardian for her mother.
33. In a more recent case, *BMO v AFM-M and RSO*,<sup>63</sup> the person, R, had suffered a severe head injury in a car accident in 1986, and his previous welfare guardian had died in 2009. Two different parties then applied to be appointed his welfare guardian and property manager. Although R had been subject to a welfare guardian order previously, the Court held that it did not automatically have jurisdiction merely because the incapacity was longstanding and the parties concerned did not dispute the appropriateness of a welfare guardian appointment.<sup>64</sup> Rather, the expert opinions of both a court-appointed neuropsychologist and R’s GP, in addition to the “various medical reports provided over the years”,<sup>65</sup> confirmed that R continued to lack capacity and there was jurisdiction for the Court to make an order.
34. In *WJH v BTH*,<sup>66</sup> the judge preferred the evidence of the applicant regarding his father’s lack of capacity to that of a medical report on file that suggested the subject person (the father) had partial capacity. In this case, the father did not participate in the hearing. After visiting him, the court-appointed lawyer agreed that he “totally” lacked capacity, and there was no suggestion that he objected to the orders being made.<sup>67</sup>
35. Similarly, in *JGB v Guardian Trust*,<sup>68</sup> where the most recent medical opinion suggested that the person’s lack of competence to manage his own affairs in relation to property was “partial but substantial”. The Court held that there was also jurisdiction for the ongoing appointment of the welfare guardian based on the medical evidence – from the first time that an order had been made in 2007, and again in 2009 and 2010 – and “nothing had changed since then”. The lawyer for the applicant stated:<sup>69</sup>

[He] is able to deal with day-to-day matters but in terms of decisions that are necessary for his welfare and being able to communicate and make major decisions in relation to his ongoing care, he is not in a position to do that without the assistance of his welfare guardian.

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<sup>61</sup> *Re “Joe”*, at 261.

<sup>62</sup> *Re Z* (1992) 9 FRNZ 397.

<sup>63</sup> *BMO v AFM-M and RSO* (2011) FAM-2002-088-000973 (unrep).

<sup>64</sup> *BMO v AFM-M and RSO*, at [21].

<sup>65</sup> *BMO v AFM-M and RSO*, at [25].

<sup>66</sup> *WJH v BTH* (2010) FAM-2010-042-000877, (unrep).

<sup>67</sup> *WJH v BTH*, at [4].

<sup>68</sup> *JGB v NZ Guardian Trust Co Ltd & PMB and JDI* (2014) FAM-2005-070-000686, [2015] NZFC 189, (unrep).

<sup>69</sup> *JGB v NZ Guardian Trust Co Ltd and others*, at [6].

36. As noted, for the appointment of a welfare guardian, it is only necessary that the person wholly lacks capacity in respect of “particular aspect or aspects” of decision-making relating to their care and welfare. In some cases, however, the notion that capacity is decision-specific is undermined where the Court appoints a welfare guardian who is, in effect, a global decision-maker in respect of all decisions in relation to the person’s care and welfare. The following two cases are examples of how the concept “wholly” lacking capacity has been very liberally interpreted.
37. In *AK, VT, NT v RJT*,<sup>70</sup> the wife and daughter of a man who had suffered frontal lobe damage in an accident applied to the court to be appointed as joint welfare guardians. The evidence was that when he became upset or angry he was unable to respond in a rational manner and his ability to make sensible and safe decisions disappeared.<sup>71</sup> The Judge concluded that, although in “general terms, [X] does have the capacity to understand the nature and foresee the consequences of his decisions”,<sup>72</sup> when he is subject to loss of control he “wholly lacks capacity”. Thus, the appointment of joint welfare guardians was considered by the Court to be warranted.
38. In *FL v KEL*,<sup>73</sup> the Court appointed KEL’s mother as his welfare guardian. KEL suffered from cerebral palsy, autism and epilepsy. Both his mother (the applicant), and the young man’s GP described him as partially lacking capacity to understand the nature and foresee consequences of decisions pertaining to his care and welfare. The proceedings were adjourned to enable a report from a neuropsychologist to report on the man’s cognitive capacity and prognosis, however no report ensued as there was “no psycho-neurologist (sic) available locally who could undertake the assessment”.<sup>74</sup> The judge spoke with the young man who told him he found decision-making “a bit of a struggle”. On the basis of this conversation, the Court held it had jurisdiction to make a welfare guardian order as “the medical evidence establishes that [X] *partly* lacks the capacity to understand the nature and foresee the consequences of decisions in respect of matters relating to his personal care and welfare”<sup>75</sup> regardless of the fact that there was no objection by KEL to the making of the order, it is hard to reconcile this approach with the legal test in the PPPR Act.

#### **d) The legal test of “partly” lacking capacity**

39. It is not uncommon for s 10 personal orders to be made under the lower threshold of “partly” lacks capacity, where jurisdiction is not established under the higher threshold of “wholly” lacks capacity for the appointment of a welfare guardian.
40. In this review there were nine cases where the application for appointing a welfare guardian was dismissed. No other orders, for example under s 10, were made. In another four cases, where welfare guardian orders were not made under s 12, there was sufficient evidence to establish that the person partly lacked capacity and a

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<sup>70</sup> *AK, VT, NT v RJT* (2011) FAM-2009-090-002264 (unrep).

<sup>71</sup> *AK, VT, NT v RJT*, at [1].

<sup>72</sup> *AK, VT, NT v RJT*, at [2].

<sup>73</sup> *FL v KEL* (2015) FAM-2014-044-000395, [2015] NZFC 2792 (unrep).

<sup>74</sup> *FL v KEL*, at [4].

<sup>75</sup> *FL v KEL*, at [8].



personal order under s 10 could be made. In five cases, the judge adjourned the s 12 application until further medical evidence could be ascertained.

41. In *Dawson v Keesing*,<sup>76</sup> where the applicant sought appointment as a welfare guardian for her mother, aged 86, out of concern that her brother was exerting undue influence and control over their mother. On appeal to the High Court, Heath J upheld the Family Court's decision that the subject person partly lacked capacity to understand the nature and foresee the consequences of decisions about her living arrangements, but did not wholly lack capacity, and therefore could only be subject to a personal order under s 10, not a welfare guardian order.
42. A similar decision was reached in *WK v NK*.<sup>77</sup> This was an application by a mother for appointment as a welfare guardian for her son, NK, aged 23, who had sustained severe head injuries as a young child and had significant intellectual disability with persisting motor impairment, difficulty with his vision, and "display[ed] occasional behavioural concerns".<sup>78</sup> The major concern was about certain financial decisions he had made which benefited a third party to his own detriment. The Court ordered an independent neuropsychological assessment of NK, and heard evidence directly from him. The Court found that the threshold of "wholly" lacking capacity was not reached, however, it had jurisdiction to make an order under s 10.<sup>79</sup>
43. The issue of what constitutes "partly" lacking capacity was discussed in some of these cases, but was only traversed thoroughly in a few cases, including *SJW v MJW*.<sup>80</sup> This was a case where an adoptive father sought a welfare guardian order for his 24 year old son, W, who had been assessed as suffering from foetal alcohol spectrum disorder. The Court had the advantage of an assessment from a psychiatrist and a psychologist, as well as report from a court-appointed clinical psychologist. These reports suggested there was "significant impairment in his overall adaptive functioning",<sup>81</sup> however, W only partially lacked capacity "in relation to matters about financial management, personal safety, relationships, addressing risk issues of substance abuse and offending, and developing realistic future plans".<sup>82</sup> The Court held that while it did not have jurisdiction to make a s 12 welfare guardian order, the threshold was met for personal orders under ss 10 and 11 of the Act. The Judge went on to say:<sup>83</sup>

It is much easier to make this finding than to decide what steps, if any, should be taken in regard to Mr [W] within the Act. Mr [W]'s disinclination to have his father have any control of his life is strong. At the present time Mr [W] calls upon his mother and father to help him out when the circumstances are very difficult. It is possible that the existence of orders may cause Mr [W] to distance himself. ... It is also to be appreciated ... that there can be no practical means to enforce personal orders if they are defied: the power in s 23 to appoint a welfare guardian in the event of non-compliance is not on the face of it very effective (putting aside the very real legal question whether non-compliance can result in such an appointment where, as here, the basic test for appointment is not met).

<sup>76</sup> *Dawson v Keesing* (2004) 23 FRNZ 475, PPR2003-092-2669 (HC), Heath J.  
<sup>77</sup> *WK v NK* (2014) FAM-2012-070-001831, [2014] NZFC 9285 (unrep).  
<sup>78</sup> *WK v NK*, at [1].  
<sup>79</sup> *WK v NK*, at [13].  
<sup>80</sup> *SJW v MJW* (2013) FAM-2011-077-000032, [2013] NZFC 1899 (unrep).  
<sup>81</sup> *SJW v MJW*, at [10].  
<sup>82</sup> *SJW v MJW*, at [11(ii)].  
<sup>83</sup> *SJW v MJW*, at [15].

44. *Hutt Valley DHB v EB*<sup>84</sup> concerned Mrs B, a 79-year-old widow who resided in her own home and had been hospitalised twice in the past year, despite receiving relatively intensive supervision at home. The Court heard evidence from six witnesses as to Mrs B's lack of capacity, which contradicted her own assessment of her ability to care for herself. On the issue of her capacity, the Judge found that:<sup>85</sup>

The real issue over capacity is to be found in what appears to be her inability therefore to appreciate the fact that she has the problems that she does have and the impact that these problems have on her quality of life. That goes to her understanding of the relevant situation and her appreciation of that, and the flow-on consequences for her.

45. The Court held that it had jurisdiction because Mrs B failed to have "the requisite degree of comprehension" and made an interim personal order requiring her to live in a specified care home.

46. In *TG v FPC*,<sup>86</sup> the application was for a property manager and a personal order for a 31-year-old man who suffered from a treatment resistant schizoaffective disorder. In deciding that the Court did have jurisdiction, the Judge said:<sup>87</sup>

When particularly unwell it would be difficult to not find that he wholly lacks that capacity, but as such periods when the Clozapine is at therapeutic levels, which it does not appear to be always, he has some partial capacity. Nevertheless I am satisfied that that partial capacity is very limited, and that he still remains subject to delusions and the particular issues of voices, and a disorder of volition that goes with those voices.

47. The Judge held that, even when "somewhat better managed under mental health treatment", Mr C's capacity to understand the nature and foresee the consequences of decisions is "seriously compromised".<sup>88</sup>

#### **e) Capacity and enduring powers of attorney (EPOAs)**

48. In 2007, Part 9 of the PPPR Act was amended to strengthen the requirements for activating an EPOA when a person becomes "mentally incapable".<sup>89</sup> The presumption of donor competence was also introduced, in line with the rest of the Act. This presumption can be displaced by a certificate from a relevant health practitioner.<sup>90</sup>
49. As part of this review, information was requested from the JDI regarding the new Part 9 provisions, which give the Court increased ability to monitor and review an attorney's powers and revoke both property and care and welfare EPOAs.<sup>91</sup> A search of published databases only revealed two cases that referred to the

<sup>84</sup> *Hutt Valley District Health Board v EB* (2011) FAM-2011-032-000589 (unrep).

<sup>85</sup> *Hutt Valley DHB v EB*, at [22].

<sup>86</sup> *TG v FPC* (2011) FAM-2010-004-002888 (unrep).

<sup>87</sup> *TG v FPC*, at [4]-[5].

<sup>88</sup> *TG v FPC*, at [6].

<sup>89</sup> Protection of Personal and Property Rights Act 1988, ss 93A and 94A.

<sup>90</sup> Protection of Personal and Property Rights Act 1988, s 93B.

<sup>91</sup> Section 102A and widens the scope of people who may make an application to a court for exercise of its jurisdiction under s 102, and gives the Court discretion whether to review any decision of an attorney and make any order it thinks fit.

2007 amendments,<sup>92</sup> and no cases were identified by the JDI. This suggests that there has been little uptake of these increased powers.

50. The review identified eight cases where the issue arose of whether an EPOA had been validly executed or activated. In *Waldron v Public Trust*,<sup>93</sup> Potter J held that under s 102(1)(a) of the PPPR Act, the Family Court has jurisdiction to determine whether an instrument is an EPOA, and whether it has been validly executed and entered into, including whether the donor had mental capacity at the time of its execution.

51. In *Re BRH*,<sup>94</sup> the issue was whether a donor, BAH, lacked capacity at the time she executed an EPOA subsequent to her hospitalisation for a stroke. Although BRH was assessed as being “compos mentis” to appoint an attorney at the time, her medical team “continued to have some concerns regarding her cognitive impairment and discharge home”.<sup>95</sup> In reviewing all the evidence, the Court held that BRH lacked capacity at the time she signed the EPOA and therefore it was not valid:<sup>96</sup>

... although there was no evidence specifically focussed upon the date the powers were signed, there is enough evidence relating to the period before and two months later to indicate that she was in a confused state that would not have allowed her to adequately understand the ramifications of the documents she was signing. Furthermore, the various communications, the manner in which the first set of documents was signed and the re-drafting and signing of a second set of documents could only have lead (sic) to more confusion of an elderly woman in a mentally fragile state.

52. In *BAH v JFE*,<sup>97</sup> the question was whether E’s execution of his EPOAs, appointing his wife attorney for personal care and welfare and for property in 2010 were valid, given Mr E had earlier granted an EPOA for property to his daughters. There was significant conflict between E’s daughters and their stepmother. The Court ordered a report from a psychogeriatrician and there was also evidence from E’s GP and the legal executive who witnessed the 2010 EPOAs. The Court held that the 2010 EPOAs were valid and nothing in the Act prevented the appointment of multiple EPOAs for property. However, due to the conflict between Mrs E and Mr E’s daughters, the least restrictive intervention was to appoint Mrs E as property manager under s 25 of the Act.<sup>98</sup>

## Conclusion

53. This analysis of reported cases dating from 1988, and unreported cases from 2010 to 2015, suggests that extended judicial analysis of whether a person lacks capacity for the purpose of establishing jurisdiction under the PPPR Act has been rare in

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<sup>92</sup> *Carrington v Carrington* [2014] NZHC 869; *Waldron v Public Trust* [2010] NZFLR 277, [2010] 28 FRNZ 403.

<sup>93</sup> *Waldron v Public Trust*, Potter J.

<sup>94</sup> *Re BRH* (2013) FAM-2012-092-000981, [2014] NZFC 10178 (unrep).

<sup>95</sup> *OEH v BAIH, BRH*, at [8].

<sup>96</sup> *OEH v BAIH, BRH*, at [28].

<sup>97</sup> *BAH v JFE* (2014) FAM-2013-091-549, [2014] NZFC 10178, (unrep).

<sup>98</sup> Section 100 of the PPPR Act states where a person who has given an EPOA subsequently becomes subject to a personal order or property order, the order shall be binding on the attorney; and, in the event of any conflict arising between the powers and the duties of the attorney and the terms of the order, the order shall prevail.

practice. This is not to suggest that the Court is not considering the medical and other evidence in capacity assessments when establishing jurisdiction. Rather, the Court's reasoning is not routinely reported as part of the judgment. When judges are concerned that there is insufficient evidence to determine jurisdiction, they sometimes order further medical reports, and the outcome of these cases is often unknown. The role of the court-appointed lawyer is relevant in this respect because many cases may be resolved "on the papers", at judicial or settlement conferences.

54. Of concern, however, is that in some cases the strict criteria of s 12(2) requiring a person to *wholly* lack capacity before a welfare guardian can be appointed, are not always followed. Compared to the early decisions, the Act is now most often used for the appointment of a welfare guardian or a property manager for older adults, many of who have dementia. Personal orders under s 10, with a lower threshold of "partly" lacks capacity, are frequently used to make significant decisions in respect of the living arrangements of people subject to the Act, such as a decision to place a person in a secure residential care facility, sometimes over the person's vehement objections.
55. There have been few cases where a person's capacity (and the jurisdiction of the Court) have been contested by way of a defended hearing<sup>99</sup> and even fewer where the person gives evidence and/or participates in the hearing.<sup>100</sup> The requirement that the person subject to an application should attend the hearing (whether contested or not), unless formally excused under s 76, seems not to be rigorously applied.
56. This review is not a comprehensive evaluation of the PPPR Act but a snapshot on how decisions on jurisdiction are made. As there is little case law in this area, there is a corresponding lack of transparency about how the concept of capacity – so central to the operation of the PPPR Act – is tested or applied. There are few fully reasoned decisions in which a person's capacity is contested or that give careful guidance on the legal tests for capacity or the differences between them.

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<sup>99</sup> See for example, *Re RMS (PPPR)* (1993) FRNZ387, Judge Inglis; *VJM v MH* (2011) FAM-2011-041-516, Judge Callinicos.

<sup>100</sup> Examples of defended hearings on jurisdiction include: *Re H & H (PPPR)* [1999] 18 FRNZ 297 Judge Inglis; *Re CLD* (2010) FAM-2002-044-001729, and *VJM v MH* (2011) FAM-2011-041-516, Judge Callinicos.

