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The International Journal of Mental Health and Capacity Law is a peer reviewed open access journal devoted to the intersection between law, mental health and mental capacity. It builds on the well-reputed Journal of Mental Health Law, with a revised name to reflect its wider focus. It also follows the desire of its predecessor to combine academic articles and commentary with material that is designed to be used by practitioners – lawyers, and medical or social work professionals – in these nuanced areas.

The Editors are keen to receive academic articles, both shorter ones of around 5000 words and longer ones of up to 12,000 words; and practice points, case notes and reports of research of around 5000 words. Submissions should be made via the Journal's website - http://journals.northumbria.ac.uk/index.php/IJMHMCL/index - and comply with the directions given there as to process. Manuscripts should comply either with the Oxford University Standard for Citation of Legal Authorities (http://www.law.ox.ac.uk/publications/oscola.php) or the APA Referencing Style Guide. If you use footnotes, we encourage short footnotes.

Submissions must be original, properly reference any third party material and comply with any copyright limitations. Any possible conflicts of interest must be identified. If an article reflects original research involving human participants, a statement is required that relevant ethical requirements have been met, including an indication as to which body gave ethical approval for the research and the relevant reference number.

All submissions will be peer-reviewed by a double blind peer review process before being accepted for publication; naturally, there will be a process whereby an article may be accepted subject to minor or more major amendments being made. We will endeavour to provide feedback as to why any rejected submission has been rejected.

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Articles and pieces in this issue have been edited by:
Kris Gledhill, Piers Gooding, Giles Newton-Howes, Kevin Stone, Penny Weller and Darius Whelan

EDITORIAL

This issue of the International Journal of Mental Health and Capacity Law opens with a call to explore the possibility of reducing the use of coercion made from the perspective of experience of being coerced and also of working for a mental health watchdog and sitting on a review of mental health law in Scotland. Graham Morgan MBE's speech to a 2023 conference reflects his experience and expertise, and considers also the value of a healthy home life.

We move then to an exploration by Shipsides and colleagues of an interesting question discussed in the context of the Mental Capacity Act 2005 in England and Wales but with implications in other jurisdictions, namely the relationship between the assessment of mental capacity and risk. The approach under the 2005 Act is that capacity is issue-specific, such that people with relevant impairments that affect their ability to make or communicate a decision may have capacity in relation to some decisions (which can be followed) but not in relation to others (such that support or some other form of decision-making is put in place). But how does the level of risk of what happens pursuant to the decision get factored into the process? They argue that the issue-specific approach to capacity will incorporate a reflection of the risk in the decision because higher-risk situations tend to have more information to be weighed and information of higher difficulty, such that enhanced cognitive capacity is needed. I hope that readers will agree that this article provides a useful addition to the debate.

The third piece outlines a project that has commenced in New Zealand, which is increasingly referred to also by its Māori name, Aotearoa, to explore what a process of supported decision-making will look like if it is designed from a Māori perspective. In particular, it explores how Mental Health Advance Preference Statements, used to allow those affected to have a voice in how they are treated, can be designed and operated so as to be culturally appropriate, relevant and hopefully successful. Since I am involved in this research, I would like to thank Professor Jill Stavert of Edinburgh Napier University for carrying out all the editorial work on this piece, most importantly the peer reviewing process, so that I was insulated from it.

In addition, the issue contains four book reviews by the indefatigable Alex Ruck Keene: he sets out why *Advance Directives Across Asia: A Comparative Socio-Legal Analysis*, edited by Daisy Cheung and Michael Dunn is a "joy" because it "goes substantially further" than what is promised in the title; why Kartina Choong's *The Mediico-Legal Development of Neurological Death in the UK* presents "an extremely useful overview" of death being viewed as a cardio-respiratory but also neurological matters, and the results of that; why *Suicide and the Law* by Elizabeth Wicks is a "stimulating and elegantly written work"; and why *The Future of Mental Health, Disability and Criminal Law*, edited by Kay Wilson, Yvette Maker, Piers Gooding and Jamie Walvisch, is a "very stimulating book" that is "a fitting tribute" to the "hugely significant" contribution of Professor Bernadette McSherry.

As always, I'd like to express my thanks to authors who submit their articles and those who provide assistance to keep this journal as a wholly open access publication, including peer reviewers and the great supporting team at the University of

Northumbria. The editorial team welcome contributions from all perspectives, whether in the form of research articles, notes about developments in statutes, policies or jurisprudence, accounts of research in progress, reviews of books, or any other output that might be of interest to readers.

Kris Gledhill

REDUCING COERCION

GRAHAM MORGAN MBE

This is a transcript of a talk by Graham Morgan MBE – Mental Welfare Commission for Scotland – to the Third UK and Ireland Mental Health and Diversity Law Conference, July 2023. Nottingham (England.)

Graham drew on the Report of the Scottish Review into Mental Health Legislation[1] *for this talk and for a better understanding of how he thinks coercion could be further reduced would especially recommend reading the chapters on Human Rights Enablement, Autonomous Decision Making Tests, Supported Decision Making and Economic Cultural and Social Rights.*

I am speaking as the Past Joint Vice Chair of the Scottish Review into Mental Health Legislation and the lead for its coercive treatment workstream. I am also currently on a compulsory community-based treatment order ('CCTO') and have a diagnosis of schizophrenia.

I work for the Mental Welfare Commission where I regularly meet with people with lived experience of mental illness and of detention.

First of all an apology – I am familiar with Scottish Legislation but less so with that of other countries. Just to set the context; my CCTO means that I am legally obliged to accept my fortnightly injection and to see psychiatric staff and let them into my house for my care and treatment. I go to a tribunal every two years when it is renewed and so far, see no prospect of that stopping.

First: the Scott review and coercive treatment. We cannot avoid the fact that treatment carried out against someone's will, sometimes involving force, is by its nature coercive. This does not have to mean that the people doing this are carrying it out with malicious intent and with the wish to cause harm; in reality we believe that the intent behind most forms of coercive treatment are to avoid much greater harm and that this is usually what happens in practice.