## Reported Cases in Part 1 Review

1. *Re Long* [1988] 5 NZFLR 545, Judge von Dadelszen.
2. *Re "Joe"* [1990] NZFLR 260, Judge Inglis.
3. *Re "Tony"* [1990] 5 NZFLR 609, Judge Inglis.
4. *Re LM (A Protected Person)* (1992) 9 FRNZ 555, Judge von Dadelszen.
5. *Re S (Shock Treatment)* [1992] NZFLR 208, Judge Twaddle.
6. *Re Barbara (aka R v C)* (1991) 8 FRNZ 169, Judge Frater.
7. *Re E* (1992) 9 FRNZ 393, Judge Inglis.
8. *Re K (A Protected Person)* (1992) 9 FRNZ 119, Judge Inglis.
9. *Re Carroll (A Protected Person)* (1992) 9 FRNZ 126, Judge Inglis.
10. *Re Z* (1992) 9 FRNZ 397, Judge Inglis.
11. *Re RMS (PPPR)* (1993) 10 FRNZ 387, Judge Inglis.
12. *Re A and Others* (1993) 10 FRNZ 537, Judge Inglis.
13. *Re G* [1994] NZFLR 445, Judge Inglis.
14. *In the Matter of M* [1994] NZFLR 164, Judge Aubin
15. *B v DR* [1994] NZFLR 898, Judge von Dadelszen.
16. *Re L (PPPR)* (1994) 11 FRNZ 114, Judge Inglis.
17. *In the Matter of A* [1996] NZFLR 359 (HC), North, Ellis, Doogue JJ
18. *Re V (Personal Order: Birth Procedure)* [1997] NZFLR 718, Judge Inglis
19. *Re H & H (PPPR)* (1998) 18 FRNZ 297, Judge Inglis
20. *Y v X (Mental Health: Sterilisation)* (2004) 23 FRNZ 493 (FC), Judge Fraser.
21. *X v Y (Mental Health: Sterilisation)* (2004) 23 FRNZ 475 (HC), Miller J.
22. *Dawson v Keesing* (2004) 23 FRNZ 952, Justice Heath.
23. *KBC v JEC* (2005) 25 FRNZ 505, Judge CP Somerville.
24. *Re N* (2006) FAM-2005-019-926, Judge Twaddle.
25. *B v W* (2006) FAM-2005-069-305, Judge O'Donovan.
26. *M v H* (2006) FAM-2006-063-52, Judge Twaddle.
27. *FJR v EMR* (2006) FAM-2005-085-716, Judge Mill.
28. *Nesbit v S* (2008) FAM-2008-004-2320, Judge Burns.
29. *Public Trust v CMS* (2008) 27 FRNZ 184, Judge Keane.
30. *DW v JPW* (2010) FAM-2009-092-001787, Judge Malosi.
31. *SSTD-E v RWELFARE GUARDIANB* (2009) CIV 2008-485-2808; [2009] NZHC 757 (HC), Young J.
32. *Waldron v Public Trust* (2010) 28 FRNZ 403, Potter J.
33. *Re CLD* (2010) FAM-2002-044-001729, Judge Walker.
34. *Re RVR* (2010) FAM-2007-054-000472, Judge CP Somerville.
35. *CCS Disability Action (Wellington) Branch Inc v JCE* (2011) FAM-2009-032-000592, Judge Grace.
36. *Loli v MWY* (2011) FAM-2009-004-001877, Judge Adams
37. *Re CCKS* [2011] NZFLR 603, Judge Hikaka
38. *VJM on behalf of the Hawkes Bay District Health Board v MH* (2011) FAM-2011-041-516, Judge Callinicos.
39. *Hutt Valley District Health Board v MJP* (2011) FAM-201.1-032-623, Judge Moss.
40. *Ellery v Hampton* (2014) NZFC 8255, Judge Geoghegan
41. *Wilson v Wilson* (2014) NZHC 2766; [2015] NZFLR 104 (HC), Brown J.

## Appendix B

### A Review of the Health and Disability Commissioner's Opinions about Capacity

#### Introduction

1. This is a review of the Health and Disability Commissioner (Commissioner) opinions and Human Rights Review Tribunal (HRRT) decisions.<sup>1</sup> It shows that over time, the issue of whether a person (consumer) lacks capacity or is vulnerable due to impaired capacity for decision-making, even where there may already be a decision-maker appointed, has become significantly more relevant in the complaints investigated by the Commissioner.<sup>2</sup> There is a greater emphasis on ensuring that providers of health and disability services (providers) adequately assess capacity, and that they are clear about the legal basis on which substitute decisions are made when a person cannot give informed consent. Substitute decisions are legally valid when they are made by a welfare guardian, an attorney under a properly activated enduring power of attorney (EPOA), or by the provider under Right 7(4) of the Code of Health and Disability Services Consumers' Rights (HDC Code) if an assessment is made that the decision to provide care and treatment is in the person's best interests.
2. When the Commissioner finds a breach of the HDC Code, there are three possible outcomes that may follow: firstly, making recommendations to the provider; secondly, reporting the Commissioner's opinion to other "appropriate persons"; and thirdly, referring the provider to the Director of Proceedings to decide whether to institute disciplinary and/or compensation proceedings in the HRRT.<sup>3</sup>

#### Method

3. This review evaluates opinions of the Commissioner published on the Health and Disability Commissioner's (HDC) website.<sup>4</sup> It covers opinions from 1997 to 2015.<sup>5</sup> These opinions were reviewed to assess whether the Commissioner found the issue of capacity for decision-making relevant to a breach of the HDC Code or an adverse finding. Twenty-eight opinions were analysed in-depth. It is relevant to note that only complaints that result in a formal opinion by the Commissioner are published on the HDC website, and this is, on average, less than 10 percent of complaints actually lodged with the HDC.<sup>6</sup>

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<sup>1</sup> Research assistance for this review was provided by Jessie Lenagh-Glue.

<sup>2</sup> Right 7 of the HDC Code refers to the "competence" to make an informed choice. In this review, the terms "competence" and "capacity" are used interchangeably.

<sup>3</sup> R Paterson "Assessment and Investigation of Complaints" in P Skegg, R Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) 903 at 920. Disciplinary proceedings under the Health Practitioners Disciplinary Tribunal are beyond the scope of this review. For an overview of the procedure see J Manning – Chapter 30 "Professional Discipline of Health Practitioners" in P Skegg, R Paterson (eds) *Health Law in New Zealand* (Thomson Reuters, Wellington, 2015) 927.

<sup>4</sup> [www.hdc.org.nz/decisions--case-notes/commissioner's-decisions](http://www.hdc.org.nz/decisions--case-notes/commissioner's-decisions).

<sup>5</sup> Search terms used were "capacity", "capacity assessment", "decision-making", "incapacity", "welfare guardian", and "EPOA".

<sup>6</sup> S Temelkovski, K Callaghan "Opportunities to learn from medical incidents: a review of published reports from the Health and Disability Commissioner" (2010) 123 NZMJ 18 at 26.



4. In addition, eight decisions of the Human Rights Review Tribunal (HRRT), relating to seven matters, were found for the period 2002 to 2015.<sup>7</sup>
5. While this review does look at a limited number of cases where a person is vulnerable due to impaired capacity, it is not a review of the broader aspects of vulnerable adults – whether they have capacity or not.

## Health and Disability Commissioner complaint process

6. The functions of the Health and Disability Commissioner are set out in the Health and Disability Commissioner Act 1994.<sup>8</sup> The Commissioner acts as the initial recipient of complaints about providers of healthcare and disability services and is required to ensure that each complaint is dealt with appropriately.<sup>9</sup> He is also responsible for investigating, either upon receiving a complaint or upon his own initiative, any action that appears to be a breach of the HDC Code.<sup>10</sup>
7. The Commissioner has the discretion to refer cases to the Director of Proceedings, to consider initiating further action, but this occurs in only a limited number of cases where a breach has been found.<sup>11</sup> Even fewer cases are actually referred for further action, whether to the HRRT, or the Health Practitioners Disciplinary Tribunal (HPDT).<sup>12</sup> This gatekeeping means that the resulting pool of potential cases before the HRRT is very small.<sup>13</sup>
8. Table B1 shows that only a small proportion of complaints made to the Commissioner lead to a formal investigation. On receipt of a complaint, the Commissioner has a range of options to choose from.<sup>14</sup> Where the Commissioner considers more information is necessary to assess the complaint, it will be sought from the complainant, the provider, in-house clinical and nursing advisors, and occasionally external experts. On the basis of this information, the Commissioner can refer the complaint back to the provider or agency;<sup>15</sup> to an advocate;<sup>16</sup> call a conference of the parties concerned for formal mediation;<sup>17</sup> launch a

<sup>7</sup> Human Rights Review Tribunal decisions were found at [www.nzlii.org/nz/cases/NZHRRT/](http://www.nzlii.org/nz/cases/NZHRRT/). *Taikura Trust and Aranui Home and Hospital* had separate decisions delivered by the HRRT, concerning a single set of events.

<sup>8</sup> Health and Disability Commissioner Act 1994, s 14.

<sup>9</sup> Health and Disability Commissioner Act 1994, s 14(da).

<sup>10</sup> Health and Disability Commissioner Act 1994, s 14(e).

<sup>11</sup> Health and Disability Commissioner Act 1994, s 45(2)(f).

<sup>12</sup> A search of Health Practitioners Disciplinary Tribunal proceedings at [www.hpdt.org.nz](http://www.hpdt.org.nz) using the same search terms yielded no obvious cases where the proceedings centred on issues arising from the lack of decision-making capacity of the patient. In *Re Dr Jonathan Graham Wright* (HPDT decision 624/Med12/263P at [27]–[28]) a physician was found guilty of professional misconduct for accepting a donation of \$150,000 from a terminally ill elderly patient. The Tribunal considered whether the patient had mental capacity at the time of the transaction and concluded he did. Similarly, it was concluded that there was no undue influence and the physician did not personally benefit from the transaction (at [29]). While there are potentially other cases that might be relevant to this review, the structure of the Tribunal's website makes access to such information difficult, and was considered beyond the scope of this review.

<sup>13</sup> Letter from Chris Moore (President, New Zealand Law Society) to the Health and Disability Commissioner regarding the review of the HDC Act and Code (17 February 2014). [www.lawsociety.org.nz/data/assets/pdf\\_file/0011/69194/I-MSD-EPAs-5-7-13.pdf](http://www.lawsociety.org.nz/data/assets/pdf_file/0011/69194/I-MSD-EPAs-5-7-13.pdf)

<sup>14</sup> Health and Disability Commissioner Act 1994, s 33.

<sup>15</sup> Health and Disability Commissioner Act 1994, s 34.

<sup>16</sup> Health and Disability Commissioner Act 1994, s 37.

<sup>17</sup> Health and Disability Commissioner Act 1994, s 33(1)(a)(iii). This option is rarely used currently. From 1998 to 2006, mediation was successfully used on average in 20 cases each year, decreasing to 5 on average from 2002 to 2010. Since 2010, it has not been used to resolve a single case. Source:

formal investigation;<sup>18</sup> or take no further action.<sup>19</sup> Once the Commissioner has compiled all the relevant information, a provisional opinion is issued, which both the consumer and the provider may review and respond to. The report is then finalised and the Commissioner may make a recommendation, ranging from the making of a formal apology to specific recommendations on how the provider could improve services.<sup>20</sup>

9. The number of formal investigations undertaken annually has decreased from a high of 748 in 1998 to an average of 57 each year for the past five years.<sup>21</sup> Breaches of the HDC Code were found in about 60% of opinions, although this number has risen slightly in the past three years.

**TABLE B1 – Health and Disability Commissioner complaints, formal investigations and breaches found 1997-2014**

| Year | Complaints laid | Complaints closed | Formal Investigations | Breaches found <sup>1</sup> | Referrals to Director of Proceedings |
|------|-----------------|-------------------|-----------------------|-----------------------------|--------------------------------------|
| 1997 | 1000            | 581               | 335                   | 25 (7%)                     | 2 → 0 ref to CRT                     |
| 1998 | 1102            | 743               | 748                   | 48 (6%)                     | 12 → 0 ref to CRT                    |
| 1999 | 1174            | 1162              | 563                   | 144 (25%)                   | 34 → 2 ref to CRT                    |
| 2000 | 1088            | 1303              | 716                   | 227 (31%)                   | 21 → 0 ref to CRT                    |
| 2001 | 1397            | 1338              | 538                   | 130 (24%)                   | 26 → 8 ref to CRT                    |
| 2002 | 1211            | 1299              | 334                   | 90 (27%)                    | 28 → 2 ref to HRRT                   |
| 2003 | 1159            | 1338              | 345                   | 113 (33%)                   | 27 → 3 ref to HRRT (2 settled)       |
| 2004 | 1142            | 1162              | 178                   | 77 (43%)                    | 18 → 3 ref to HRRT                   |
| 2005 | 1124            | 1158              | 172                   | 71 (41%)                    | 14 → 4 ref to HRRT                   |
| 2006 | 1076            | 1100              | 116                   | 59 (51%)                    | 19 → 8 ref to HRRT (1 settled)       |
| 2007 | 1289            | 1273              | 89                    | 53 (60%)                    | 19 → 5 ref to HRRT (3 settled)       |
| 2008 | 1292            | 1295              | 100                   | 59 (60%)                    | 22 → 4 ref to HRRT                   |
| 2009 | 1360            | 1378              | 109                   | 72 (64%)                    | 22 → 5 ref to HRRT                   |
| 2010 | 1573            | 1524              | 51                    | 2 (1%)                      | 6 → 4 ref to HRRT                    |
| 2011 | 1405            | 1355              | 27                    | 11 (40%)                    | 4 → 3 ref to HRRT                    |
| 2012 | 1564            | 1380              | 44                    | 29 (66%)                    | 8 → 4 ref to HRRT (3 settled)        |
| 2013 | 1619            | 1551              | 60                    | 42 (70%)                    | 16 → 6 ref to HRRT                   |
| 2014 | 1784            | 1901              | 115                   | 79 (68%)                    | 23 → 11 ref to HRRT (10 settled)     |
| 2015 | 1880            | 1910              | 100                   | 70 (70%)                    | 14 → 11 ref to HRRT (7 settled)      |

<sup>1</sup> Percentage of breaches found refers to the percentage of investigations completed in that year, not necessarily a total of all complaints. Source: [www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports?page=1](http://www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports?page=1) Annual Reports 1997-2015.

<sup>18</sup> HDC Annual Reports (1997 to 2014) at [www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports](http://www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports).

<sup>19</sup> Health and Disability Commissioner Act 1994, s 40.

<sup>20</sup> Health and Disability Commissioner Act 1994, s 38.

<sup>21</sup> Health and Disability Commissioner Act 1994, s 45.

HDC Annual Reports (1997 to 2014) at [www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports](http://www.hdc.org.nz/publications/other-publications-from-hdc/annual-reports).

10. Table B2 shows opinions where capacity for decision-making was relevant to a finding of breach of the HDC Code.

**Table B2 – Health and Disability Commissioner opinions where capacity for decision-making was relevant to finding a breach of the HDC Code**

| Case Record | Assess Capacity | EPOA | Welfare Guardians | Informed Consent | Informed Choice | Undue Influence |
|-------------|-----------------|------|-------------------|------------------|-----------------|-----------------|
| 97HDC9172   |                 |      |                   | ✓                | ✓               |                 |
| 97HDC7679   |                 |      |                   |                  | ✓               |                 |
| 02HDC08905  |                 |      |                   |                  |                 |                 |
| 02HDC18190  |                 | ✓    |                   |                  |                 |                 |
| 02HDC15234  |                 | ✓    |                   |                  |                 |                 |
| 04HDC10605  | ✓               |      |                   |                  |                 |                 |
| 05HDC06957  |                 | ✓    |                   |                  | ✓               |                 |
| 06HDC04441  |                 |      | ✓                 |                  |                 |                 |
| 06HDC15791  |                 |      |                   |                  |                 | ✓               |
| 07HDC17744  |                 |      |                   | ✓                |                 |                 |
| 08HDC04291  |                 | ✓    |                   |                  |                 |                 |
| 08HDC20829  |                 |      | ✓                 |                  |                 |                 |
| 08HDC17105  |                 | ✓    |                   | ✓                |                 |                 |
| 08HDC20957  | ✓               |      |                   | ✓                |                 |                 |
| 09HDC01050  |                 | ✓    |                   |                  | ✓               |                 |
| 09HDC01035  |                 | ✓    |                   |                  | ✓               |                 |
| 10HDC01231  |                 | ✓    |                   |                  | ✓               |                 |
| 11HDC00512  | ✓               | ✓    |                   | ✓                | ✓               |                 |
| 11HDC00647  | ✓               |      |                   |                  |                 |                 |
| 11HDC00940  | ✓               | ✓    |                   | ✓                | ✓               |                 |
| 12HDC00630  | ✓               | ✓    |                   | ✓                |                 |                 |
| 12HDC00779  |                 |      |                   | ✓                |                 |                 |
| 12HDC00915  | ✓               | ✓    |                   | ✓                |                 |                 |
| 12HDC01403  | ✓               |      |                   | ✓                |                 |                 |
| 12HDC01420  |                 |      |                   | ✓                |                 |                 |
| 13HDC00538  | ✓               |      |                   | ✓                |                 |                 |
| 13HDC00732  | ✓               |      |                   | ✓                |                 |                 |
| 13HDC01252  | ✓               |      |                   | ✓                | ✓               |                 |

11. The majority of these opinions concerned findings of a breach of Right 4, the right to services of an appropriate standard; and/or Right 6, the right to be fully informed; or Right 7, the right to make an informed choice and give informed consent. Almost half of the cases in

this review concerned breaches of the Code in relation to EPOAs and related to either the process of assessing capacity and/or whether informed consent had been properly obtained. The capacity issues concerned:

- a) assessing capacity, including failure to determine competence or adequately assess competence;
- b) enduring powers of attorney (EPOA), including an EPOA not being properly activated, inadequate communication from the healthcare provider to the attorney, and multiple attorneys for personal health and welfare decision;<sup>22</sup>
- c) welfare guardians, including the welfare guardian not being adequately consulted, and the welfare guardian failing to fulfil their duties;
- d) informed consent (Right 7), including lack of consent, consent given with no legal authority, and Right 7(4) being applicable but not relied upon by the healthcare provider;
- e) informed choice and information disclosure (Right 6), including failure to ensure an informed choice was made and failure to keep the family informed; and
- f) undue influence where the person had impaired capacity and undue influence was exerted.