However even though such actions are often carried out to save life I can still vividly remember running down corridors with nurses chasing me and alarms blaring and hate the memory of having a nurse follow me wherever I might go even when I went to the toilet or the shower. I know it was done to stop me harming myself but when I visit a hospital nowadays and hear the alarm go off or see people on 'constant obs' it can bring me back to difficult times in the past. It is for these sorts of reasons that we agree with the Royal College of Psychiatrists that coercive treatment is often traumatic and people need help with this trauma.

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[1] Available via: https://webarchive.nrscotland.gov.uk/20230327160310/https://www.mentalhealthlawreview.scot/ (accessed 19 July 2023).

We agreed that forms of coercion will need to continue for the foreseeable future and that maybe it will never be possible to eliminate it. We based these opinions on the evidence provided by people with lived experience in Scotland and on international evidence that we obtained but in keeping with Piers Gooding's research[2] we think we should work towards the eventual elimination of coercive treatment, if at all possible.

Regarding reducing coercion, I am going to fall into my idealistic 'what if' mode. I think mental illness, however we define it and however we see trauma and the social environment as a part of it, is a horrific experience. I have a terrible feeling that some people think that if people were just nice to us and kind and addressed a few inequalities that face us everything would be ok, but we can enter realms where our reality is not amenable to reason and we can find we have emotions and behaviours that, far from being the grateful awkward response to the offer of support are raw wild expressions of grief and pain and anger. We do not always seek out help; sometimes all we feel is pain and pain is rarely something that we can easily deal with. It can be utterly disruptive and destructive even when we are begging and not begging for help at the same time.

This is, I think, one of the key reasons why coercive treatment is sometimes needed and will continue to be but to contradict what I just said; I do believe that if we have a society and services where belonging and trust are taken for granted, then kindness and the very love and compassion this implies may prevent alienation and otherness. If we had a society and services where people like me are not looked on with suspicion and fear, then maybe we would not look on society and services in turn, with the same fear. Maybe distress would not get to the point that coercion is necessary or the preferred route.

If we had services we could turn to in the community, such as community and peer support as well as Wellbeing hubs and some alternatives to hospital when we are in crisis. If Psychiatric emergency plans were living documents and the infrastructure of community services were truly in place. If hospital wards were designed so we want to be there and are made to feel safe rather than a clinical environment we feel alienated in and if, in future, new buildings are informed by our lived experience and look at reasonable adjustment and universal design we might end up with something we appreciate but which also serves its purpose well.

If we had policies like 'Safe Wards' adopted in hospital and if we can align between the human-rights based approach which we recommended, and the recovery approach: into an approach which would include mutual support, hope, appreciation, being valued, having people 'on our side' and having activity which we value and in addition, if we had the beds we needed when we needed them and if our friends and relatives were listened to and supported. And If we anticipate crisis and relapse with genuinely participative joint crisis planning which comes into effect before we lose capacity, then maybe we would cope better for longer, have better lives and when, as

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[2] Gooding, P., McSherry, B., Roper, C., & Grey, F. (2018). Alternatives to coercion in mental health settings: A literature review. *Melbourne: Melbourne Social Equity Institute, University of Melbourne*.

will always happen, life falls apart, maybe we will have safe places and people to go to without coercion becoming necessary and. if it does, maybe it will be less often and for less time. That is the hope.

As I said hugely idealistic and, quite rightly, we had many replies to our consultation saying for these things to happen we need resources; that this is less a question of legislation and more about services. And yes it is. It is all about resources, as is developing community and trust and knowing we are a part of our communities. It is more than investing in mental health services; it is about investing in our society, investing and valuing staff and in the elements that mean that some of the most isolated people of all feel a part of and welcomed.

We found out many international approaches which have been shown to reduce coercion but rather than dictate what we want to happen years and years before anything is implemented in Scotland we suggest that we have an improvement group with lived and carer experience central to it which looks at and makes recommendations, alongside government, about some of the approaches that may ultimately lead to less coercion in the future but which also in line with our economic social and cultural rights, help create a better quality of life for us. Alongside that we need to invest in research into these issues, especially coercion, and to encourage high quality lived experience led research.

Regarding detention, I mentioned trust and belonging at the beginning and also different communities of people. We think we should learn from research carried out by the Mental Welfare Commission and elsewhere to make sure that the treatment of people from diverse ethnic communities is such that all assessments have been made on the same basis as for all people. People should have been offered at least the same level of support for decision-making as for any other person. Their cultural, linguistic, religious or belief requirements should have been identified and professionals need to show how these needs will be met. If they or their supporters have said that racism or cultural insensitivity may be present we need to know these issues are being addressed. We also want to be sure there is culturally appropriate collective advocacy that the Government will resource and will also empower leaders of Scotland's minoritised ethnic communities to lead on solutions which ensure access to mental disability services for their communities. It should also address racial discrimination through an approach which develops the Patient Carer Racial Equality framework, with monitoring and enforcement by scrutiny bodies.

My personal opinion is that comparable actions should also happen with other marginalised communities who, I imagine, future research might also reveal comparable levels of discrimination in mental health services and coercive treatment.

Despite the considerable amount of research that has been done into rising rates of detention here and elsewhere it is very hard to tell why a rise or reduction in detention rates has happened. It may be that a rise in detention reflects a rise in rates of mental illness and that with austerity and economic hardship; crisis and distress increases. Detention in these circumstances may be, strangely, a right and proper way to protect people from harm.

Alternatively, a shortage of community services or perhaps, with staff shortages and pressure on beds and services, a culture may develop where it is easier to detain than to give the sort of support people have a right to.

Ideally further research would reflect on the Human rights approach we took with the review. There is almost no research around coercive treatment that uses a human rights framework as the basis of the research. We would like to see future research designed that seeks to decide if a person’s human rights are enhanced by certain interventions or not; those balances between the right to life and health compared to rights to liberty and independent living and so on.