#### **a) Failure to undertake a capacity assessment**

12. In 11 of the cases reviewed the (lack of) assessment of capacity was directly at issue. In *General Surgeon* (2014),<sup>23</sup> the patient's wife signed a consent form for a surgical procedure.<sup>24</sup> The Commissioner made an adverse comment that:<sup>25</sup>

There was no evidence that Mrs A was Mr A's legal representative, nor is there any clear record of any assessment of Mr A's competence to consent on his own behalf.

13. Similarly, in *Waitemata DHB* (2015)<sup>26</sup> the Commissioner made an adverse comment against the District Health Board (DHB). The patient was an elderly man who had arrived in hospital by ambulance, conscious but confused. Evidence showed that the anaesthesia consent form was signed by one daughter, and the consent to surgery was signed by a second daughter. There was no record of any assessment of capacity to consent, and neither daughter had any legal right to consent on their father's behalf.
14. In both these opinions, the Commissioner observed that, in the circumstances, the relevant health practitioners could have proceeded with treatment in the absence of the consumer being able to consent, if it was in the consumer's best interests, under Right 7(4) of the Code. Concern was expressed about the DHB lacking understanding of the legal requirements for consent where the consumer was incompetent to consent and there was no legally authorised substitute decision maker.<sup>27</sup>

<sup>22</sup> Protection of Personal and Property Rights Act 1988, s 98(2) provides that an EPOA may not appoint more than one individual to be attorneys to act in relation to the donor's personal care and welfare.

<sup>23</sup> *HDC Opinion 13HDC00538 – General Surgeon, A DHB* (20 October 2014).

<sup>24</sup> The Code discusses "consumers" when discussing people receiving services from health practitioners. In this report, "patient" and "consumer" are used interchangeably.

<sup>25</sup> *General Surgeon*, at [54].

<sup>26</sup> *HDC Opinion 13HDC00732 – Waitemata DHB* (26 June 2015) at 18.

<sup>27</sup> *General Surgeon*, at [89].

15. In *Dr C* (2013), a General Practitioner (GP) failed to assess a patient over a ten-year period, even though she knew the woman had Huntington's disease.<sup>28</sup> The patient's psychiatrist had recorded suspected dementia in 1997. Beginning in 2001, Dr C made home visits to Mrs A and was aware of her deteriorating condition, but promised to help her live at home as she was strongly opposed to institutionalisation. Between 2006 and 2010, the GP had contact with Mrs A only on the telephone or through a curtained door. Mrs A became reclusive and refused home help and support, living in circumstances described as "extreme squalor". The Commissioner opined that Dr C had breached Right 4(1) of the Code.<sup>29</sup>

Given the known trajectory of patients with HD and the probability that Mrs A would at some stage lose competence, Dr C's failure to assess Mrs A's competence to make the relevant decision was suboptimal care and unacceptable.

## b) Enduring powers of attorney (EPOAs)

16. In many cases where there has been an issue regarding an EPOA, the focus is on whether it has been properly activated. Section 98(3)(a) of the PPPR Act requires certification by either a relevant health practitioner or the court before the attorney can act in a significant matter relating to the donor's personal care and welfare.
17. A "significant matter" is defined in the legislation as being "a matter that has, or is likely to have, a significant effect on the health, wellbeing, or enjoyment of life of the donor, for example, a permanent change in the donor's residence, entering residential care, or undergoing a major medical procedure".<sup>30</sup> The New Zealand Law Society has highlighted the lack of independent oversight of the medical certification process required to certify a donor's mental incapacity.<sup>31</sup>
18. In *Ross Home and Hospital* (2010), a wife had been appointed as care and welfare attorney under an EPOA for her husband who was in a dementia unit.<sup>32</sup> The Deputy Commissioner opined that the EPOA had not been activated because Mr A's mental incapacity was not certified as required by the PPPR Act. The rest home was found to be in breach of Right 4(1) for failing to ensure that Mr A's condition was assessed and evaluated effectively.
19. In *Killarney Rest Home* (2013),<sup>33</sup> an 81-year old woman with advanced dementia was admitted to a secure dementia unit for short-term respite care. Nurse D advised the Commissioner that she had completed an admission assessment and care plan, although no records were found. The records stated that Mrs A's son-in-law was her attorney under an EPOA, but no copy of the document or evidence of its activation was found in Mrs A's records. The Deputy Commissioner opined that the rest home and the nurse were in breach of Right 4(1) for multiple reasons, including failure to clarify or document an EPOA, and for failing to inform the attorney or family of Mrs A's falls which resulted in her being left

<sup>28</sup> HDC Opinion 11HDC00647 – GP, Dr C (10 June 2013).

<sup>29</sup> GP, Dr C, at [171].

<sup>30</sup> Protection of Personal and Property Rights Act, s 98(6).

<sup>31</sup> Letter from Chris Moore (President, New Zealand Law Society) to Claire Kibblewhite (Ministry of Social Development Office for Senior Citizens) regarding the 2007 Amendments to Enduring Powers of Attorney provisions (5 July 2013).

<sup>32</sup> HDC Opinion 10HDC01231 – *Presbyterian Support Otago (Ross Home and Hospital)* (23 April 2010). See also 12HDC01403 – *Presbyterian Support Central (Operating as Kandahar Home) and RN A* (27 June 2014) where it was opined that although both the rest home and the attorney thought the EPOA was valid, "there is no evidence that Mrs C was certified as incompetent. Accordingly, the EPOA was never activated" (at 23 [152]).

<sup>33</sup> HDC Opinion 11HDC00940 *Killarney Rest Home (2009) Ltd* (28 November 2013).

untreated with a fractured pelvis for five days, despite believing there was a valid EPOA. The matter was referred to the HRRT, which determined that Killarney failed to communicate effectively with Mrs A's family and power of attorney, and there was a breach of Rights 4(1) and 4(2) of the HDC Code.<sup>34</sup>

20. The appointment of multiple attorneys, despite restrictions in the PPR Act limiting an attorney for care and welfare to one individual, can also cause problems.<sup>35</sup> In *Villa Gardens* (2009),<sup>36</sup> an elderly woman with dementia had jointly appointed two of her four daughters as her attorneys under a care and welfare EPOA. One daughter was nominated as first contact, yet all four daughters were involved in making contradictory decisions regarding their mother's care. The Deputy Commissioner opined that there was a breach of Right 4(1) as Villa Gardens had taken "no steps ... to resolve who the attorney was".<sup>37</sup> The care manager should have known that the PPR Act "provides that an EPA (sic) may not appoint more than one person as attorney".<sup>38</sup>
21. There can also be an issue of how to "de-activate" an EPOA after a person has been certified mentally incapable, but subsequently regains capacity for decision-making. In *Canterbury District Health Board* (2013),<sup>39</sup> Mrs A had a complex medical history including suspected dementia. Mrs A's daughter appointed her daughter as her attorney under an EPOA, but it had not been activated in the required manner. When Mrs A was admitted to hospital with a diagnosis of pneumonia, she was delirious and haloperidol was prescribed. The Deputy Commissioner found the DHB was in breach of Right 7(1) as the clinicians should not have administered haloperidol unless they had a legal basis to do so, either through Right 7(4) of the HDC Code or through activation of her EPOA if Mrs A was not competent to consent to its administration due to delirium.<sup>40</sup> The opinion cited a senior DHB clinician as stating that one-third of all patients over 65 years old in an acute clinical setting will present with delirium, which by its very nature is transient and variable.<sup>41</sup> One of the Commissioner's recommendations was for the DHB to provide guidelines on consent in such cases where a patient's ability to consent may fluctuate due to delirium.<sup>42</sup>

### c) Welfare guardians

22. As with EPOAs, the role of welfare guardians is to protect and promote the welfare and best interests of the subject person.<sup>43</sup> Even when families go to considerable trouble to have a welfare guardian appointed, there is no guarantee that the welfare guardian will then be consulted by health care providers.
23. In *Nilsson v Summerset Care Ltd* (2012),<sup>44</sup> Mrs A was a frail, elderly woman with pneumonia discharged from hospital to a Summerset rest home. The hospital discharge summary instructed the caregivers at Summerset to closely monitor Mrs A's fluid intake and hydration. Four days after her admission, Mrs A's daughter and welfare guardian informed the staff

<sup>34</sup> *Director of Proceedings v Killarney Rest Home (2009) Ltd* [2104] NZHRRT 28 (17 June 2014).

<sup>35</sup> Protection of Personal and Property Rights Act 1988, s 98(2).

<sup>36</sup> *HDC Opinion 08HDC17105 – Oceania Care Company (Trading as Villa Gardens)* (26 August 2009). See also *HDC Opinion 11HDC00512 – Fairview Care Ltd* (16 April 2014).

<sup>37</sup> *Villa Gardens*, at 3.

<sup>38</sup> *Villa Gardens*, at 26.

<sup>39</sup> *HDC Opinion 13HDC01252 Canterbury District Health Board* (23 June 2015).

<sup>40</sup> *Canterbury DHB*, at 19 [118].

<sup>41</sup> *Canterbury DHB*, at 17 [108].

<sup>42</sup> *Canterbury DHB*, at 20 [123].

<sup>43</sup> Protection of Personal and Property Rights Act 1988, s 18(3), s 98A(2).

<sup>44</sup> *HDC Opinion 08HDC20829 Summerset Care Ltd, Nurse Manager Ms C* (18 January 2010) at 11-13.



nurse of her mother's deteriorating condition and requested that her mother be seen by a GP, but was told this would not occur for another four days, on the GP's regular weekly visit. Mrs A died two days later. The Commissioner found that Summerset Care Ltd and the nurse manager were in breach of Right 4 for failing to provide services of an appropriate standard, particularly by not obtaining medical intervention in a timely manner; and in breach of Right 6 for failing to consult and inform Mrs A's welfare guardian of her mother's deteriorating condition, or of treatment decisions. Proceedings were issued and settled in the HRRT, including a compensatory sum.<sup>45</sup>

24. *Spectrum Care Trust* (2007),<sup>46</sup> concerned a 45-year old man who had been in care since the age of three and had a welfare guardian since 1995. The Commissioner opined that the caregiver breached Rights 1, 3 and 4 of the Code with regard to his care. The Commissioner commented:<sup>47</sup>

... I am disappointed that Spectrum Care did not seek assistance or support from Mr A's welfare guardian, Mr McEvoy. This shows serious lack of judgement and lack of willingness to work with Mr McEvoy to provide Mr A the best care possible in the circumstances.

25. At times, failure by welfare guardians to adequately fulfil their duties – in conjunction with a care agency's failure to keep them informed – can lead to serious abuse of vulnerable adults. In the case of *Registered Nurse Mr B* (2004),<sup>48</sup> an elderly woman with deteriorating dementia and severely reduced physical mobility was being cared for by a nursing agency in her own home. She had a welfare guardian and two property managers who arranged for the nursing agency to provide two full-time caregivers at all times. Subsequently, staffing levels were reduced as a cost-saving measure. An aged care nursing expert commissioned by the Commissioner to comment on the case stated that:<sup>49</sup>

Mrs A was subjected to a severe form of abuse and neglect .... The court order gave the Welfare Guardian the power to make all decisions on [Mrs A's] behalf and the responsibility to ensure she was cared for at the level required either in her own home or in private hospital or rest home care. Instead [Mrs A's] care was compromised when a decision was made by [the nursing agency], [Mr J] and [Mr I] to reduce the staffing levels below the level she required for her safety and well being. [Mrs A's] nutritional needs were not considered and her dramatic weight loss was not followed up by her welfare guardian, the nursing agency or her GP. On the development of pressure areas, Mrs A received wholly inadequate care....

#### d) Informed consent

26. Capacity is an essential component of informed consent. Many of the opinions that discuss informed consent were concerned with the failure to conduct an adequate assessment of capacity and/or consent being sought from persons not legally entitled to consent.<sup>50</sup> In some circumstances, however, there were more fundamental breaches of the requirement for informed consent.

<sup>45</sup> *Nilsson v Summerset Care Limited* [2012] NZHRRT 25 (16 November 2012).

<sup>46</sup> *HDC Opinion 06HDC04441 Caregiver, Ms C; Caregiver Ms D; Care Coordinator Ms E; Spectrum Care Trust* (16 August 2007).

<sup>47</sup> *Spectrum Care Trust*, at 21.

<sup>48</sup> *HDC Opinion 02HDC08905 Registered Nurse, Mr B* (15 November 2004).

<sup>49</sup> *Registered Nurse Mr B*, at 60.

<sup>50</sup> See Table B2, and a) Failure to undertake a capacity agreement.

27. In *Taikura Trust*,<sup>51</sup> Ms A, a 43-year old woman with a complex history of mental illness and alcohol abuse, was held in a secure dementia unit for almost a year, against her will, without legal authority. Although she had initially been appropriately admitted to hospital, having been assessed as not having the capacity to make decisions relating to her care and welfare, the hospital incorrectly assumed an application for a personal order under the PPPR Act had been obtained from the Court. Despite expressing a wish for a more suitable placement, she was effectively detained for over a year in a situation that was not in accord with her wishes or needs. In the absence of any oversight of a Court order there was no reassessment of the woman's changing capacity over time.
28. Although Right 7(4) was a defence for the initial admission to the hospital, it was not specifically relied upon. The Health and Disability Commissioner found there was a failure to provide Ms A with appropriate care under Right 4. Even if a personal order to place Ms A in the dementia unit of Oak Park had been in place, the health care providers did not take the steps to reassess Ms A's capacity and address the fact that she was inappropriately placed in a dementia unit. The case went to the HRRT where the two Auckland health and disability service providers agreed to pay compensation to the estate of the woman, who had subsequently died after release from her unlawful detention.<sup>52</sup> The Tribunal made declarations that the providers had failed to provide services in a manner that respected her dignity and independence and failed to provide services with reasonable care and skill.
29. In *The Retirement Centre* (2002),<sup>53</sup> the Commissioner opined that Mr A had been admitted to a rest home against his will, without informed consent, and the Centre had accepted his daughter acting as decision-maker for him when she had no valid authority to do so. It was clear that Mr A had capacity to make decisions in his own right. Mr A was taken for a "drive" against his wishes shortly after the death of his second wife and brought to the Centre. The admittance forms were signed by his daughter. Mr A subsequently left the Centre and paid a portion of the fees that were demanded, but refused to pay for further charges added. Mr A's solicitor advised the Centre that Mr A accepted no liability for the sum as he claimed the Centre knew he had been brought there involuntarily.
30. The Retirement Centre was found to have breached Rights 6(2) and 7(1) for failing to obtain informed consent and failure to provide all the relevant information to the appropriate decision-maker. When the Retirement Centre suggested that Mr A should be liable for all costs associated with his stay at the Centre, the Commissioner clarified that relevant information is required to be *voluntarily* disclosed to the consumer.

#### e) Right 6 and information disclosure

31. In some cases, a breach of Right 6, concerning the right to make an informed choice, is associated with a failure to assess whether a patient is competent, with the result that decision-making is entrusted to someone without legal authority. An example is when no assessment is undertaken prior to a provider acting on the apparent authority of an EPOA.

<sup>51</sup> HDC Opinion 08HDC20957 *Auckland District Health Board, Taikura Trust, Aranui Home and Hospital Ltd (Trading as Oak Park Dementia Unit)* (3 November 2010).

<sup>52</sup> *Director of Proceedings v Taikura Trust - Needs Assessment and Service Co-ordination Service* HRRT No. 024/2011 [2012] NZHRRT 3 (22 March 2012) *Director of Proceedings v Aranui Home & Hospital Ltd - Rest Home* HRRT No. 025/2011 [2012] NZHRRT 4 (22 March 2012). Letter from Dr Katie Elkin (Associate Commissioner, HDC) to Alison Douglass regarding this research project (18 August 2014).

<sup>53</sup> HDC Opinion 97HDC9172 *The Retirement Centre, Proprietor of the Retirement Centre* (11 July 2002).

In *Manis Aged Care Ltd* (2015),<sup>54</sup> healthcare staff failed to ensure that a 96-year old man, who had not been assessed for competence, received relevant information regarding his condition. His own GP had prescribed him antibiotics on a Wednesday. Two days later his condition worsened, but he was not considered terminally ill. Over the weekend, nursing staff advised the doctor on call that Mr A was receiving “end of life” care and the doctor prescribed morphine over the phone. The healthcare staff decided to stop administering amoxicillin, and began administering morphine in accord with palliative care, without getting his consent. Mr A died on the Sunday. The Commissioner found that there was a breach of Rights 6(1) and 7(1) for failure to obtain informed consent, and a breach of Right 4(5) for failure to ensure continuity of services.

#### **f) Undue influence and impaired capacity**

32. Adults with impaired capacity for decision-making can be especially susceptible to undue influence. The following two examples demonstrate the breadth of situations where caregivers can exploit vulnerable adults who lack capacity in their care.

33. In *Caregiver H*, disability support worker Mr H was found to have breached Rights 2, 3, and 4(2) with regard to his relationship with an 18-year old client, Mr B, who had been assessed as having the capacity of a “10-year old boy”.<sup>55</sup> Mr B was in an independent flatting situation. Mr H was a caregiver that Mr B knew from church, and believed to be a friend. The caregiver introduced “sexual elements” to games that they would play and failed to maintain professional boundaries in his relationship with Mr B. In his opinion, the Commissioner stated that:<sup>56</sup>

Mr H used the caregiver-client relationship as an opportunity to sexually exploit Mr B. A power imbalance existed between Mr H, as a caregiver, and his client, Mr B. Mr B was in a vulnerable position. ... Mr H took full advantage of Mr B’s vulnerability, knowing of Mr B’s impairment.