Now onto detention and things like the time we are detained for.

You will hear elsewhere at this conference about research by the Mental Welfare Commission into the length of short term detentions; following this we have proposed pilot projects into the length of such sections.

Regarding Compulsory Community Based Treatment Orders we are also aware that the evidence of their effectiveness is very weak, with contradictory findings from different studies. Some studies in Scotland show they provide protection for life and reduce days spent in hospital while others show no effect. We suggest that more research is carried out into them to help determine future policy, again looking at their value through a human rights lens, including our economic social and cultural rights, but also trying to work out why they have been rising, how they can be best used and who they may or may not be effective with.

We also think we should make sure that CCTOs will ensure access to recovery-focussed, trauma-informed, community-based services and that from the beginning there are revocation strategies built in to ensure they are being used for the right reasons and to best effect.

I am going to finish with what may seem to be throw away comments but which are important to me and maybe relevant to this discussion.

It is often those we love most who are witness to the worst of our distress and are most affected by it. I will never forget my brothers voice cracking with anger when I last talked of how I looked forward to stopping my medication. He said that each time that happened the whole family was on standby for the time I finally succeed in killing myself: those around us need listened to and respected and supported.

I constantly meet people who are told that have the capacity to decide whether to live or die when they are seeking help and that this is their choice. It is utterly insulting and depressing.

Sometimes I wonder at our definition of mental disability and feel for those who are dismissed as ‘just’ being unhappy and told to take a walk or run a bath when they cannot imagine living another moment and sometimes I am aghast when people say they get better treatment from the police when they are in crisis than from the NHS. I am fed up with hearing stories about people told to go home at three in the morning with no money in their pockets, freezing temperatures and despair in their hearts. When they are returned to A&E by the police or ambulance a couple of hours later, we should hang our heads in shame.

And although our freedom and our rights are crucial issues I think just as crucial a rights issue; needing just as much debate and legislation, are the people who die, end up homeless or in prison or just alone and scared and isolated because they are denied support and care and services. This is fundamental too. The rights we lose; the horror we experience when society seemingly couldn’t care less what happens to us.

On a completely different note. Once I lived in a toxic relationship, and getting sectioned was a frequent occurrence. Now, although I am on a CTO, I haven’t been in hospital for ten years. I now live with a family where respect is a given, as is laughter and giggles and cuddles. I walk by the sea with the curlews, seals and terns. I go to Argyll and Bute Rape Crisis and the difference in approach is incredible and liberating.

I work, I write books. I go to Jeans Bothy, which is a mental health and wellbeing hub in the nearby town where I can be me without hiding my reality. I have found a life where, everyday I feel treasured. Maybe my medication is vital but so is Wendy my partner, James and Charlotte the twins, and Dash the dog who sleeps on my bed. Most people in my situation do not have anything approaching this. Why not?

It is no wonder we end up sectioned when our lives are close to unliveable. We may need advance statements, or care plans, depot clinics and tribunals but above all we need to shift our focus to say “How do people like me find friendship and love? How do we get to find security in where we live, or glimpses of beauty when we walk out the house, someone who wants to kiss us every day, enough money to afford a treat, or to heat the house?”

Having this in my life means I am less convinced when I say out loud that “I want to die” whenever no one is near me. I get my jag every two weeks; its irritating, I sometimes get fed up with the nurses and sometimes I like them but they are a tiny part of my life.

The laws, services and policies we obsess with about for our freedom and rights are important but equally important, is when we recognise that even though I miss the feeling of colour in my life, I have everything I could ever want and that other people could have similar.

That did not come from the NHS; it came from my partner, my family, my friends, people believing I had the skills to work and speak. It came from knowing when I get home I will probably sit on the beach and look out at the mud flats with a book in my lap, the breeze on my face, crows picking at the seaweed, herons standing still and a home I look forward to returning to. Such things as this are just as important as the formal help I am meant to be given. With this the can of petrol or the train tracks become less of an obsession and I can dare to dream of something different altogether.

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RISK AND CAPACITY: DOES THE MENTAL CAPACITY ACT INCORPORATE A SLIDING SCALE OF CAPACITY?

DANIEL SHIPSIDES, ALEX RUCK KEENE & WAYNE MARTIN[*]

ABSTRACT

The law places considerable weight on the question of whether a person has, or lacks, mental capacity. But approaches differ over whether and how capacity assessments should be sensitive to risk. Should a more stringent test be applied where risk is high? The question has generated considerable debate among bioethicists and jurists. In this paper, we review the literature and consider the standard of capacity defined in the Mental Capacity Act 2005 in England/Wales (MCA). While the MCA has been extensively discussed, the question of whether it adopts a 'sliding scale' for assessments of capacity has not been squarely addressed. We review the knotty legal history of the statute regarding this issue, and argue that the MCA is best understood as adopting neither a risk-ability nor a risk-evidence sliding scale. We show that the MCA nonetheless accommodates risk-sensitivity in capacity assessment in at least three different ways. The first derives the MCA's approach to decision-specificity, the second from a risk-investment sliding scale, the third from what Law Commission once described as a 'general authority' for carers to act. We argue that the resulting approach steers around two objections that critics have levied against sliding scales for capacity assessment.

Keywords: capacity assessment, civil standard of proof, decision-making capacity, Mental Capacity Act, risk, sliding-scale

I. INTRODUCTION

In this paper we consider whether and how the assessment of decision-making capacity under the Mental Capacity Act 2005 (the 'MCA') should be sensitive to information about the degree of risk involved with the decision. To frame the issue that shall concern us, it will be useful to begin with three simplified scenarios:

> Scenario 1: A and B are recovering from head injuries incurred in accidents. Each expresses an intention to make a high-risk-high-gain unsecured investment with a portion of their financial assets. Family members express concern about whether, in light of continuing cognitive impairments consequent upon their accidents, A and B have the capacity to make investment decisions. For A, the amount of the proposed investment is small, and amounts to only a tiny fraction of the overall value of his savings. For B, the amount of the proposed investment is large, and amounts to nearly the totality of his assets.
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> Scenario 2: C and D face medical decisions. C has been offered a treatment that is well-tested and known to have minimal side-effects and a high chance of success. D has been offered an experimental treatment that is known to have severe side effects in a small number of patients.