34. Proceedings before the HRRT found that the caregiver’s conduct had breached Rights 1, 2, 3 and 4 of the Code and awarded compensatory damages of \$20,000. The Tribunal also agreed that exemplary damages of \$10,000 were appropriate, particularly due to A’s extreme vulnerability and the abuse of Mr B’s trust.<sup>57</sup>

35. In *Director of Proceedings v Nikau* (2010),<sup>58</sup> the complainant, Ms A, had a long history of depression and bipolar affective disorders and received respite care and support from a community health coordinator.<sup>59</sup> The HRRT held that Ms Nikau, a community health coordinator, had “obviously” breached Right 2 of the HDC Code by taking advantage of her position as a caregiver to enrich herself at the Ms A’s expense. Evidence at the hearing established that the complainant had given Ms Nikau money and goods in excess of \$40,000. The Tribunal also found Ms Nikau had breached Right 4(2) of the Code for unethical abuse of the relationship with a client for personal financial gain. The Tribunal awarded compensatory damages of \$50,000, damages for emotional harm of \$30,000, and

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<sup>54</sup> HDC Opinion 12HDC01420 *Manis Aged Care Ltd (Trading as Cameron Courts Rest Home)* (24 June 2015).

<sup>55</sup> HDC Opinion 06HDC15791 *Caregiver Mr H, Disability Service Provider* (24 September 2007).

<sup>56</sup> *Caregiver Mr H*, at 19.

<sup>57</sup> *Director of Proceedings v O'Malley* [2009] NZHRRT 2 (2 February 2009), at [52].

<sup>58</sup> *Director of Proceedings v Nikau* [2010] NZHRRT 26 (14 December 2010).

<sup>59</sup> *Nikau*, at [22].

exemplary damages for “flagrant disregard of the complainant’s rights under the Code” of \$20,000.

## **Summary**

36. This review shows that 28 of the Commissioner’s published opinions since 2009 have concerned a breach of the HDC Code related to a person’s impaired capacity to consent to, or refuse, decisions concerning their healthcare. Over time, the issue of whether a person lacks capacity or has impaired capacity for decision-making is becoming more prevalent in the complaints investigated by the Commissioner. Even where there is a substitute decision-maker appointed, there have been breaches of Rights 6 and 7 of the HDC Code in circumstances where the person is unable to make an informed choice or give informed consent. These breaches have occurred when there has been a failure by the provider to determine or adequately assess capacity, or when there has been a failure to properly activate an EPOA, or to consult with the legally appointed substitute decision-maker.
37. The Commissioner’s opinions and decisions of the HRRT highlight the importance of having systems in place to ensure a person’s capacity is assessed when there are doubts about a person’s capacity to give or refuse consent to care and treatment decisions; that capacity assessments are clearly understood and implemented by all providers involved with a person’s care; and, the importance of attorneys and welfare guardians being involved in the decision-making process.



# Appendix C

## Legislation and International Human Rights Conventions

This Appendix sets out the relevant sections of the mental capacity legislation, the Code of Health and Disability Services Consumers' Rights (the HDC Code) and the international human rights conventions referred to in this report. These are:

- **Mental Capacity Act (England and Wales) 2005 (MCA)**
- **Protection of Personal and Property Rights Act 1988 (PPPR Act)**
- **Code of Health and Disability Services Consumers' Rights Regulation 1996 (HDC Code)**
- **United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD)**
- **European Convention on Human Rights 1950 (ECHR)**

### **Mental Capacity Act (England and Wales) 2005 (MCA)**

#### **PART 1**

#### **PERSONS WHO LACK CAPACITY**

##### *The principles*

#### **1. The principles**

- (1) The following principles apply for the purposes of this Act.
- (2) A person must be assumed to have capacity unless it is established that he lacks capacity.
- (3) A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
- (4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
- (5) An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
- (6) Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.



## **2. People who lack capacity**

- (1) For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.
- (2) It does not matter whether the impairment or disturbance is permanent or temporary.
- (3) A lack of capacity cannot be established merely by reference to—
  - (a) a person's age or appearance, or
  - (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about his capacity.
- (4) In proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.
- (5) No power which a person ("D") may exercise under this Act—
  - (a) in relation to a person who lacks capacity, or
  - (b) where D reasonably thinks that a person lacks capacity, is exercisable in relation to a person under 16.
- (6) Subsection (5) is subject to section 18(3).

## **3. Inability to make decisions**

- (1) For the purposes of section 2, a person is unable to make a decision for himself if he is unable—
  - (a) to understand the information relevant to the decision,
  - (b) to retain that information,
  - (c) to use or weigh that information as part of the process of making the decision, or
  - (d) to communicate his decision (whether by talking, using sign language or any other means).
- (2) A person is not to be regarded as unable to understand the information relevant to a decision if he is able to understand an explanation of it given to him in a way that is appropriate to his circumstances (using simple language, visual aids or any other means).

- (3) The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent him from being regarded as able to make the decision.
- (4) The information relevant to a decision includes information about the reasonably foreseeable consequences of—
  - (a) deciding one way or another, or
  - (b) failing to make the decision.

#### **4. Best interests**

- (1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—
  - (a) the person's age or appearance, or
  - (b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.
- (2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.
- (3) He must consider—
  - (a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and
  - (b) if it appears likely that he will, when that is likely to be.
- (4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.
- (5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.
- (6) He must consider, so far as is reasonably ascertainable—
  - (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
  - (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
  - (c) the other factors that he would be likely to consider if he were able to do so.

- (7) He must take into account, if it is practicable and appropriate to consult them, the views of—
- (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
  - (b) anyone engaged in caring for the person or interested in his welfare,
  - (c) any donee of a lasting power of attorney granted by the person, and
  - (d) any deputy appointed for the person by the court, as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).
- (8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which—
- (a) are exercisable under a lasting power of attorney, or
  - (b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.
- (9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.
- (10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.
- (11) "Relevant circumstances" are those—
- (a) of which the person making the determination is aware, and
  - (b) which it would be reasonable to regard as relevant.

## **Mental Capacity Act 2005 ss 30-34**

### **30 Research**

- (1) Intrusive research carried out on, or in relation to, a person who lacks capacity to consent to it is unlawful unless it is carried out—
  - (a) as part of a research project which is for the time being approved by the appropriate body for the purposes of this Act in accordance with section 31, and
  - (b) in accordance with sections 32 and 33.
- (2) Research is intrusive if it is of a kind that would be unlawful if it was carried out—
  - (a) on or in relation to a person who had capacity to consent to it, but
  - (b) without his consent.
- (3) A clinical trial which is subject to the provisions of clinical trials regulations is not to be treated as research for the purposes of this section.
- (4) “Appropriate body”, in relation to a research project, means the person, committee or other body specified in regulations made by the appropriate authority as the appropriate body in relation to a project of the kind in question.
- (5) “Clinical trials regulations” means
  - (a) the Medicines for Human Use (Clinical Trials) Regulations 2004 (S.I. 2004/1031) and any other regulations replacing those regulations or amending them, and
  - (b) any other regulations relating to clinical trials and designated by the Secretary of State as clinical trials regulations for the purposes of this section.
- (6) In this section, section 32 and section 34, “appropriate authority” means—
  - (a) in relation to the carrying out of research in England, the Secretary of State, and
  - (b) in relation to the carrying out of research in Wales, the National Assembly for Wales.

### **31 Requirements for approval**

- (1) The appropriate body may not approve a research project for the purposes of this Act unless satisfied that the following requirements will be met in relation to research carried out as part of the project on, or in relation to, a person who lacks capacity to consent to taking part in the project (“P”).
- (2) The research must be connected with—

- (a) an impairing condition affecting P, or
  - (b) its treatment.
- (3) “Impairing condition” means a condition which is (or may be) attributable to, or which causes or contributes to (or may cause or contribute to), the impairment of, or disturbance in the functioning of, the mind or brain.
- (4) There must be reasonable grounds for believing that research of comparable effectiveness cannot be carried out if the project has to be confined to, or relate only to, persons who have capacity to consent to taking part in it.
- (5) The research must—
- (a) have the potential to benefit P without imposing on P a burden that is disproportionate to the potential benefit to P, or
  - (b) be intended to provide knowledge of the causes or treatment of, or of the care of persons affected by, the same or a similar condition.
- (6) If the research falls within paragraph (b) of subsection (5) but not within paragraph (a), there must be reasonable grounds for believing—
- (a) that the risk to P from taking part in the project is likely to be negligible, and
  - (b) that anything done to, or in relation to, P will not—
    - (i) interfere with P’s freedom of action or privacy in a significant way, or
    - (ii) be unduly invasive or restrictive.
- (7) There must be reasonable arrangements in place for ensuring that the requirements of sections 32 and 33 will be met.

## **32 Consulting carers etc.**

- (1) This section applies if a person (“R”)—
- (a) is conducting an approved research project, and
  - (b) wishes to carry out research, as part of the project, on or in relation to a person (“P”) who lacks capacity to consent to taking part in the project.
- (2) R must take reasonable steps to identify a person who—
- (a) otherwise than in a professional capacity or for remuneration, is engaged in caring for P or is interested in P’s welfare, and

- (b) is prepared to be consulted by R under this section.
- (3) If R is unable to identify such a person he must, in accordance with guidance issued by the appropriate authority, nominate a person who—
  - (a) is prepared to be consulted by R under this section, but
  - (b) has no connection with the project.
- (4) R must provide the person identified under subsection (2), or nominated under subsection (3), with information about the project and ask him—
  - (a) for advice as to whether P should take part in the project, and
  - (b) what, in his opinion, P's wishes and feelings about taking part in the project would be likely to be if P had capacity in relation to the matter.
- (5) If, at any time, the person consulted advises R that in his opinion P's wishes and feelings would be likely to lead him to decline to take part in the project (or to wish to withdraw from it) if he had capacity in relation to the matter, R must ensure—
  - (a) if P is not already taking part in the project, that he does not take part in it;
  - (b) if P is taking part in the project, that he is withdrawn from it.
- (6) But subsection (5)(b) does not require treatment that P has been receiving as part of the project to be discontinued if R has reasonable grounds for believing that there would be a significant risk to P's health if it were discontinued.
- (7) The fact that a person is the donee of a lasting power of attorney given by P, or is P's deputy, does not prevent him from being the person consulted under this section.
- (8) Subsection (9) applies if treatment is being, or is about to be, provided for P as a matter of urgency and R considers that, having regard to the nature of the research and of the particular circumstances of the case—
  - (a) it is also necessary to take action for the purposes of the research as a matter of urgency, but
  - (b) it is not reasonably practicable to consult under the previous provisions of this section.
- (9) R may take the action if—
  - (a) he has the agreement of a registered medical practitioner who is not involved in the organisation or conduct of the research project, or
  - (b) where it is not reasonably practicable in the time available to obtain that agreement, he acts in accordance with a procedure approved by the appropriate



body at the time when the research project was approved under section 31.

- (10) But R may not continue to act in reliance on subsection (9) if he has reasonable grounds for believing that it is no longer necessary to take the action as a matter of urgency.

### **33 Additional safeguards**

- (1) This section applies in relation to a person who is taking part in an approved research project even though he lacks capacity to consent to taking part.
- (2) Nothing may be done to, or in relation to, him in the course of the research—
  - (a) to which he appears to object (whether by showing signs of resistance or otherwise) except where what is being done is intended to protect him from harm or to reduce or prevent pain or discomfort, or
  - (b) which would be contrary to—
    - (i) an advance decision of his which has effect, or
    - (ii) any other form of statement made by him and not subsequently withdrawn, of which R is aware.
- (3) The interests of the person must be assumed to outweigh those of science and society.
- (4) If he indicates (in any way) that he wishes to be withdrawn from the project he must be withdrawn without delay.
- (5) P must be withdrawn from the project, without delay, if at any time the person conducting the research has reasonable grounds for believing that one or more of the requirements set out in section 31(2) to (7) is no longer met in relation to research being carried out on, or in relation to, P.
- (6) But neither subsection (4) nor subsection (5) requires treatment that P has been receiving as part of the project to be discontinued if R has reasonable grounds for believing that there would be a significant risk to P's health if it were discontinued.

### **34 Loss of capacity during research project**

- (1) This section applies where a person ("P")—
  - (a) has consented to take part in a research project begun before the commencement of section 30, but
  - (b) before the conclusion of the project, loses capacity to consent to continue to take part in it.
- (2) The appropriate authority may by regulations provide that, despite P's loss of capacity, research of a prescribed kind may be carried out on, or in relation to, P if—

- (a) the project satisfies prescribed requirements,
  - (b) any information or material relating to P which is used in the research is of a prescribed description and was obtained before P's loss of capacity, and
  - (c) the person conducting the project takes in relation to P such steps as may be prescribed for the purpose of protecting him.
- (3) The regulations may, in particular,—
  - (a) make provision about when, for the purposes of the regulations, a project is to be treated as having begun;
  - (b) include provision similar to any made by section 31, 32 or 33.

# **Protection of Personal and Property Rights Act 1988 (PPPR Act)**

## **Part 1**

### **Personal Rights**

#### **4. Legal capacity of persons subject to orders under this Act**

Except as provided by or under this Act or any other enactment, the rights, privileges, powers, capacities, duties, and liabilities of any person subject to an order under this Act whether in a personal, official, representative, or fiduciary capacity, shall, for all the purposes of the law of New Zealand (whether substantive, procedural, evidential, or otherwise), be the same as those of any other person.

#### **5. Presumption of competence**

For the purposes of this Part, every person shall be presumed, until the contrary is proved, to have the capacity—

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

#### **6. Jurisdiction of court under this Part**

- (1) Subject to subsection (2), a court shall have jurisdiction under this Part in respect of any person who is ordinarily resident in New Zealand and who—
  - (a) lacks, wholly or partly, the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; or
  - (b) has the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare, but wholly lacks the capacity to communicate decisions in respect of such matters.
- (2) Subject to section 12(3), no court has jurisdiction under this Part in respect of a person who has not attained the age of 18 years and who—
  - (a) is not, and never has been, married or in a civil union; or
  - (b) is 16 years old or older and is not living, and never has lived, with another person as a de facto partner.
- (3) The fact that the person in respect of whom the application is made for the exercise of the court's jurisdiction has made or is intending to make any decision that a person exercising ordinary prudence would not have made or would not make given the same circumstances is not in itself sufficient ground for the exercise of that jurisdiction by the court.

...

## **8. Primary objectives of court in exercise of jurisdiction under this Part**

The primary objectives of a court on an application for the exercise of its jurisdiction under this Part shall be as follows:

- (a) to make the least restrictive intervention possible in the life of the person in respect of whom the application is made, having regard to the degree of that person's incapacity:
- (b) to enable or encourage that person to exercise and develop such capacity as he or she has to the greatest extent possible.

## **9. Course to be followed by court**

- (1) In considering an application for the exercise of its jurisdiction under this Part, a court shall determine whether or not the person in respect of whom the application is made is a person in relation to whom it has jurisdiction under this Part in accordance with section 6.
- (2) If the court is satisfied that the person in respect of whom the application is made is a person in relation to whom it has jurisdiction under this Part in accordance with section 6, the court shall determine whether or not it should make an order under section 10 or section 11 or section 12, and (if so) what kind of order or orders, having regard to the primary objectives specified in section 8.

## **10. Kinds of order**

- (1) On an application for the exercise of a court's jurisdiction under this Part in respect of any person, the court may, subject to subsection (2), make any 1 or more of the following orders:
  - (a) *[Repealed]*
  - (b) an order that any parent of the person make suitable arrangements for the personal care of the person after the parent's death:
  - (c) an order that the arrangements made by any parent of the person for the personal care of the person after the parent's death be observed, or be varied in any particular specified in the order:
  - (d) an order that the person shall enter, attend at, or leave an institution specified in the order, not being a psychiatric hospital or a licensed institution under the Mental Health Act 1969:
  - (e) an order that the person be provided with living arrangements of a kind specified in the order:
  - (f) an order that the person be provided with medical advice or treatment of a kind specified in the order:
  - (g) an order that the person be provided with educational, rehabilitative, therapeutic, or other services of a kind specified in the order:
  - (h) an order that the person shall not leave New Zealand without the permission of the court, or shall leave New Zealand only on conditions specified in the order:

- (i) an order appointing a person named in the order as next friend or guardian ad litem for the person for the purposes of any proceedings in a District Court:
  - (j) an order under section 11 that a person named in the order administer any item of property specified in the order:
  - (k) an order under section 12 appointing a welfare guardian for the person.
- (2) No person (other than the person in respect of whom the application is made) shall be bound by a personal order unless that person is a party to the proceedings in which the order is made.
  - (3) In any order made under any of paragraphs (a) to (i) of subsection (1), the court may specify a date by which the order is to be reviewed by the court; and, if it does so, the court shall also specify in the order the person or persons who is or are to be responsible for applying to the court for a review of the order before the specified date.
  - (4) Where a court makes any personal order, it may also make such other orders and give such directions as may be necessary or expedient to give effect, or better effect, to the personal order.

#### **11. Order to administer property**

- (1) Where, on an application to a court for the exercise of its jurisdiction under this Part,—
  - (a) the person in respect of whom the application is made is not subject to a property order; and
  - (b) the court considers that the making of a property order or the giving of a direction under section 64(3) would not be in accordance with section 8; and
  - (c) the court considers the making of an order under this section necessary in all the circumstances,—

the court may, subject to subsection (2), by order, appoint any person (but only 1 person) named in the order to administer, on behalf of the person in respect of whom the application is made, any property or income or benefit, belonging to the person or to which that person is or may become entitled, and specified in the order.
- (2) No order may be made under this section in respect of either—
  - (a) any item of property that exceeds \$5,000 in value, or such other amount as is, from time to time, prescribed by Order in Council for the purposes of this paragraph; or
  - (b) any income or benefit in excess, in any one year, of \$20,000, or such other amount as is, from time to time, prescribed by Order in Council for the purposes of this paragraph.
- (3) Every person who administers any property, income, or benefit pursuant to an order made under this section shall do so in such a way as to enable or encourage the person for whom he or she is acting to exercise and develop such capacity as that person has to the greatest extent possible.