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> Scenario 3: E faces a medical decision. The doctors have recommended a low-risk treatment for a high-risk medical condition.

The question that concerns us arises in each of these three scenarios. A and B each face a financial decision. But the risks faced by A are negligible while those faced by B are substantial. Should both be assessed by the same standard of decision-making capacity? Or does it make sense to use a lower standard in assessing A's ability to make a low-risk decision, while holding B to a higher standard, given the higher stakes? The same question arises with respect to C and D, in the context of their medical decisions. In the case of E we have one patient, facing a choice between consent or refusal. But the risks of consenting are low while the risks of refusal are high. So is it reasonable and lawful to apply a higher standard of capacity to E's refusal than to E's consent?

In what follows we argue that the assessment of decision-making capacity under the MCA can and should be sensitive to information about risk, but that it does not rely on the kind of 'sliding scale of capacity' that has been endorsed by some authorities and criticised by others. We survey the history of debate on this topic, reconstruct the genesis of the MCA's distinctive approach, survey its advantages and limitations before setting out how risk can be considered within the framework of the MCA.

II. BACKGROUND AND SCOPE

Reliance on the assessment of decision-making capacity (or 'competence' or 'mental capacity' or simply 'capacity') is an increasingly familiar feature of the legal landscape all over the world. [1] The presence or absence of the ability to make a decision functions as a legal threshold. With a few notable exceptions, those who have capacity enjoy the right to make a decision for themselves; where capacity is found to be absent, even after support has been provided, the decision is made by someone else, typically on the basis of an assessment of their interests (whether framed as 'best interests' or otherwise).

This paper is not concerned with the application of the best interests standard or other modes of proxy decision-making. Our focus is the legally antecedent question as to whether mental capacity is present or absent. Although the issue with which we are concerned has legal relevance in many jurisdictions around the world, our focus shall be the law in England and Wales, in part because the relevant legislation (the MCA) continues to be a point of reference internationally.[2] Under the MCA, mental capacity

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[1] Under the United Nations Convention on the Rights of Persons with Disabilities, the concept of 'capacity' and the use of capacity-based legislation has been called into question. This paper, however, will sidestep the issues raised by the Convention because capacity-based legislation is likely to remain in place in many jurisdictions (including England and Wales) for the foreseeable future (see A Ruck Keene, N Kane, S Kim & G Owen, 'Mental capacity—why look for a paradigm shift?' (2023) Medical Law Review).

[2] For statute and case law influenced by the MCA, see Singapore's Mental Capacity Act (2008), the Republic of Ireland's Assisted Decision Making (Capacity) Act 2015, and Australia's *PBU & NJE v Mental Health Tribunal* [2018] VSC 564. International academic discussions of capacity also use the MCA as a point of reference, e.g. see S Kim, N Kane, A Ruck Keene & G Owen, 'Broad concepts and messy

is legally defined as being person-, time- and decision-specific, and it is treated as a binary matter of fact. That is, for any particular person, time and decision falling within its scope,[3] the MCA stipulates that the person either has or lacks mental capacity to make the decision for themselves. No grey area is recognised in the law.

Mental capacity is defined in the MCA indirectly – through the definition of its opposite, mental incapacity:

> 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. (MCA sec. 2.1)

Extending the *via negativa*, the Act goes on to define the inability to make decisions as follows:

> [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 … (MCA sec 3.1)

It is worth noticing that at least three of these four 'statutory abilities' can vary by degree. A person's understanding of information can range more-or-less continuously from broad-and-superficial to detailed-and-profound. A person might have greater or lesser retentional abilities. And they might have a more or less fine-grained ability to use and weigh the relevant information. So where along these analogue gradients do we locate the digital tipping point between capacity and incapacity? And in identifying this tipping point, should an assessor apply a fixed standard that applies across the board – regardless of the risk involved? Or should the assessor be looking for a higher degree of understanding, for example, in cases where risks are high, while being content with a lower degree of understanding in a low-risk context?

III. SUPPORT FOR A SLIDING SCALE

The issue that concerns us was extensively discussed in the American bioethics literature in the 1980s and 1990s, where we find widespread (although not universal) support for what has come to be known as a *sliding scale approach* in the assessment of capacity. In 1982, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research endorsed a sliding scale approach in its landmark report on *Making Health Care Decisions*:

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realities: optimising the application of mental capacity criteria' (2022) 48 Journal of Medical Ethics 838-844.

[3] The MCA 2005 does not cover all situations where a person's legal capacity has to be considered by reference to their mental capacity. Examples where the MCA's test does not apply include such situations as to whether person has capacity to enter into a contract, which remains governed by the common law. However, the MCA 2005 is, in practice, the governing framework for considering capacity in most health and welfare contexts.

> When little turns on the decision, the level of decisionmaking capacity required may be appropriately reduced (even though the constituent elements remain the same) and less scrutiny may be required about whether the patient possesses even the reduced level of capacity.[4]

Shortly thereafter, two US academics who had worked on the Commission's report defended the same conclusion in a widely cited article that was later re-published as an influential book:

> [T]he degree of expected harm from choices made at a given level of understanding and reasoning can vary from virtually none to the most serious, including major disability or death. … The standard of competence ought to vary in part with the expected harms or benefits to the patient of acting in accordance with the patient's choice[.][5]

One advocate for this approach summed it up with a pithy slogan: *The greater the risk, the stricter the standard*.[6] Proposals for implementing the sliding scale approach varied. Some advocated for a 'tiered' assessment procedure, defining distinct standards of capacity for decisions with different risk profiles.[7] Others defended a 'movable fulcrum' approach, in which the level or quantity of decision-making abilities required for a finding of capacity varies continuously as a function of the risk-to-gain ratio associated with a choice.[8]

A number of rationales have been offered in support of the sliding scale approach. Some defences are frankly descriptive, being predicated on the claim that such an approach reflects the practices of capacity-assessment that have emerged in case law and informal practice.[9] But a more directly normative consideration has also played a role. It is often claimed that a primary purpose for the practice of capacity assessment is to strike a balance between two sometimes competing policy objectives: respect for autonomy and protection of well-being.[10] Standards of decision-making capacity are intended to allocate due recognition to both of these values by generally protecting a person's right to make their own decisions, while nonetheless allowing limitations of that right in the service of the person's health, safety and well-being when appropriate. Given this rationale, a risk-sensitive framework for capacity assessment has clear attractions. Where a person faces only a small chance of a small loss in well-being, the sliding scale approach makes it more difficult to justify an interference in

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[4] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research *Making Health Care Decisions Volume One: Report* (US Government Printing Office 1982), 60. The Commission's report does not use the expression 'sliding scale', but this terminology quickly became common in the literature that it prompted. See for example J Drane, 'The Many Faces of Competency' (1984) 15:2 The Hastings Center Report 295-297.

[5] A Buchanan and D Brock, 'Deciding for Others' (1986) 64 The Millbank Quarterly 17-94 [34]. See also A Buchanan and D Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press 1990) [51].

[6] Drane (n 4) [17].

[7] For a three-tiered approach, see Drane (n 4) and J Drane, 'Competency to Give an Informed Consent' (1985) 252 JAMA 17-21.

[8] For the metaphor of the movable fulcrum, see T Grisso and P Appelbaum, *Assessing Competence to Consent to Treatment* (Oxford University Press 1998) [Ch. 7].

[9] See for example Buchanan and Brock (n 5) [39].

[10] President's Commission (n 4), 60; Drane (n 7) [17]; Buchanan and Brock (n 5) [28-34]; Grisso and Appelbaum (n 8) [130-140].

autonomy; where there is a high chance of a large loss in well-being, interference in autonomy is proportionately easier to justify.

Support for the sliding scale approach is by no means confined to the US context. In pre-MCA case law in England and Wales, it found a forceful endorsement in Lord Donaldson's memorable dictum in a 1992 Court of Appeal case: 'The more serious the decision, the greater the capacity required'.[11] Five years later Dame Elizabeth Butler-Sloss offered a much-quoted variant on the same thought: 'The graver the consequences of the decision, the commensurately greater the level of competence is required to take the decision'.[12]

Despite this widespread support, the sliding scale approach has not escaped criticism. Two themes predominate among the critics. One line of criticism concerns the *asymmetry* between consent and refusal that can result from a sliding scale approach. In our third simplified scenario at the outset, for example, reliance on a sliding scale could mean that E has the capacity to consent to, but not to refuse, the recommended treatment. Critics object that such an outcome is conceptually muddled:

> Insofar as a choice between these options [accepting and forgoing treatment] requires an ability to comprehend and to weigh the consequences of both, it seems odd to maintain that accepting treatment calls for significantly less decision- making ability than refusing treatment.[13]

A second cluster of objections focuses on the impact of a sliding scale upon the *autonomy* of the person whose capacity is being assessed. In a wide-ranging 1991 paper on 'Competence to Refuse Treatment', Saks described the sliding scale approach as 'simply unsound' on the grounds that it 'impermissibly encroaches on the decision-maker's freedom to evaluate the worth and importance of decisions for herself'.[14] The most challenging among Saks' objections pertains to a practical matter that arises in calibrating a sliding scale. On the sliding scale approach, the standard of capacity depends on the risk of harm involved with the decision. But the degree of harm associated with a particular outcome is in no small part a function of what is viewed as valuable. So how should a sliding scale be applied in circumstances where the assessor and the patient differ over what is viewed as valuable, and hence over what is viewed as harm? Saks claims:

> The [sliding scale] view treats 'good' decisions as inconsequential and 'bad' decisions as consequential, and, by raising the level of competency for 'bad' decisions, would protect those who would harm themselves. The critical problem is, who is to define harm?[15]

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[11] *Re T* [1992] EWCA All ER 649 [para 28].

[12] *RE MB* [1997] EWCA Civ 3093 [para 30].

[13] M Wicclair, 'Patient Decision-Making Capacity and Risk' (1991) 5:2 Bioethics 91-104 [103-4]. For further discussion of the asymmetry objection, see Buchanan and Brock (n 5); M Wicclair *Ethics and the Elderly* (Oxford University Press 1993); I Wilks 'Asymmetrical Competence' (1999) 13:2 Bioethics 154-159.

[14] E Saks, 'Competency to Refuse Treatment' (1991) 69:3 North Carolina Law Review 945-999 [998].

[15] ibid [996].

In a later discussion of the matter, Saks qualified her opposition to sliding scales, allowing for a risk-sensitive approach in assessing the capacity to make 'extremely consequential' decisions,[16] but she continued to argue that competency doctrine has 'its foundation in autonomy', and that employment of a variable standard 'sets up someone else – the evaluator – as the judge of the goodness or badness of the decision'.[17]

Although the sliding-scale approach was much discussed between the 1980s and early 2000s, its place within the MCA itself remains unclear. There is no language in the MCA itself which prescribes such an approach, nor do the formal Explanatory Notes address the issue.[18] The original MCA Code of Practice (under review at the time of writing) comes closest to the question that concerns us in its section on 'professional involvement' in the assessment of mental capacity. Paragraph 4.53 indicates that professional involvement 'might be needed' in cases where 'the decision that needs to be made is complicated *or has serious consequences*'.[19] This is fine as far as it goes, but it does not address the question of the sliding scale, which is not about *who* should be involved in an assessment but about the standard of capacity that should be applied. Looking to the Law Commission's 1995 report on *Mental Incapacity*,[20] which laid the groundwork for the statute that followed, we find more silence on the question that concerns us. Although the report surveys a broad range of issues and cites academic literature in which the sliding scale plays a central role, it says nothing about whether the standard of capacity should vary with the risk associated with the decision. Since its passage in 2005, the MCA has generated an extensive academic literature. But to the best of our knowledge, none of this literature squarely engages the question of whether the MCA adopts a sliding scale – although some authors implicitly assume that it does so.[21]

IV.AN ANALYTICAL TOOLBOX

Before tackling our central question head-on, it will be useful to equip ourselves with three analytical tools. Think of the first tool under the heading: *Risk Relative to What?*

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[16] Saks and Jeste, 'Capacity to Consent to or Refuse Treatment and/or Research' (2006) 24 Behavioral Sciences and the Law 411-429 [423].