- (4) In any order made under this section, the court shall specify a date, being not later than 3 years after the date of the order, by which the person appointed to administer the property is required to apply to the court for a review of the order.

## **12. Court may appoint welfare guardian**

- (1) Subject to the succeeding provisions of this section, on an application for the exercise of a court's jurisdiction under this Part, the court may make an order appointing a welfare guardian for the person in respect of whom the application is made in relation to such aspect or aspects of the personal care and welfare of that person as the court specifies in the order.
- (2) A court shall not make an order under subsection (1) unless it is satisfied—
  - (a) that the person in respect of whom the application is made wholly lacks the capacity to make or to communicate decisions relating to any particular aspect or particular aspects of the personal care and welfare of that person; and
  - (b) that the appointment of a welfare guardian is the only satisfactory way to ensure that appropriate decisions are made relating to that particular aspect or those particular aspects of the personal care and welfare of that person.
- (3) A court may make an order under subsection (1) in respect of a person of the kind referred to in section 6(2) if, but only if,—
  - (a) no parent or guardian of that person is then living; or
  - (b) no parent or guardian of that person is in regular contact with that person, and the court is satisfied in all the circumstances that it would be in the interests of that person to appoint a welfare guardian for that person.
- (4) No person under the age of 20 years, and no body corporate, shall be appointed a welfare guardian under this section.
- (5) A court shall not appoint any person as a welfare guardian under this section unless it is satisfied—
  - (a) that the proposed appointee is capable of carrying out the duties of a welfare guardian in a satisfactory manner, having regard to the needs of the person in respect of whom the application is made, and the relationship between that person and the proposed appointee; and
  - (b) that the proposed appointee will act in the best interests of the person in respect of whom the application is made; and
  - (c) there is unlikely to be any conflict between the interests of the proposed appointee and those of the person in respect of whom the application is made; and
  - (d) the proposed appointee consents to the appointment.
- (6) The court shall not appoint more than 1 welfare guardian for any person unless, in the exceptional circumstances of the case, the court is satisfied that it would be in the interests of that person to do so.



- (7) So far as is practicable in the circumstances, a court shall ascertain the wishes of the person in respect of whom the application is made when determining whom to appoint as welfare guardian under this section.
- (8) In any order under this section, the court shall specify a date, being not later than 3 years after the date of the order, by which the welfare guardian is required to apply to the court for a review of the order.

...

## **Part 2**

### **Welfare Guardians**

#### **18. Powers and duties of welfare guardian**

- (1) No court shall empower a welfare guardian, and no welfare guardian shall have power,—
  - (a) to make any decision relating to the entering into marriage or civil union by the person for whom the welfare guardian is acting, or to the dissolution of that person's marriage or civil union; or
  - (b) to make any decision relating to the adoption of any child of that person; or
  - (c) to refuse consent to the administering to that person of any standard medical treatment or procedure intended to save that person's life or to prevent serious damage to that person's health; or
  - (d) to consent to the administering to that person of electroconvulsive treatment; or
  - (e) to consent to the performance on that person of any surgery or other treatment designed to destroy any part of the brain or any brain function for the purpose of changing that person's behaviour; or
  - (f) to consent to that person's taking part in any medical experiment other than one to be conducted for the purpose of saving that person's life or of preventing serious damage to that person's health.
- (2) Subject to subsection (1), a welfare guardian shall have all such powers as may be reasonably required to enable the welfare guardian to make and implement decisions for the person for whom the welfare guardian is acting in respect of each aspect specified by the court in the order by which the appointment of the welfare guardian is made.
- (3) In exercising those powers, the first and paramount consideration of a welfare guardian shall be the promotion and protection of the welfare and best interests of the person for whom the welfare guardian is acting, while seeking at all times to encourage that person to develop and exercise such capacity as that person has to understand the nature and foresee the consequences of decisions relating to the personal care and welfare of that person, and to communicate such decisions.
- (4) Without limiting the generality of subsection (3), a welfare guardian shall—
  - (a) encourage the person for whom the welfare guardian is acting to act on his or her own behalf to the greatest extent possible; and

- (b) seek to facilitate the integration of the person for whom the welfare guardian is acting into the community to the greatest extent possible; and
- (c) consult, so far as may be practicable,—
  - (i) the person for whom the welfare guardian is acting; and
  - (ii) such other persons, as are, in the opinion of the welfare guardian, interested in the welfare of the person and competent to advise the welfare guardian in relation to the personal care and welfare of that person; and
  - (iii) a representative of any group that is engaged, otherwise than for commercial gain, in the provision of services and facilities for the welfare of persons in respect of whom the court has jurisdiction in accordance with section 6, and that, in the opinion of the welfare guardian, is interested in the welfare of the person and competent to advise the welfare guardian in relation to the personal care and welfare of that person.
- (5) In addition to subsection (4)(c), where the person for whom the welfare guardian is acting is subject to a property order, the welfare guardian shall consult on a regular basis with the manager of that person's property to ensure that the interests of that person are not prejudiced through any breakdown in communication between the welfare guardian and the manager.
- (6) A welfare guardian may apply to a court for directions relating to the exercise of the powers of the welfare guardian, and the court may give such directions as it thinks fit.

...

### **Part 3**

#### **Property rights**

#### **24. Presumption of competence**

For the purposes of this Part, every person shall be presumed, until the contrary is proved, to be competent to manage his or her own affairs in relation to his or her property.

#### **25. Jurisdiction of court under this Part**

- (1) A court shall have jurisdiction under this Part in respect of any property owned by any person—
  - (a) who is domiciled or is ordinarily resident in New Zealand; and
  - (b) who, in the opinion of the court, lacks wholly or partly the competence to manage his or her own affairs in relation to his or her property.
- (2) A court shall also have jurisdiction under this Part in respect of any property situated in New Zealand and owned by any person—

- (a) who is not domiciled nor is ordinarily resident in New Zealand; and
  - (b) who, in the opinion of the court, lacks wholly or partly the competence to manage his or her own affairs in relation to his or her property so situated.
- (3) The fact that the person in respect of whom an application is made for the exercise of the court's jurisdiction is managing or is intending to manage his or her own affairs in relation to his or her property in a manner that a person of ordinary prudence would not adopt given the same circumstances is not in itself sufficient ground for the exercise of that jurisdiction by the court.
- (4) In determining whether or not it should exercise its jurisdiction under this Part in relation to any person, a court may have regard to the degree to which the person is subject, or is liable to be subjected, to undue influence in the management of his or her own affairs in relation to his or her property.

...

## **28. Primary objectives of court in exercise of jurisdiction under this Part**

The primary objectives of a court on an application for the exercise of its jurisdiction under this Part shall be as follows:

- (a) to make the least restrictive intervention possible in the management of the affairs of the person in respect of whom the application is made in relation to his or her property, having regard to the degree of that person's lack of competence:
- (b) to enable or encourage that person to exercise and develop such competence as he or she has to manage his or her own affairs in relation to his or her property to the greatest extent possible.

...

## **Part 9**

### **Enduring powers of attorney**

#### **93A. Purpose of this Part**

- (1) The purpose of this Part is to enable a person (the donor) to—
- (a) grant to another person an enduring power of attorney to act in relation to the donor's personal care and welfare if the donor becomes mentally incapable:
  - (b) grant to another person or persons enduring powers of attorney to act in relation to the donor's property affairs—
    - (i) if the donor becomes mentally incapable; or
    - (ii) while the donor is mentally capable and if the donor becomes mentally incapable:
  - (c) grant to another person an enduring power of attorney to act in both capacities.

- (2) Accordingly, this Part—
- (a) states the requirements for creating an enduring power of attorney:
  - (b) defines when a donor is mentally incapable for the purposes of this Part:
  - (c) states the duties of an attorney (in addition to those set out in the enduring power of attorney):
  - (d) sets out the court's jurisdiction in respect of an enduring power of attorney:
  - (e) provides for the review by the court of any decision of an attorney:
  - (f) establishes the circumstances in which an enduring power of attorney may be suspended or revoked.
- ...

### **93B. Presumption of competence**

- (1) For the purposes of this Part, every person is presumed, until the contrary is shown,—
- (a) to be competent to manage his or her own affairs in relation to his or her property:
  - (b) to have the capacity—
    - (i) to understand the nature of decisions about matters relating to his or her personal care and welfare; and
    - (ii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; and
    - (iii) to communicate decisions about those matters.
- (2) A person must not be presumed to lack the competence described in subsection (1)(a) just because the person manages or intends to manage his or her own affairs in relation to his or her property in a manner that a person exercising ordinary prudence would not adopt in the same circumstances.
- (3) A person must not be presumed to lack the capacity described in subsection (1)(b) just because the person makes or intends to make a decision in relation to his or her personal care and welfare that a person exercising ordinary prudence would not make in the same circumstances.
- (4) A person must not be presumed to lack the competence described in subsection (1)(a) or, as the case may be, the capacity described in subsection (1)(b), just because the person is subject to compulsory treatment or has special patient status under the Mental Health (Compulsory Assessment and Treatment) Act 1992.

...

## 94. Interpretation

- (1) For the purposes of this Part, the donor of an enduring power of attorney is mentally incapable in relation to property if the donor is not wholly competent to manage his or her own affairs in relation to his or her property.
- (2) For the purposes of this Part, the donor of an enduring power of attorney is mentally incapable in relation to personal care and welfare if the donor—
  - (a) lacks the capacity—
    - (i) to make a decision about a matter relating to his or her personal care and welfare; or
    - (ii) to understand the nature of decisions about matters relating to his or her personal care and welfare; or
    - (iii) to foresee the consequences of decisions about matters relating to his or her personal care and welfare or of any failure to make such decisions; or
  - (b) lacks the capacity to communicate decisions about matters relating to his or her personal care and welfare.
- (3) Nothing in subsection (1) or (2) affects any rule of law relating to capacity to give or to revoke a power of attorney.
- (4) In this Part—
  - health practitioner—
    - (a) has the meaning given to it by section 5(1) of the Health Practitioners Competence Assurance Act 2003:
    - (b) in the case of a certificate of mental incapacity issued outside New Zealand, means a person registered as a medical practitioner by the competent authority of the State concerned
  - relevant health practitioner means a health practitioner—
    - (a) whose scope of practice includes the assessment of a person's mental capacity; or
    - (b) whose scope of practice—
      - (i) includes the assessment of a person's mental capacity; and
      - (ii) is specified in the enduring power of attorney (for example, a specialist).

...

**98. Enduring power of attorney in relation to personal care and welfare**

- (1) Subject to subsections (3) and (4), a donor of an enduring power of attorney may authorise the attorney to act in relation to the donor's personal care and welfare, either generally or in relation to specific matters, and in either case such authorisation may be given subject to conditions and restrictions.
- (2) Notwithstanding section 95(3), an enduring power of attorney may not appoint a trustee corporation to be an attorney, nor may it appoint more than 1 individual to be attorneys, to act in relation to the donor's personal care and welfare.
- (3) The attorney—
  - (a) must not act in respect of a significant matter relating to the donor's personal care and welfare unless a relevant health practitioner has certified, or the court has determined, that the donor is mentally incapable; and
  - (b) must not act in respect of any other matter relating to the donor's personal care and welfare unless the attorney believes on reasonable grounds that the donor is mentally incapable.
- (3A) For the purposes of subsection (3), a donor's mental capacity is determined—
  - (a) at the time a decision about the matter relating to the donor's personal care and welfare is being made or is proposed to be made; and
  - (b) in relation to the personal care and welfare matter concerned.
- (3B) Despite subsection (3A),—
  - (a) if the donor is certified as mentally incapable because of a health condition that is likely to continue indefinitely, no further certificates are required under subsection (3)(a) in relation to any further personal care and welfare matters:
  - (b) if the donor is certified as mentally incapable because of a health condition that is likely to continue for a period specified in the certificate, no further certificates are required under subsection (3)(a) in relation to any further personal care and welfare matters that arise during the specified period.
- (4) The attorney shall not act in respect of any matter relating to the donor's personal care and welfare where, if the attorney were the welfare guardian of the donor, the attorney would be denied the power to act by section 18.
- (5) Subject to subsections (3) and (4), any action taken by the attorney in relation to the donor's personal care and welfare shall have the same effect as it would have had if it had been taken by the donor and the donor had had full capacity to take it.
- (6) In subsection (3)(a), a significant matter relating to the donor's personal care and welfare means a matter that has, or is likely to have, a significant effect on the health, well-being, or enjoyment of life of the donor (for example, a permanent change in the donor's residence, entering residential care, or undergoing a major medical procedure).



#### **98A. Exercise of enduring power of attorney in relation to personal care and welfare**

- (1) This section applies to an attorney acting under an enduring power of attorney in relation to the donor's personal care and welfare.
- (2) The paramount consideration of the attorney is the promotion and protection of the welfare and best interests of the donor, while seeking at all times to encourage the donor to develop and exercise his or her capacity to—
  - (a) understand the nature and foresee the consequences of decisions relating to his or her personal care and welfare; and
  - (b) communicate such decisions.
- (3) Without limiting the generality of subsection (2), the attorney must—
  - (a) encourage the donor to act on his or her own behalf to the greatest extent possible; and
  - (b) seek to facilitate the integration of the donor into the community to the greatest extent possible.
- (5) When deciding any matter relating to the donor's personal care and welfare, the attorney must give due consideration to the financial implications of that decision in respect of the donor's property.

...

#### **99D. Medical certification of incapacity**

- (1) A certificate of the donor's mental incapacity under this Part must be—
  - (a) in the prescribed form; or
  - (b) if the certificate is issued outside New Zealand, in a form acceptable to the competent authority of the State concerned.
- (2) The donor may specify in an enduring power of attorney that the assessment of his or her mental capacity for the purposes of this Part be undertaken by a health practitioner with a specified scope of practice, but only if the scope of practice specified includes the assessment of a person's mental capacity.
- (3) The cost of any medical assessment or examination reasonably required for the purpose of certifying whether the donor is mentally incapable under this Part is recoverable as a debt from the donor's property.

## **Code of Health and Disability Services Consumers' Rights Regulation 1996**

### **(HDC Code)**

#### **RIGHT 5**

##### ***Right to Effective Communication***

- 1) Every consumer has the right to effective communication in a form, language, and manner that enables the consumer to understand the information provided. Where necessary and reasonably practicable, this includes the right to a competent interpreter.
- 2) Every consumer has the right to an environment that enables both consumer and provider to communicate openly, honestly, and effectively.

#### **RIGHT 6**

##### ***Right to be Fully Informed***

- 1) Every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, would expect to receive, including -
  - a) An explanation of his or her condition; and
  - b) An explanation of the options available, including an assessment of the expected risks, side effects, benefits, and costs of each option; and
  - c) Advice of the estimated time within which the services will be provided; and
  - d) Notification of any proposed participation in teaching or research, including whether the research requires and has received ethical approval; and
  - e) Any other information required by legal, professional, ethical, and other relevant standards; and
  - f) The results of tests; and
  - g) The results of procedures.
- 2) Before making a choice or giving consent, every consumer has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent.
- 3) Every consumer has the right to honest and accurate answers to questions relating to services, including questions about -
  - a) The identity and qualifications of the provider; and
  - b) The recommendation of the provider; and
  - c) How to obtain an opinion from another provider; and

- d) The results of research.
- 4) Every consumer has the right to receive, on request, a written summary of information provided.

## **RIGHT 7**

### ***Right to Make an Informed Choice and Give Informed Consent***

- 1) Services may be provided to a consumer only if that consumer makes an informed choice and gives informed consent, except where any enactment, or the common law, or any other provision of this Code provides otherwise.
- 2) Every consumer must be presumed competent to make an informed choice and give informed consent, unless there are reasonable grounds for believing that the consumer is not competent.
- 3) Where a consumer has diminished competence, that consumer retains the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.
- 4) Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where -
  - a) It is in the best interests of the consumer; and
  - b) Reasonable steps have been taken to ascertain the views of the consumer; and
  - c) Either, -
    - i) If the consumer's views have been ascertained, and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services is consistent with the informed choice the consumer would make if he or she were competent; or
    - ii) If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider.
- 5) Every consumer may use an advance directive in accordance with the common law.
- 6) Where informed consent to a health care procedure is required, it must be in writing if -
  - a) The consumer is to participate in any research; or
  - b) The procedure is experimental; or
  - c) The consumer will be under general anaesthetic; or
  - d) There is a significant risk of adverse effects on the consumer.
- 7) Every consumer has the right to refuse services and to withdraw consent to services.

- 8) Every consumer has the right to express a preference as to who will provide services and have that preference met where practicable.
- 9) Every consumer has the right to make a decision about the return or disposal of any body parts or bodily substances removed or obtained in the course of a health care procedure.
- 10) No body part or bodily substance removed or obtained in the course of a health care procedure may be stored, preserved, or used otherwise than
  - a) with the informed consent of the consumer; or
  - b) For the purposes of research that has received the approval of an ethics committee; or
  - c) For the purposes of 1 or more of the following activities, being activities that are each undertaken to assure or improve the quality of services:
    - i) a professionally recognised quality assurance programme:
    - ii) an external audit of services:
    - iii) an external evaluation of services.

## **United Nations Conventions on the Rights of Persons with Disabilities (CRPD)**

### **Article 1 - Purpose**

The purpose of the present Convention 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. 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.

...