[17] ibid [422].

[18] Department of Health, *Mental Capacity Act: Explanatory Notes* (2005).

[19] Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (2007) [para 4.53]; emphasis added. See also: 'If a decision could have serious or grave consequences, it is even more important that a person understands the information relevant to that decision' [para 4.19]. The latter paragraph has recently been referred to by Lord Stephens in *A Local Authority v JB* [2021] UKSC 52 – the first case in which the Supreme Court had to consider the question of capacity under the MCA [para 74].

[20] Law Commission, *Mental Incapacity* (HMSO 1995).

[21] See for example G Owen, G Szmukler, G Richardson and others, 'Mental Capacity and psychiatric in-patients: implications for the new mental health law in England Wales' (2009) 195 Psychiatry 257-263 [258]. In a paper concerned with 'patients meeting the incapacity criterion of the Mental Capacity Act', the authors indicate that they have 'followed the approach outlined by Grisso & Appelbaum. This incorporates the "sliding scale" concept whereby decisions that carry a greater risk require greater evidence of the relevant decision-making abilities. This concept is similar to the English law notion that "the graver the consequences of the decision, the commensurately greater the level of competence that is required to make it."'

As we have seen, defenders of sliding scale approaches hold that the assessment of capacity should be sensitive to the level of risk involved in the decision. As risk rises, so does something else. But what exactly is the second variable? Here we can distinguish at least three different answers. The first approach is what we will refer to as the *risk-ability sliding scale*. This is the approach that finds expression in Lord Donaldson's Dictum and related slogans: 'The more serious the decision, *the greater the capacity* required' (emphasis added). Applied to someone like Patient E, this would mean that a relatively poor ability to understand treatment information might undermine E's capacity to refuse treatment, while leaving the capacity to consent intact.

But ability is not the only candidate for the second variable in a sliding scale. An alternative is to vary the *amount of evidence* required to warrant a finding of incapacity. Applied to Patients A and B, this would mean that a judge could find A capable of making the low-risk investment based on rather meagre evidence about his decision-making abilities. When it comes to B's high-risk investment decision, however, the judge would require more and clearer evidence. We shall refer to this approach as a *risk-evidence sliding scale*. Each of these two approaches finds defenders in the academic literature. Drane prefers a tiered risk-ability scale, for example, whereas DeMarco defends a risk-evidence approach.[22]

A third variant focuses neither on the level of capacity nor on the amount of evidence but on the *investment* made in the assessment itself. On a *risk-investment sliding scale,* the assessor invests more resources (whether in time, money, staff-resources, consultation with experts, …) when risk is high. Where risk is low, a lower level of investment is appropriate. These three variants on the sliding scale are analytically distinct, and can make a difference in practice. But they are not mutually exclusive, and some proponents of a sliding scale appear to advocate for a mixed approach.[23]

A second analytical distinction is closely related to the first. As we shall see, discussion of sliding scales in England and Wales often implicates two legal questions: (a) What is the standard of capacity? (b) What is the standard of proof? In practice, these two issues are closely related. Both pertain to the broader question of what has to be established in order to warrant a finding of incapacity. But the two issues are legally distinct, and the MCA addresses them separately. As we have seen, MCA sec. 2(1) and MCA sec. 3(1) jointly specify a standard of mental capacity. The standard of proof for legal proceedings under the Act is specified separately, in MCA sec. 2(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.[24]

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[22] Drane (n 4); Drane (n 7); J DeMarco 'Competence and Paternalism' (2002) 16:3 Bioethics 231-245.

[23] See, for example, the passage quoted above from the President's Commission, which refers both to the 'level of decision-making capacity required' and to the degree of 'scrutiny [that] may be required'. Supra.

[24] MCA 2005, sec. 2(4).

This is what is known in law as *the civil standard of proof*, which is elaborated in the MCA Code of Practice as follows: 'This means being able to show that it is more likely than not that the person lacks capacity to make the decision in question'.[25]

The third tool in our toolkit pertains to the idea of an 'outcome test' for capacity. In its 1995 report, the Law Commission distinguished three broad approaches to the definition of mental capacity, referring to the three approaches as 'status tests', outcome tests' and 'functional tests' respectively.[26] Under an outcome test, 'any decision which is inconsistent with conventional values, or with which the assessor disagrees, may be classified as incompetent'.[27] Outcome tests for capacity have been roundly rejected both in the academic and policy literature. Grisso and Appelbaum sum up the consensus position as follows:

> Virtually all legal and ethical perspectives on competence to consent to treatment agree that whether a patient's choice would be considered wise by most people is not a requirement for competence to consent to treatment.[28]

The Law Commission followed this consensus in firmly rejecting an outcome test,[29] and its position was ultimately reflected in one of the headline principles of the MCA: 'A person is not to be treated as unable to make a decision merely because he makes an unwise decision'.[30]

It should be clear that any sliding scale approach makes outcome relevant to capacity. Think again of Patient E as an example. On a sliding scale approach, E might well have capacity to consent to a medical treatment but lack capacity to refuse it. So would a sliding scale approach represent a relapse into the roundly denounced 'outcome test' approach to capacity? This is where we need the third tool in our tool kit. The crucial point to recognise is that there are a variety of ways in which outcomes might play a role in an assessment of capacity. Accordingly, there are more and less stringent ways of rejecting an outcome test. The most stringent approach would be to insist that a capacity assessment be *blind to outcome*. Some judicial statements appear to come close to this.[31] But this is not what we find in the relevant passage of the MCA. The crucial word there is *merely*: 'A person is not to be treated as unable to make a

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[25] Department of Constitutional Affairs (n 19) [para 4.10].

[26] Law Commission *Mental Incapacity* (n 20) [para 3.3].

[27] ibid [para 3.4].

[28] Grisso and Appelbaum (n 8) [33]. See also President's Commission (n 4); Law Commission *Mental Incapacity* (n 20); Donnelly *Autonomy, Capacity and the Limitations of Liberalism: An Exploration of the Law Relating to Treatment Refusal* (Thesis, University of Wales 2006) [234-237].

[29] Law Commission *Mental Incapacity* (n 20) [39-40, para 3.20].

[30] MCA 2005, sec. 1(4).

[31] 'The outcome of the decision made is not relevant to the question of whether the person taking the decision has capacity for the purposes of the Mental Capacity Act 2005', per MacDonald J in *Kings College Hospital NHS Foundation Trust v C & Anor* [2015] EWCOP 80 [para 29]. In context, this is a less absolute statement than it appears, tied as it is to the judge's framing of the principle in sec. 1(4), and the observation that 'the fact that a decision not to have life saving medical treatment may be considered an unwise decision and may have a fatal outcome is not of itself evidence of a lack of capacity to take that decision'.

decision *merely* because he makes an unwise decision'.[32] What is disallowed under MCA sec. 1(4) is that an assessor arrives at a determination of capacity *entirely* on the basis of the outcome. But this leaves open the possibility that variation in outcomes (and specifically in the risk associated with different outcomes) might be *relevant* in reaching a determination of capacity.

V. A KNOTTY LEGAL PREHISTORY

With these three analytical points in hand, let's turn to consider whether the MCA adopts (or permits) a sliding scale approach in the assessment of capacity. In this section we approach this question by revisiting some of the legal history of the Act, examining the Law Commission's work that helped pave the way for its eventual adoption. It is true, of course, that the draft Bill proposed by the Law Commission was not, in all particulars, the Act adopted by Parliament.[33] Nonetheless, the Law Commission's detailed work has, understandably, played a continuing role in the interpretation of the Act.[34] And, importantly for the purposes of this paper, the Law Commission's work brings to light themes that illuminate our later arguments about the ways in which risk-sensitivity is (and is not) incorporated in the later statute.

We have already observed that the 1995 Law Commission report on *Legal Incapacity* contains few clues to guide us on the issues surrounding the sliding scale. But that 1995 report was preceded by a series of Consultation Papers in which the Law Commission worked through some of the relevant options. For our purposes, the two relevant consultation papers are CP128 and CP129, both published in 1993. The Law Commission's position evolved over time, and requires some unpacking.

In its first attempts to grapple with the issues of interest in CP128, the Law Commission addresses the question of 'the amount and complexity of the information which the person might have to be able to understand'.[35] Its initial answer to the question is formulated using the idea of a *broad terms understanding*.[36] An understanding of the relevant information 'in broad terms' is legally sufficient for capacity. This approach has the flavour of a fixed, as opposed to a variable, standard for capacity. Notably, however, the paragraph concludes with a further thought, which sounds a rather different note:

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[32] Emphasis added. The crucial word 'merely' is sometimes missed in training materials on the MCA. For example, materials shared by the Social Care Institute for Excellence state the principle as follows: 'A person should not be treated as incapable of making a decision because their decision may seem unwise'. (British Institute of Learning Disabilities, publication date unknown, <https://www.scie.org.uk/files/mca/directory/bild-poster.pdf?res=true?> accessed online 9 May 2023)

[33] Notably, some of the differences between the draft Bill and the Act pertain to the precise definition of incapacity.

[34] For one notable example, see *Aintree University Hospitals NHS Foundation Trust v James* UKSC [2013] UKSC 67 [para 24].

[35] Law Commission, *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction*, Consultation Paper No.128 (HMSO 1993) [para. 3.23].

[36] 'The present law generally sets the threshold of understanding quite low, by requiring only a capacity to understand what is proposed in "broad terms". We consider that this approach is consistent with the desire to enable people to take as many decisions as possible for themselves and to limit intervention to the most serious cases' ibid [para 3.23].

> It is also consistent with the view recently expressed in the Court of Appeal that *the greater the gravity of the consequences of any decision, the greater the degree of understanding required.*[37]

We can recognise here a variant of Lord Donaldson's Dictum, which had only recently been formulated in the Court of Appeal's ruling in *Re T*. On this approach, the standard for capacity is not fixed, but incorporates a risk-ability sliding scale. There appears, then, to be a tension here between fixed and variable standards. Perhaps the best understanding of the Law Commission's position at this stage is that it contemplated that a 'broad terms' standard would suffice for most decisions, but that 'grave' decisions might require a more stringent standard.

However, the Law Commission later came to be sceptical about the use of an ability-risk sliding scale. In CP129 it states:

> [W]e have some difficulty with the idea that there should be a 'greater capacity' as opposed to an ability to understand more, or more significant, information. We do not consider that more than a 'broad terms' understanding is required[.][38]

The Commission now clearly recognises that the amount and complexity of *information* that must be understood will vary from one decision to another.[39] But its considered position reached in CP129 is that the standard as regards *understanding* that information should remain a constant: 'broad understanding' should suffice. This position is tracked through into the draft Bill attached to its final report, which noted that its approach had been supported by many respondents to its consultation,[40] and provided (in clause 2(3)) that

> [a] person shall not be regarded as unable to understand the [relevant information] if he is able to understand an explanation of that information in broad terms and in simple language.