### **Article 3 - General principles**

The principles of the present Convention shall be:

- (a) Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- (b) Non-discrimination;
- (c) Full and effective participation and inclusion in society;
- (d) Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- (e) Equality of opportunity;
- (f) Accessibility;
- (g) Equality between men and women;
- (h) Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.

...

### **Article 12 - Equal recognition before the law**

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

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

5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.

...

#### **Article 14 - Liberty and security of the person**

1. States Parties shall ensure that persons with disabilities, on an equal basis with others:
  - (a) Enjoy the right to liberty and security of person;
  - (b) Are not deprived of their liberty unlawfully or arbitrarily, and that any deprivation of liberty is in conformity with the law, and that the existence of a disability shall in no case justify a deprivation of liberty.
2. States Parties shall ensure that if persons with disabilities are deprived of their liberty through any process, they are, on an equal basis with others, entitled to guarantees in accordance with international human rights law and shall be treated in compliance with the objectives and principles of this Convention, including by provision of reasonable accommodation.



## **European Convention on Human Rights (ECHR)**

### **ARTICLE 5**

#### **Right to liberty and security**

1. Everyone has the right to liberty and security of person. No one shall be deprived of his liberty save in the following cases and in accordance with a procedure prescribed by law:
  - (a) the lawful detention of a person after conviction by a competent court;
  - (b) the lawful arrest or detention of a person for noncompliance with the lawful order of a court or in order to secure the fulfilment of any obligation prescribed by law;
  - (c) the lawful arrest or detention of a person effected for the purpose of bringing him before the competent legal authority on reasonable suspicion of having committed an offence or when it is reasonably considered necessary to prevent his committing an offence or fleeing after having done so;
  - (d) the detention of a minor by lawful order for the purpose of educational supervision or his lawful detention for the purpose of bringing him before the competent legal authority;
  - (e) the lawful detention of persons for the prevention of the spreading of infectious diseases, of persons of unsound mind, alcoholics or drug addicts or vagrants;
  - (f) the lawful arrest or detention of a person to prevent his effecting an unauthorised entry into the country or of a person against whom action is being taken with a view to deportation or extradition.
2. Everyone who is arrested shall be informed promptly, in a language which he understands, of the reasons for his arrest and of any charge against him.
3. Everyone arrested or detained in accordance with the provisions of paragraph 1 (c) of this Article shall be brought promptly before a judge or other officer authorised by law to exercise judicial power and shall be entitled to trial within a reasonable time or to release pending trial. Release may be conditioned by guarantees to appear for trial.
4. Everyone who is deprived of his liberty by arrest or detention shall be entitled to take proceedings by which the lawfulness of his detention shall be decided speedily by a court and his release ordered if the detention is not lawful.
5. Everyone who has been the victim of arrest or detention in contravention of the provisions of this Article shall have an enforceable right to compensation.

# Appendix D

## A Toolkit for Assessing Capacity

A Douglass, G Young and J McMillan<sup>♦</sup>

### CHECKLIST FOR ASSESSING CAPACITY

This toolkit is a clinical, legal and practical guide for health practitioners (clinicians) when assessing an adult's capacity to make decisions. The checklist is a summary of the toolkit. It is intended to assist clinicians who do capacity assessments infrequently. Each bullet point is hyperlinked to the [main](#) Toolkit or to external websites and resources to provide more information. There is more information on the [legal framework](#) at the end of the toolkit.

### KEY PRACTICE POINTS

- A person is [presumed to have](#) the capacity to make a decision unless there are good reasons to doubt this presumption.
- In general, capacity is assessed with respect to a [specific decision at a specific time](#).
- Assessment is of a person's [ability to make a decision](#), not the decision they make. A person is entitled in law to make unwise or imprudent decisions, provided they have the capacity to make the decision.
- [Supported decision-making](#) involves doing everything possible to maximise the opportunity for a person to make a decision for themselves
- Capacity assessment procedures need to consider [tikanga Māori](#) and cultural diversity.

### Legal Test for Capacity

A person lacks capacity if they are unable to:

- [understand](#) the nature and purpose of a particular decision and appreciate its significance for them;
- [retain](#) relevant, essential information for the time required to make the decision;
- [use or weigh](#) the relevant information as part of the reasoning process of making the decision and to consider the consequences of the possible options, (and the option of not making the decision); or
- [communicate](#) their decision, either verbally, in writing, or by some other means.

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<sup>♦</sup> This toolkit may be cited as: A Douglass, G Young and J McMillan *A Toolkit for Assessing Capacity* in A Douglass "Mental Capacity: updating New Zealand's Law and Practice" (Report for the New Zealand Law Foundation, July 2016) [www.lawfoundation.org.nz/](http://www.lawfoundation.org.nz/)

## CARRYING OUT A CAPACITY ASSESSMENT

### Stage One: Preparing for the Assessment

- **Triggers:** why is this person's capacity being questioned now?
- **Decision:** what is the capacity decision to be assessed?
- **Legal test:** what is the legal test against which capacity is to be assessed, under the PPPR Act or other laws? (for example, "wholly" or "partly" lacking capacity)
- **Gathering Information:** do you have all the relevant information about the decision, including the circumstances and details of the choices available?
- **Medical history:** does the person have a [medical condition](#) that impairs their capacity and does this need treatment before the assessment can be done?
- **Support measures:** what can be done to [assist](#) the person to make the decision?
- **Cultural considerations:** is [cultural support](#) needed?
- **Where and when:** what is the best time and place for the assessment?

### Stage Two: The Assessment Interview

- **Engagement:** have you explained who you are and the [purpose of the assessment](#)?
- **General health and cognition:** what is the person's mental state? Is there a [medical condition](#) that is currently active and is impairing the person's cognitive function? If so, can you measure its severity using a cognitive screening test?
- **Legal test:** have you asked [questions](#) to determine whether the person is able to understand, retain, use or weigh the information or, communicate the decisions by any means?

### Stage Three: After the Interview

- **Decide:** do you have enough information to [decide](#) if the person has capacity or not: is a second interview necessary?
- **Communicate:** have you told the person, and where appropriate their family, the outcome of the assessment?
- **Document:** have you [recorded](#) your reasons in the person's clinical records that the person has or lacks capacity for a particular decision? Is a medical certificate or report required?

# A TOOLKIT FOR ASSESSING CAPACITY

## A INTRODUCTION

### Purpose

1. The purpose of this toolkit is to guide health practitioners when assessing an adult's capacity to make decisions. The toolkit is intended to assist doctors and other health practitioners including psychologists, nurses, occupational therapists (clinicians) and social workers who may be involved in assessing capacity.<sup>1</sup>
2. The toolkit provides a consistent and systematic approach to assessing capacity within the New Zealand healthcare setting. It covers: key practice points, how to carry out a capacity assessment, and an overview of the relevant law.
3. The [UN Convention on the Rights of Persons with Disabilities](#) has shifted the focus towards supported decision-making for people with impaired capacity: not only is it important that good judgements are made about whether or not a person has decision-making capacity but it is equally important to provide ways in which a person can be supported so as to make their own decisions.
4. This toolkit aims to recognise supported decision-making within New Zealand's diverse cultural contexts and that [tikanga Māori](#) is central to capacity assessment of Māori people.
5. A list of [useful resources](#) is provided at the end of the toolkit.

### Guidance, not legal advice

6. This toolkit does not take the place of legal advice. Where a formal assessment has been requested, the referrer should clarify: the legal test, the particular questions to be answered, and that the clinician has been given all the necessary information to be able to complete the assessment.
7. People with impaired decision-making capacity may be vulnerable to abuse, coercion and undue influence from others, which may compromise their decisions being made freely and voluntarily. If there is suspicion of undue influence, then consider whether other professionals, or social agencies need to be involved and who can support the person in obtaining that advice. For example, whether the person should obtain independent advice from a lawyer or accountant, or support from Age Concern.
8. Assessing a person's decision-making capacity may not be straightforward. Where the decision involves significant risk, or where there is conflict about the decision, it can be difficult to separate incapacity from differing personal values or unwise decisions. In these situations it is a good idea to seek the advice of colleagues and members of the multi-disciplinary team, or where possible, to seek advice from a clinical ethics advisory group.

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<sup>1</sup> For ease of reference, health practitioners who assess capacity are referred to as "clinicians". The word "person" rather than patient or consumer, is used in recognition that the person (an adult) being assessed may not actually be undergoing health treatment, and in law is referred to as the "subject person".

## Defining capacity

9. Decision-making capacity (or simply, “capacity”) refers to a person’s ability to make decisions. Examples range from simple decisions about what to have for breakfast, to whether to go to the doctor when feeling ill, to far-reaching decisions about serious medical treatment or financial matters.
10. In New Zealand legislation, both “capacity” and “competence” are used interchangeably. In a clinical context, “competence” tends to refer to the process of decision-making, and capacity to the legal term that is used.<sup>2</sup> In this toolkit, the term “capacity” is used throughout.
11. Deciding whether a person has the capacity to make a particular decision has legal implications and in some cases may need to be determined at a court hearing. A capacity assessment is part of the evidence that informs the legal decision. There are legal tests which are applied to determine whether a person has capacity to make specific decisions or whether someone else or the court, a substitute decision-maker, should make decisions for them.

## Legal test for capacity

12. The purpose of assessing capacity is to determine by clinical interview whether the person is unable to make a legally effective decision. A functional test is used. A person lacks capacity if they are unable to:
  - **understand** the nature and purpose of a particular decision and appreciate its significance for them;
  - **retain** relevant, essential information for the time required to make the decision;
  - **use or weigh** the relevant information as part of the reasoning process of making the decision and to consider the consequences of the possible options, (including the option of not making the decision); or
  - **communicate** their decision, either verbally, in writing or by some other means.

## B KEY PRACTICE POINTS

### Presumption of capacity

13. The starting point when assessing capacity is always to [presume that a person has capacity](#) to make the decision. However, the assessment will be taking place because a reason exists to question the presumption of capacity. The capacity assessment is an examination of the person’s decision-making process.
14. Clinicians need to be alert to triggers that question the person’s capacity for the present decision and the reasons why they are being asked to assess a person’s capacity.

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<sup>2</sup> “Capacity” and “mental capacity” are generally the terms used in Europe and the United Kingdom, and “competence” in the United States.

### Capacity is decision and time specific

15. A person's capacity should be assessed in relation to a particular task or decision. Capacity cannot generally be inferred from one task or decision to another.
16. The person's incapacity may be temporary, or fluctuating. If possible, an assessment of capacity should be done when the person's condition has improved. For example, if the person has a delirium, it is better to wait until this has resolved.

### Assessment of a person's decision-making ability, not the decision they make

17. Assessing capacity involves examining the mental processes a person goes through in order to arrive at a decision: it is not an assessment of the decision made. A person cannot be assessed as lacking capacity simply because they make a decision that is considered [unwise or imprudent](#).

### Supported decision-making

18. [Supported decision-making](#) involves doing everything possible to maximise the opportunity for a person to make a decision for themselves. A capacity assessment can give guidance about the extent and nature of the support the person requires.
19. Supported decision-making is in keeping with established [legal principles](#), including:
  - using the least restrictive intervention;
  - maximising a person's capacity to the greatest extent possible; and
  - people being entitled to make unwise or imprudent decisions.

### Substitute decision-making as a last resort

20. If all efforts made to support a person through the decision-making process are unsuccessful, and the person does not meet the legal test for capacity, then a substitute decision-maker can make the decision for the person. Where a substitute decision-maker is involved, a capacity assessment can provide useful information about the person's views, values and beliefs, which remain central to them being supported in the decision-making process, as well as the nature of the difficulty they may have with decision making.

### Tikanga Māori and cultural diversity

21. There is a need to recognise [cultural diversity](#), and in particular the rights of Māori as tangata whenua, in all aspects of clinical practice in New Zealand. This remains true when assessing capacity; culture, language, and religion are integral factors in how a person makes decisions and in what decisions they make.
22. Having respect for the needs, values, and beliefs of Māori is crucial when assessing capacity with [Māori](#). *Whanaungatanga* provides a platform for capacity assessment and supported decision-making and is fundamental to culturally responsive practice.



[Whakawhanaungatanga](#) refers to the process of establishing what connections, either through family or other social relationships, exist between people. For Maori in particular, formal relationships such as that between the parties in a capacity assessment will be greatly enhanced if efforts are made to establish connections and relatedness at the outset, and if the assessment is conducted in a manner that is mindful of those connections. This is one way in which the mana and dignity of the person being assessed can be supported.

23. An example would be where a Māori elder has a stated preference to stay living in their home when the whānau believe the support of hospital care is needed. In such instances there may be tension between recognising the collective view of whānau and ensuring that the elder's mana is accorded respect. Both aspects, and their interdependent nature, need to be understood.
24. In practice, carrying out capacity assessments requires clinicians to be [culturally competent](#), especially if the person is from a different culture than the clinician. This involves knowing when and how to enlist the support or assistance from whānau and others to support the person through the assessment process.

### Form of assessment

25. There are broadly two contexts in which clinicians assess capacity:
  - **Informal assessments:** These may often occur in the context of assessing a person's capacity to give or refuse consent to medical treatment. They are narrowly focused on the knowledge of the relevant information, available options, and consequences, and on the reasoning and communication abilities of the person giving consent. These capacity assessments are often conducted "intuitively" or informally by clinicians, without recourse to courts or formal legal processes. The assessment by the clinician should still be documented in the person's medical record.
  - **Formal assessments:** These are assessments that are required to provide an opinion (often with a medical certificate) under the adult guardianship law (PPPR Act) or for other legal proceedings, or for some other legal purpose. This type of assessment is intrinsically more formal. These capacity assessments are used to support, for example, the activation of an Enduring Power of Attorney (EPOA) or an application to the Family Court to appoint a welfare guardian, or they may take the form of advice to a lawyer or other professional on whether to accept a person's capacity to make a certain decision, such as the making of a will.
26. Other more immediately practical decisions, such as the decision to move into supported accommodation, may also require a formal assessment of capacity. An important aspect of the assessment of capacity where a decision with long term consequences is to be made, is the likely cause of the incapacity and the probability of the person regaining their capacity to make decisions.
27. In many contexts, an intuitive assessment, which is the type of assessment most commonly used in medical practice, is not accurate enough and will not withstand legal scrutiny, for example when assessing a person's capacity to make a will or to gift significant assets.

## Who should carry out the assessment?

28. If the assessment is about a medical decision, the [clinician who is providing the treatment](#) should assess the person's capacity to consent to that treatment, though they may consult others for assistance.
29. Where the decision is about other matters such as personal welfare, living arrangements or property matters, it is usually best for a clinician who is well-known to the person, for example, the family GP, to do the assessment. Where this is not the case, particular attention will need to be given to the process of engagement, and, in the case of Māori, whakawhanaungatanga.
30. In cases of doubt, or in relation to complex major decisions, it may be advisable to collaborate with other health practitioners with experience in relation to the needs of the person, such as a nurse, occupational therapist, psychologist, or speech and language therapist.
31. Final responsibility for obtaining effective [consent for treatment](#) rests with the person intending to carry out the proposed medical procedure, not with other health practitioners advising about capacity.

## C CARRYING OUT A CAPACITY ASSESSMENT

32. It is useful to think of the process of assessing capacity as consisting of three stages:
  - **Preparing for the assessment:** What is the decision to be made, why is the person's capacity in doubt, is there a reversible cause for the incapacity, or is the incapacity due to a permanent or progressive condition? Usually there will need to be some contact with family members or other professionals involved in the person's affairs at this stage to clarify these issues, especially where the person being assessed suffers from dementia and the assessment is more heavily reliant on collateral information. It may also be useful to involve a supportive family member or friend to assist the person in getting to the assessment. This stage of the process is particularly important if there is any question of undue influence or financial abuse, as it will be vital to obtain a history from a range of people to ensure the reliability of the information.
  - **The assessment interview:** Attention needs to be paid to engaging the person. There needs to be a brief review of the person's health, mental state and cognition, and the clinician needs to assess the four abilities central to the functional test to capacity.
  - **Actions following the interview:** These can include a second assessment interview to assess the consistency of the person's decision making, referral for review of a medical condition, feedback to the person and family, recording the assessment and/or or completion of a report or legal certificate.

## Stage One: Preparing for the Assessment

### Triggers: why is this person's capacity being questioned now?

33. The starting point is that a person is presumed to have capacity. Concern or doubt about the person's capacity usually occurs when the person has a medical or psychiatric condition affecting their mental state, and in the context of that condition the person is required to make a decision that has serious consequences or high risk. The combination of the mental condition and the significant decision can be thought of as a trigger for the assessment. The clinician will need to have a clear understanding of the trigger, which should be documented. In some situations the trigger for the assessment may be simply an unusual feature of a proposed decision, and the mental condition may only be discovered at the assessment. For example, assessment might be considered if a person makes a decision that deviates markedly from their known disposition, without justification.
- The condition affecting the person's mental state is most frequently cognitive decline or dementia, but may also be psychiatric illness such as severe depression, psychotic illness, profound grief or stress, or severe physical illness associated with pain, insomnia or emotional distress.
  - A number of factors about the decision may cause the person's capacity to be questioned. These include significant risk or long-lasting consequences associated with the decision, the decision the person is proposing to make is contrary to reasonable advice, without justification (for example, refusal of standard medical treatment for a serious but treatable condition), or the person is unable to make a decision at all despite being provided with all the relevant information and the appropriate support, where it is imperative that a decision needs to be made (for example, about residential care).
  - A person is unable to communicate a decision (for example, a person affected by a stroke).
  - A family member, carer, lawyer or service provider has expressed concern about a person's decision-making ability. This may occur before a diagnosis of dementia has been made or it may be part of future planning, for example, encouraging a person to appoint an attorney for an EPOA.
34. People have the right to make unwise or imprudent decisions, as long as they retain capacity to make the decision at the time they are making it. Nonetheless, an unwise decision may trigger a more detailed assessment, particularly if the decision is out of character or has significant consequences.

### Identifying the decision

35. Clarify what the decision is that the person needs to make, why it needs to be made now, what information would be needed for anyone making a similar decision, what are the alternative options available, and what are the reasonably likely consequences of those options or of not making a decision at all. Where, for example, the decision concerns a legal matter, the clinician can reasonably expect this information to be provided in writing by the lawyer. If it concerns moving into residential care, the notes of the multidisciplinary team that

assessed the person as needing to move, giving the reasons for the move being recommended, should be available to the clinician assessing capacity.

36. For the appointment of a welfare guardian or property manager, it is important to identify the kinds of decisions or aspects of them that will be relevant to a person's current circumstances and those decisions that will need to be made in the foreseeable future. For example, a person may be capable of consenting to routine treatment medical or dental treatment but would not be able to weigh up more complex decisions and the risks and benefits about whether to consent to elective surgery or chemotherapy.

### **Medical conditions that impair capacity**

37. Consider whether there are any medical conditions that could be impairing the person's capacity and if so, what treatment is being given and how effective it is. This step includes reviewing medical notes and contacting the person's usual doctor if required. Medical conditions that could impair capacity include:

- dementia and degenerative and other neurological diseases;
- acquired brain injury, including traumatic injury and stroke;
- delirium;
- any physical condition that is causing severe discomfort or distress;
- severe mental illness, either persistent, such as schizophrenia, or acute such as acute depression or mania;
- alcohol and substance addiction; and
- learning disability, including intellectual disability and autistic spectrum disorder.

38. Consider referring the person for further assessment if there is a realistic possibility that the person's capacity is impaired by a condition that is outside the clinician's scope or expertise. The purpose of this referral will be for the condition to be diagnosed and treated, and not for the capacity assessment itself to be passed on to another health practitioner, although a second opinion about the person's capacity may be helpful.

### **Support measures and communication**

39. The clinician has a role in ensuring that the person to be assessed has already been given the best chance of making a decision, for example, by the existing health care team or service and/ or with assistance of the person's family. All reasonable attempts that have been made to support the person make a decision should be documented, including what these attempts have entailed. Examples of what may be done include:

- Treating a medical condition which may be affecting the person's capacity (for example, delirium);

- Using a different form of communication (for example, providing written material) or by providing information in a more accessible form (for example, drawings); and
  - Ensuring that discussions with the person about the decision have been conducted in an appropriate environment (for example, respecting a person's privacy and minimising distractions on a busy hospital ward or visiting the person in their own home).
40. Where necessary, arrange to have the assistance of a professional interpreter with appropriate accreditation and experience in health interpreting. If English is the person's second language, it is common for a person whose capacity is deteriorating to lose their ability to communicate in a second language early in the process. Using a family member or friend is not acceptable. Even with an interpreter available, a fully bilingual clinician, if available, may be a preferable option for undertaking the assessment.

### **Involvement of family/whānau and support**

41. It is a matter of judgment as to whether an immediate family member should be present for the assessment interview. If the person is accompanied by a family member or friend, it will be necessary to consider conducting at least part of the interview privately with the person, especially if there are reasonable grounds for suspecting undue influence or coercion. In this case it may be necessary to consider having another professional person, such as a trusted carer, a health and disability advocate, or a [cultural support person](#) present.
42. Where the person being assessed is Māori, consider the relevant cultural competencies and tikanga Māori. For all persons being assessed, thought needs to be given to the process of engagement as capacity assessment, which is motivated essentially by doubts about the person's capacity, may be experienced by some as demeaning or humiliating.

### **Where and when**

43. Consider the time and place for the interview; ensure that enough time is available for the interview to be conducted at an easy pace and that the place chosen for the interview is comfortable and private. It is important to avoid interviewing later in the day for older persons when they may be suffering from fatigue or "sundowning".
44. Hearing, visual and communication aids, where used, should be brought to the interview.

### **Gathering information**

45. It is vital that all relevant information to the decision is accurate and complete. For example, the outcome of a needs assessment is relevant for the person to decide between living in supported residential care and living at home. Family or other professionals involved, such as the person's lawyer, should be consulted as appropriate.
46. It may be helpful, or even essential, to obtain background history from an informant, a friend or family member, particularly where the person has dementia and there is likely to be a progressive decline in the person's capacity. The purpose of contacting informants is to use the information objectively and to check the extent to whether the proposed decision is out of character or inconsistent with the person's previous decisions and life patterns. This

information may include the history of cognitive decline, problems with previous decisions of a similar nature and may involve getting a range of views from other informants if need be.

47. Once all the relevant information has been gathered, the clinician assesses capacity by interviewing the person.

## **Stage Two: the Assessment Interview**

### **The interview process**

48. The assessment interview follows the usual process of a clinical interview, however, because of the legal implications of the assessment, the interview needs to be more structured than a clinical interview. Particular care may be required when a formal assessment is carried out by the person's own clinician and takes place within the context of a continuing therapeutic relationship. If the clinician is unfamiliar with the person, extra care may be needed to engage with them and attention should be paid to ensuring that the person has the appropriate personal and cultural support. The success of the assessment is very dependent on the cooperation of the person being assessed.
49. Explain to the person that the purpose of the assessment is to ensure that they are fully informed about the decision, and whether they are in a position to either make the decision independently or make the decision with further support.

### **General health and cognition**

50. Consider what assessment needs to be done of the person's general health and cognitive state. If the assessing clinician is the patient's regular GP, it may only be necessary to check that the patient's level of cognition is "as good as it usually is in the present circumstances", and to exclude such conditions as delirium aggravating the cognitive impairment of a known dementia. Where the person does not already have a diagnosis of dementia, for example, a more detailed assessment would be needed.
51. Cognitive functioning may be assessed with a recognised test such as the Montreal Cognitive Assessment (MOCA) or Mini Mental State Examination (MMSE), which provide a measure of the severity of cognitive impairment. It is important for the clinician to be aware that brief tests of cognitive function do not provide a measure of capacity. Their value is in the providing some rigour to the assessment of cognition and to allow a comparison of the person's cognition at the time of the capacity assessment to their own, and the population baseline. Specific tests of frontal lobe function correlate better with measures of capacity because they assess problem solving, judgment and mental flexibility, which are all frontal lobe tasks.

### **Consider the four elements of the legal test: understand, retain, use or weigh, and communicate**

52. **Understand:** *does the person know what the decision is, why it is important for them (ie appreciate its significance) and why it needs to be made now, the alternative options available and the option to make no decision at all?*



- It may be useful to explain all of the information relevant to the decision to the person at the beginning of the assessment interview, unless it is apparent it has been clearly explained to them recently.
- The level of understanding required must not be set too high. It is not necessary that the person has the ability to understand every element of what is being explained to them.
- The person must be given all the necessary information and options so that their capacity to weigh up those options can be fairly assessed: they do not need to start with a “blank canvas”.

53. **Retain:** *is the person able to retain enough information for a sufficient amount of time for them to go through the decision-making process?*

- The length of time for which the person should be able to retain the information depends to some extent on the decision being made. In the case of a treatment decision, it may only be necessary to retain information about the possible complications and alternative options for long enough to make the decision or give consent. In that case the test would be asking the person to repeat the information back to the assessing clinician when the assessment is being done. On the other hand, it would be expected that if the decision was to change a will, the relevant information would be retained for longer.

54. **Use or weigh:** *is the person able to state the benefits and risks (consequences) of each option using relevant information and explain why they prefer one of the options?*

- This element includes the idea that the person is thinking about or “weighing” the options and that their thinking process is either logical, or at least based on the information available.
- Using and weighing information is the most difficult element to evaluate when assessing capacity for a number of reasons. It is an assessment of a thinking process that the person may not easily demonstrate to the clinician.
- The standard of “weighing up” or “using information” can be difficult if the person is weighing the important medical facts against their personal convictions, beliefs or values. The assessment of an apparently bizarre idea or irrational decision, for example to refuse treatment, needs to be considered in the context of the person’s related beliefs and values taken as a whole. It may or may not turn out to be coherent in that light.
- The standard of weighing up is usually a basic one; the information is considered in the decision-making process, and the person shows some flexibility to change their decision if additional information, even if hypothetical, is offered. For example, “if this decision could result in you suffering serious medical consequences or death, would you consider doing something different?” A person might not be considered able to use or weigh the information if they are unable to accept that they suffer from the condition that is requiring treatment. However, if the person refuses the

advice of professionals, despite serious consequences, they may still be regarded as retaining capacity as long as they acknowledge these serious consequences.

- It is also important to consider whether a person's ability to use or weigh information is freely and voluntarily made where there is suspicion of susceptibility to undue influence or coercion from others.

55. **Communicate:** *can the person communicate a decision or choice?*

- The inability to communicate is a stand-alone ground for establishing a person lacks capacity. Where a person cannot communicate a decision in any way, by talking, using sign language or any other means, they are unable to make a decision for themselves.
- Any residual ability to communicate is enough so long as the person can make themselves understood.
- An assessor should help facilitate communication, for example, by providing all necessary tools and aids, and enlisting the support of any carers or family who may assist with communication.

### **Stage Three: After the Interview**

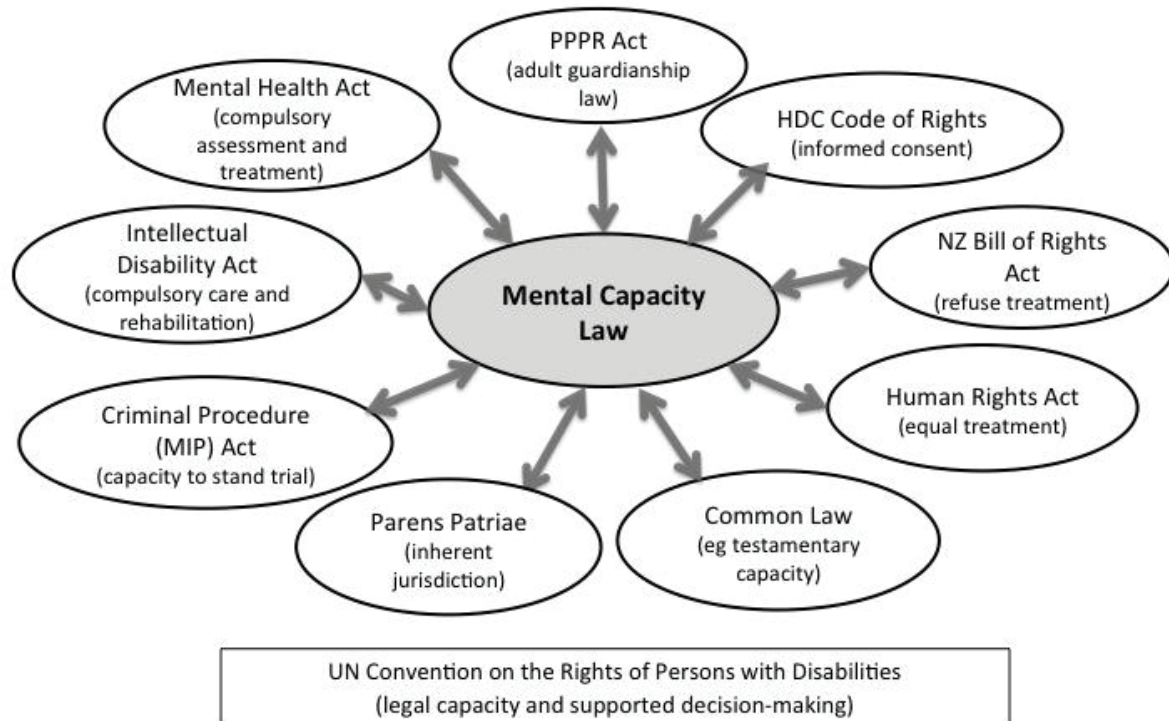
#### **Consider the findings of the capacity assessment process and decide how to proceed**

56. It may be possible to form an opinion about the person's capacity during the assessment interview, and decide that no further assessment is required. As a rule, this opinion should be explained to the person, either at the interview or at a suitable occasion after the interview. Capacity assessments for decisions that carry greater risk, are for the longer-term, or that may be contested in court, for example, testamentary capacity, may often require more than a single interview, particularly where the person's condition may change.
57. Inconsistency in decision-making may suggest that the person lacks capacity. For example, a person with fluctuating cognition due to delirium may make contradictory decisions. Another type of inconsistency is the person who makes a will that is radically different from a number of previous wills and that contradicts their previously stated intentions. Information from other members of the multidisciplinary team or from the person's family may be another way of checking inconsistency with previous decisions or expressed wishes and out of character decisions.
58. Based on the findings of the whole assessment, the doctor will then need to decide whether the person has capacity to make the decision that they now need to make. Even though the person may have some ability to make the decision, a binary yes/no assessment of their capacity to make the current decision may be required. For example, regarding the activation of an enduring power of attorney or an application for the Family Court to make an personal care order, the clinician may be required to decide whether the person lacks capacity to make a significant decision (or range of decisions) or not.

## Recording your assessment

59. Document the findings of the assessment. Any report or opinion for a formal assessment should be prefaced with an outline of the clinician's expertise, experience, and contact and professional relationship with the person (for example, acting as their GP for 20 years), and the circumstances of assessment (for example, carried out in the person's home for one hour). Informal assessments should be recorded in the person's clinical records.
60. The report of the assessment requires the clinician to be clear about the capacity decision that is being assessed, the information that is relevant to the decision, and an explanation whether the person was unable to satisfy the legal test and why. The person will be considered to lack capacity if they are unable to satisfy any one of the elements of the test of: understand, retain, use or weigh, or communicate a decision. The clinician should give detailed, specific examples (actual quotes) of where the person has not shown the requisite abilities.
61. Where an intervention will be longer-lasting, for example an order to move into supported residential care, the clinician will need to describe the medical condition or disability that is causing the incapacity and whether any treatment is available that could restore the person's capacity.
62. Where the person has capacity for the specific decision, but serious concerns have been expressed by family members or others, or where the decision carries significant risk, it is equally important to document the findings of the assessment, showing that the condition that is causing the impairment has been assessed and that despite the condition, the person has the ability to understand, retain, reason, and communicate adequately for the decision.
63. The [medical certificates and report form](#) that are required for activating EPOAs and court proceedings under the Protection of Personal and Property Rights Act 1988 (PPPR Act) are in the resources at the end of the toolkit.

## D THE LEGAL FRAMEWORK



### Mental capacity law in New Zealand

64. There is a wide range of legislation and common law (case law) in New Zealand that is relevant to people with impaired capacity for decision-making. This section explains the main New Zealand law and legal tests relevant to capacity assessments.
65. The [\*Protection of Personal and Property Rights Act 1988 \(PPPR Act\)\*](#) is the adult guardianship law that applies to people who lack capacity and are 18 or older. It authorises the appointment of substitute decision-makers by the Family Court (welfare guardians and property managers) or “one-off” orders for care and treatment decisions (personal orders), and provides the mechanisms for making and activating enduring powers of attorney (EPOAs), when a person lacks capacity for decision-making.
66. The [\*Code of Health and Disability Services Consumers’ Rights \(HDC Code\)\*](#) concerns consent to health care treatment and procedures. Under the HDC Code, consent to health care procedures is necessary as required under Rights 5, 6 and 7, including the right to make an informed choice and give or refuse consent.
67. Under the PPPR Act and the HDC Code, a substitute decision-maker can include:
- an attorney appointed by the person for property or care and welfare decisions under an enduring power of attorney (EPOA);

- a welfare guardian or property manager appointed by the Court;
- the Court making a specific personal order about the person's care and treatment or approving the person's will made by the person or the person's property manager;
- the clinician that is providing care and treatment to the person can make a decision in the person's best interests where there is no substitute decision-maker, provided reasonable steps are taken to ascertain the views of the person and others as set out in Right 7(4) of the HDC Code.

### Identifying the relevant legal test

68. To assess capacity, it is necessary to identify the decision required to be made and the relevant legal test. As with many countries, New Zealand follows a functional, not a status approach to capacity.
69. The test of capacity used in this toolkit is based on a review of the functional approach in the PPPR Act and case law, which broadly reflects the functional test and the same concepts in the Mental Capacity Act 2005 (England and Wales) (MCA test). The four elements of the MCA test are the inability to: *understand, retain, use or weigh relevant information, or to communicate the decision*, and provides simple and logical steps to assessing capacity.
70. There are several tests for capacity in other legislation, for example, capacity to stand trial in the Criminal Procedure (Mentally Impaired Persons) Act 2003. There are tests that have been developed in court cases (known as common law). These cover the capacity to: make a will; make a gift; to enter a contract; litigate (take part in legal cases); and to enter a marriage.

### PPPR Act: capacity thresholds

71. In general terms, a person lacks capacity if they cannot understand the nature and foresee the consequences of decisions, or are unable to communicate them.
72. The PPPR Act has four different tests for capacity depending on the kind of appointment or decision to be made. For example, the threshold for appointing a welfare guardian requires that the person "wholly" lack capacity whereas the court may make a personal or property order if the person "partly" lacks capacity.
73. There are two different thresholds for when the Court makes an order (and a [report form](#) to complete):

### Court orders

- "[partly](#)" lacks the capacity: personal order, ss 6 and 10 (for example, medical treatment or living arrangements), order to administer property (low level assets and income); and "wholly or partly" lacks the capacity: property manager, s 25 (2)(b).
- "[wholly](#)" lacks the capacity in respect of particular aspect(s) of a person's care and welfare: welfare guardian, ss 6 and 12.

## Activating EPOAs

74. An enduring power of attorney (EPOA) is a legal document where the donor gives someone else (the attorney) the power to act for the donor if they become “mentally incapable” and lose the ability to make significant decisions for themselves. There are two different thresholds for activating an EPOA (and [certificates](#) to complete):

- [“not wholly competent”](#): property EPOA , s 94(1)
- [“lacks the capacity”](#): care and welfare EPOA, s 94(2)

## HDC Code: capacity to consent to treatment

75. Capacity is an essential component to validating consent, or refusal to consent, but there is no specific legal test for capacity set out in the HDC Code itself. The person must be able to understand, the nature and effects of the proposed treatment, the purpose for which it is needed, the likelihood of success and any alternative forms of treatment. The possible consequences to the person of receiving, or not receiving, the proposed treatment should be explained. Even where there is an appointed welfare guardian or attorney, every effort should be made to help the person participate as much as possible in the decision to be made.

## Right 7(4) of the HDC Code

76. Where a person lacks capacity for consent and there is no authorised decision-maker, [Right 7\(4\)](#) sets out the legal position for providing services to them.

77. Right 7(4) provides that if a person is not competent to make a particular personal care and welfare or treatment decision, and they do not have a an EPOA or welfare guardian (or the EPOA or welfare guardian is not available), services can be provided or treatment given if it is in the best interests of the person. Clinicians are required to follow the steps in Right 7(4) in reaching a decision, including taking into account the views of the person, or where these are not possible to ascertain, the views of other suitable people interested in the welfare of the person.

78. The use of Right 7(4) is most appropriate where decisions need to be made in the short-term and should not be relied upon for ongoing decision-making regarding longer-term care and treatment. In these circumstances, those involved with these decisions should consider making an application to the Court for orders under the PPPR Act.

## Capacity to make a will

79. The essential elements of capacity for making a will (testamentary capacity) have remained unchanged since the decision in *Banks v Goodfellow*.<sup>3</sup> This requires that the person understands:

- the nature and effect of making a will;
- the extent of the property which the person has for disposal; and

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<sup>3</sup> (1870) LR QB 549; *Woodward v Smith* [2009] NZCA 215.



- the moral claims of potential beneficiaries when making the will.
80. The person making the will must have the requisite mental capacity at the time they execute the will. Susceptibility of the will-maker to undue influence or the extent to which they have suffered from a serious mental illness, immediately before and subsequent to, making a will, may be relevant to legal grounds in challenging whether the will is valid.
81. A capacity assessment may be required for a person subject to a property order under the PPPR Act. The person or their property manager may make a will only with the permission of the Court: PPPR Act, ss 54 and 55.

### **Refusal to undergo a capacity assessment**

82. Apathy or lack of cooperation to undergo a capacity assessment should not lead to the conclusion that a person lacks capacity. In circumstances where a person refuses to undergo a capacity assessment, it may be possible to persuade them to agree to an assessment if the consequences of refusal are carefully explained for example, the implications of a medical procedure. However, in the face of an outright refusal, (and in the absence of a Court order), no one can be forced to undergo a capacity assessment. Refusal to cooperate with an assessment together with other available information may be relevant in a legal decision about the person's capacity.
83. Where there are serious concerns about the person's mental health, the Mental Health (Compulsory Assessment and Treatment) Act 1992 may be used but only for the purpose of assessment or treatment of the mental disorder itself.

## **E USEFUL RESOURCES**

### **Legal resources**

- Ministry of Justice website for the PPPR Act forms: <http://www.justice.govt.nz/family-justice/other-court-matters/power-to-act/getting-an-order-reviewed/forms-fees-and-cost>
- PPPR Act: <http://www.legislation.govt.nz/act/public/1988/0004/latest/DLM126576.html>
- Health and Disability Commission fact sheet: Consent for consumers who are not competent: <http://www.hdc.org.nz/publications/other-publications-from-hdc/fact-sheets/fact-sheet-1--%E2%80%93informed-consent-for-consumers-who-are-not-competent>
- UN Convention on the Rights of Persons with Disabilities – Office for Disability Issues: <http://www.odi.govt.nz/what-we-do/un-convention/index.html>

### **Education video**

- E Plesner, L Fergus and G Young, Training Video on Capacity Assessment, University of Otago, Wellington <https://vimeo.com/uow/capacityassessment>

## Cultural competence

- Health Quality and Safety Commission in conjunction with eCALD (Culturally And Linguistically Diverse) groups: <http://www.ecald.com/Courses/CALD-Courses-Overview>
- Free foundation course in Cultural Competency (Māori) Mauriora Health Education Research: <http://mauriora.co.nz/cultural-competency-maori/>

## International guides to capacity assessment

### England and Wales

- 39 Essex Street: “Mental Capacity Act: A brief guide to carrying out capacity assessments” (2014) <http://www.39essex.com/mental-capacity-law-guidance-note-brief-guide-carrying-capacity-assessments/>
- Mental Capacity Act 2005 *Code of Practice* (TSO, London, 2007) - Chapter 4 “How does the Act define a person’s capacity to make a decision and how should capacity be assessed” [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/497253/Mental-capacity-act-code-of-practice.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497253/Mental-capacity-act-code-of-practice.pdf)

### Australia

- Capacity Australia: “Capacity Mini-legal Kits” for use by health care professionals in assessing decision-making capacity: <http://capacityaustralia.org.au/resources/mini-legal-kits/>
- NSW Capacity Toolkit: [http://www.justice.nsw.gov.au/diversityservices/Documents/capacity\\_toolkit0609.pdf](http://www.justice.nsw.gov.au/diversityservices/Documents/capacity_toolkit0609.pdf)

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## Appendix E

### Letters of Support and People Consulted for this Project

#### Application for New Zealand Law Foundation International Research Fellowship

|   |  |
|---|--|
| Dr John Adams                             | Psychiatrist, Associate Dean of Student Affairs, Dunedin School of Medicine, University of Otago         |
| Sylvia Bell                               | Former Principal Legal and Policy Advisor, Human Rights Commission                                       |
| Marie Bennett                             | Social Worker, Elder Abuse and Neglect Prevention Service, Age Concern, Otago                            |
| Professor Alastair Campbell               | Professor in Medical Ethics and Director, Centre for Biomedical Ethics, National University of Singapore |
| Justice David Collins QC                  | High Court Judge   |
| Louise Collins                            | National Advisor, Elder Abuse and Neglect Services, Age Concern New Zealand Inc                          |
| Rachael Dewar                             | Principal, Rachael Dewar Law, Wellington   |
| Professor Tony Dowell                     | Department of Primary Health Care and General Practice, University of Otago, Wellington                  |
| Dr Crawford Duncan                        | Consultant Psychiatrist, Psychiatry of Old Age, Capital & Coast Health DHB                               |
| Dr Katie Elkin                            | Associate Commissioner, Legal and Strategic Relations, Health and Disability Commission                  |
| Caroline Greaney                          | Policy Manager, Access to Justice, Ministry of Justice   |
| Professor Mark Henaghan                   | Dean, Faculty of Law, University of Otago  |
| Greg Kelly                                | Principal, Greg Kelly Law, Wellington  |
| Dr Susie Lawless                          | GP, Amity Health Centre, Dunedin   |
| Senior Judge Denzil Lush                  | Senior Judge, Court of Protection, England and Wales   |
| Dr Alastair Macdonald                     | Renal Physician, Capital & Coast Health DHB  |
| Dr Frances Matthews                       | GP and Lawyer, Dublin, Ireland and Dunedin, New Zealand  |
| Professor John McMillan                   | Director, Bioethics Centre, University of Otago  |
| Dr Jennifer Moore                         | Acting Director, Legal Issues Centre, Faculty of Law, University of Otago                                |
| Memo Musa (via Margaret Barnett-Davidson) | Chief Executive, New Zealand Nurses Organisation   |
| Professor Michael Parker                  | Professor of Bioethics and Director of the Ethox Centre, University of Oxford                            |
| Professor Ron Paterson                    | Ombudsman, former Health and Disability Commissioner   |
| Professor Paul Rishworth QC               | Faculty of Law, University of Auckland   |
| Judge Lawrence Ryan                       | Principal Family Court Judge   |

|                         |   |
|-------------------------|---|
| Dr Royden Somerville QC | Barristers Chambers, Dunedin  |
| Dr Sue Walthert         | GP, Convenor Professional Development, Dunedin School of Medicine, University of Otago                          |
| Dr G Philip White       | GP, Amity Health Centre, Dunedin  |
| Dr Greg Young           | Consultant Psychiatrist, Capital and Coast Health DHB; Clinical Lecturer, Bioethics Centre, University of Otago |

## People consulted and/or interviewed for this project

### Singapore, United Kingdom and Ireland

|                                 |  |
|---------------------------------|--|
| Judge Elizabeth Batten          | District Judge, Court of Protection  |
| Marion Bowgen                   | Manager, Supervision Project, Office of the Public Guardian, London  |
| Professor Margot Brazier        | School of Law, University of Manchester, (together with Nicola Glover-Thomas, Paul Skowron and Laura Pritchard-Jones)  |
| Victoria Butler-Cole            | Barrister, 39 Essex Chambers, London   |
| Professor Alistair Campbell     | Professor in Medical Ethics and Director, Centre for Biomedical Ethics Yong Loo Lin School of Medicine, National University of Singapore                                 |
| Emeritus Professor Terry Carney | Law School, University of Sydney   |
| Mr Justice Charles              | Vice-President of the Court of Protection, England and Wales   |
| Helen Clift                     | Lawyer, Office of the Official Solicitor, London   |
| Clive Collett                   | Ethics Guidance and Strategy Manager, Health Research Authority, London  |
| Dr Michael Dunn                 | Ethox Centre, Nuffield Department of Population Health, Medical Sciences Division, University of Oxford; member, National Social Care Research Ethics Committee (NSCREC) |
| Dr Charles Foster               | Barrister, Fellow of Green Templeton College, Oxford   |
| Dr Tania Gergel                 | Visiting Research Fellow in Ancient Philosophy (Classics) and Philosophy and Psychiatry (Psychological Medicine) Kings College London                                    |
| Lady Brenda Hale                | Baroness Hale of Richmond, Deputy President of the Supreme Court of the United Kingdom   |
| Professor Jonathan Herring      | Professor of Law, Exeter College, University of Oxford   |

|                                      |   |
|--------------------------------------|---|
| Dr Calvin Wai Loon Ho                | Assistant Professor, Centre for Biomedical Ethics<br>Yong Loo Lin School of Medicine, National University<br>of Singapore   |
| Dr Ruth Horn                         | Wellcome Trust Research Fellow, Ethox Centre,<br>University of Oxford   |
| Dr Paul Hutton                       | Psychologist, School of Health in Social Science,<br>University of Edinburgh  |
| Janet Ilett                          | Deputy Official Solicitor, London   |
| Professor Emily Jackson              | Department of Law, London School of Economics   |
| Judge Susan Jackson                  | District Judge, Court of Protection   |
| Alex Ruck Keene                      | Barrister, 39 Essex Chambers, London; Consultant to<br>the Law Commission of England and Wales  |
| Dr Camillia Kong                     | Researcher, Ethox Centre, University of Oxford  |
| Professor Graeme Laurie              | Professor of Medical Jurisprudence, JK Mason<br>Institute for Medicine, Life Sciences and the Law,<br>University of Edinburgh   |
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| The Rt Hon Sir David Lloyd-<br>Jones | Chairman of the Law Commission of England and<br>Wales  |
| Senior Judge Denzil Lush             | Senior Judge, Court of Protection, England and Wales  |
| Dr Frances Matthews                  | GP and Lawyer, Ireland and Dunedin, New Zealand   |
| Colin McKay                          | Chief Executive, Mental Welfare Commission for<br>Scotland  |
| Sumytra Menon                        | Senior Assistant Director, Centre for Biomedical Ethics<br>Yong Loo Lin School of Medicine, National University<br>of Singapore   |
| Dr Gareth Owen                       | Consultant Psychiatrist; Clinical Senior Lecturer in<br>Mental Health, Ethics and Law; Wellcome Trust,<br>Senior Research Fellow, Kings College London,<br>Institute of Psychiatry, Psychology and Neuroscience |
| Nicholas Paines QC                   | Commissioner, Law Commission of England and<br>Wales  |
| Professor Genevra Richardson         | Dickson Poon School of Law, Kings College London;<br>Chair of the Expert Committee established by the<br>Department of Health to advise Ministers on the<br>reform of mental health legislation (1999)          |
| Dr Lucy Series                       | Research Associate, Cardiff Law School, Wales   |
| Dr Mark Sheehan                      | Biomedical Research Centre Ethics Fellow, Ethox<br>Centre, University of Oxford, member of the National<br>Research Ethics Advisors Panel (NREAP)   |
| Tim Spencer-Lane                     | Lawyer, Public Law team, Law Commission of<br>England and Wales   |
| Dr Martin Stevens                    | Chair, National Social Care Research Ethics<br>Committee, England (NSCREC)  |



|                                       |   |
|---------------------------------------|---|
| Professor George Sz mukler            | Professor of Psychiatry and Society Institute, Institute of Psychiatry, Psychology and Neuroscience, Kings College London   |
| Adrian Ward                           | Solicitor, TC Young, Glasgow; recipient, Scotsman Lifetime Achievement Award at the Scottish Legal Awards in recognition of his contribution to the field of Adult Incapacity Law |
| Associate Professor Dominic Wilkinson | Director of Medical Ethics, Oxford Uehiro Centre for Practical Ethics, Consultant Neonatologist, John Radcliffe Hospital, Oxford  |

## **New Zealand**

|                                     |   |
|-------------------------------------|---|
| Associate Professor Lynley Anderson | Bioethics Centre, University of Otago   |
| Dr Jo Baxter                        | Associate Dean of Māori, University of Otago  |
| Wayne Campbell                      | Social Worker and Advanced Clinician, Auckland DHB  |
| Kay Cunningham                      | Clinical Psychologist/Neuropsychologist   |
| Professor John Dawson               | Faculty of Law, University of Otago   |
| Paul Dickey                         | Senior Advisor, Office for Disability Issues, Ministry of Social Development  |
| Professor Kate Diesfeld             | Faculty of Health and Environmental Sciences, Auckland University of Technology   |
| David Dunbar                        | Registrar, Medical Council of New Zealand   |
| Dr Anthony Duncan                   | Psychiatrist, Capital & Coast DHB, National Advisor to the Intellectual Disability (Compulsory Care and Rehabilitation) Act, Ministry of Health |
| Dr Crawford Duncan                  | Psychiatrist, Psychogeriatric Service, Kenepuru Community Hospital, Capital & Coast DHB   |
| Gillian Ferguson                    | Lawyer, Dunedin   |
| Dr Mark Fisher                      | Consultant Psychiatrist, Mental Health Services for Older People, Middlemore Hospital, Counties Manukau DHB                                     |
| Paul Gibson                         | Disability Rights Commissioner  |
| Associate Professor Kris Gledhill   | Auckland University of Technology   |
| Dr Ben Gray                         | GP, Senior Lecturer, Department of Primary Healthcare and General Practice  |
| Douglas Hancock                     | Policy & Advocacy Team Leader, New Zealand Human Rights Commission  |
| Ellen Hewitt                        | Statistical advice for survey   |
| Professor Jo Manning                | Faculty of Law, University of Auckland  |
| Christine Maxwell                   | Nurse Practitioner (Mental Health), Southern DHB  |
| Dr Brigit Mirfin-Veitch             | Director, Donald Beasley Institute, University of Otago   |
| Associate Professor Jing-Bao Nie    | Bioethics Centre, University of Otago   |

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| Iris Reuvecamp                      | Lawyer, Wellington  |
| Dr Gordon Royle                     | Haematologist and Clinical Researcher, Middlemore Hospital, Counties Manukau DHB                      |
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| Dr Barry Smith                      | QSM: PhD, Te Rarawa and Ngāti Kahu, Chair of the Health Research Council Ethics Committee             |
| Dr Jeanne Snelling                  | Research Fellow Bioethics Centre, University of Otago   |
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| Dr Cordelia Thomas                  | Associate Commissioner Investigations, Office of the Health and Disability Commissioner               |
| Dr Jesse Wall                       | Faculty of Law, University of Otago   |
| Justice Joseph Williams             | High Court Judge  |
| Dr Greg Young                       | Consultant Psychiatrist, Capital & Coast DHB, Clinical Lecturer Bioethics Centre, University of Otago |

## **Survey of doctors and feedback on draft Toolkit for Assessing Capacity**

The following people either contributed to the survey of doctors and/or gave feedback on the draft toolkit:

Associate Professor Lynley Anderson, Dr Jo Baxter, Dr Jane Casey, Dr Gary Cheung, Dr Kay Cunningham, Dr Lorraine Davison, Professor John Dawson, Professor Tony Dowell, Dr Anthony Duncan, Dr Crawford Duncan, Dr Lucy Fergus, Dr Mark Fisher, Dr Yvonne Fullerton, Professor Grant Gillett, Dr John Gommans, Dr Ben Gray, Dr Roger Harris, Dr Paul Hendy, Ellen Hewitt, Dr Sistra Jayathissa, Alex Ruck Keene, Dr Jenny Keightley, Dr David Maplesdon, Professor John McMillan, Denal Meihana, Dr Maha Naguib, Dr Giles Newton-Howes, Dr Gareth Owen, Associate Professor Carmelle Peisah, Dr Neil Pickering, Dr Elaine Plesner, Iris Reuvecamp, Dr Anel Reyneke, Dr Geoff Robinson, Professor Chris Ryan, Dr Scott Schalk du Toit, Dr Jeanne Snelling, Dr Tim Stokes, Professor George Szukler, Deanne Wong, Dr Greg Young; and the respondents to the survey who are doctors at Hawkes' Bay, Wellington and Hutt hospitals and general practitioners all over New Zealand.