In this final position there are no echoes of Lord Donaldson's dictum – no endorsement of a risk-ability sliding scale. A person is required only to have a 'broad terms' understanding of information; information which, in relation to different decisions, may vary in amount or complexity.

Whilst the Law Commission remained sceptical about the use of a risk-ability sliding scale, it nevertheless adopted positions that opened two other ways of incorporating risk-sensitivity in capacity assessment. First, it endorsed the use of an evidence-risk

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[37] ibid [para 3.23, emphasis added].

[38] Law Commission *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research*, Consultation Paper No.129 (HMSO 1993) [para 2.16].

[39] 'It is certainly true that a patient will need to be given, and understand, more information before making some decisions than others, and that a doctor faced with a refusal which will have serious consequences should offer the patient more information'. Ibid [para 2.16].

[40] Law Commission *Mental Incapacity* (n 20) [para 3.18], although it should be noted that the framing of this discussion was not by reference to the matters that we have been considering to date: 'Many respondents supported this attempt [i.e. referring to understanding 'in broad terms and simple language'] to ensure that persons should not be found to lack capacity unless and until someone has gone to the trouble to put forward a suitable explanation of the relevant information. This focus requires an assessor to approach any apparent inability as something which may be dynamic and changeable'.

sliding scale in connection with the standard of proof used in formal capacity assessments. In CP128, reporting on the results of an earlier consultation exercise, the Commission reviews three rival positions that had emerged: some had argued for reliance on the criminal standard of proof in proceedings regarding incapacity; others had argued for the civil standard of proof; and some had argued for an 'intermediate standard of proof' – higher than the balance of probabilities but lower than 'beyond a reasonable doubt'.[41] It will come as no surprise that the Law Commission endorsed the civil standard of proof.[42] But what is noteworthy is its reasoning in rejecting the third option.

> Some commentators have argued for an intermediate standard of proof, higher than the normal civil standard[:] the 'clear and convincing' standard. In fact, however, although the normal civil standard is the 'balance of probabilities', this is qualified by the requirement that *the graver the consequences the greater the standard of proof required*. We consider that this is entirely appropriate[.] (emphasis added)[43]

In rejecting an intermediate standard as unnecessary, the Law Commission makes clear that it understands the civil standard of proof to be 'qualified', incorporating a version of the sliding scale. And what kind of sliding scale? Despite the rhetorical echoes of Lord Donaldson's dictum, the proposed sliding scale is not Lord Donaldson's risk-ability approach; it is a risk-evidence sliding scale: more compelling evidence should be required where consequences are potentially 'grave'. In its final report the Law Commission maintained, although without detailed discussion, its stance in relation to the use of the civil standard of proof in legal proceedings.[44]

A second way of incorporating a form of risk-sensitivity left open by the Law Commission concerns capacity assessments undertaken outside of formal legal proceedings. Alongside considering the role of capacity assessments in the courts, the Law Commission at the same time proposed that there be a codification of the common law doctrine of necessity to provide a statutory authority for carers (both professional and informal) to act without any recourse to the courts.[45] In its final position, in what it proposed to call a 'general authority', the Law Commission's recommended that:

> In the absence of certifications or authorisations, persons acting informally[46] can only be expected to have reasonable grounds to believe that (1) the other person lacks capacity in relation to the matter in hand and (2) they are acting in the best interests of that person.[47]

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[41] Law Commission Consultation Paper 128 (n 35) [para 3.42].

[42] It should be noted that the Law Commission's endorsement of the civil standard comes in the context of its consideration of *legal proceedings*. We consider below the Law Commission's proposals for distinct provisions regarding capacity assessments undertaken outside such proceedings.

[43] Law Commission Consultation Paper 128 (n 35) [para 3.42].

[44] Law Commission *Mental Incapacity* (n 20) [para 3.2]. Note that in endorsing the civil standard of proof the Law Commission explicitly refer back to their discussion in Consultation Paper 128 which endorses the 'qualified' civil standard of proof.

[45] Law Commission Consultation Paper 128 (n 35) [paras 2.10-2.13].

[46] I.e. without recourse to a court – such a person could be a professional involved in the care of the person, as can be seen by reference to the example of the 'district nurse [giving] a regular injection and nursing care' as the sort of person who could be covered by this authority: Law Commission *Mental Incapacity* (n 20) [para 4.4].

[47] ibid [para 4.5].

The Law Commission did not amplify what it meant by having 'reasonable grounds to believe' that the other person lacks capacity, but the importance of this position is three-fold. First, external to legal proceedings, informal determinations of capacity are not required to be adjudicated by the civil standard of proof, rather, they are only required to be adjudicated in terms of a person's 'reasonable grounds to believe' that the other person lacks capacity in relation to the matter in hand. Second, by emphasising that the person could 'only' be expected to have such grounds, the Law Commission could be seen as implying that this was a bar which could be crossed relatively easily. Third, although risk is not mentioned in its discussion of 'general authority', the position here is consistent with the idea that risk may play a role in informal determinations of whether the other person lacks capacity.

To conclude this section, there are three themes that can be extracted from the knotty prehistory to illuminate the role of risk-sensitivity which we will shortly argue is incorporated in the MCA. First, the Law Commission was sceptical of a risk-ability sliding scale but remained sympathetic towards the idea that decision-making requires a 'broad terms' understanding of information that may vary in amount or complexity. Second, the Law Commission endorsed a risk-evidence sliding scale which it held to be congruent with the ('qualified') civil standard of proof. Third, although not discussed in detail, the Law Commission outlined how informal proceedings on the basis of the 'general authority' were to approach matters, an approach based upon 'reasonable grounds to believe' in incapacity. In Section VII, we argue that analogues of the first and third of these themes are tracked through into the MCA and ground two ways in which the statute incorporates risk-sensitivity. The second theme, however, as we show in the next section, is not one that is tracked through into the statute.

VI. UNRAVELLING THE ENHANCED CIVIL STANDARD OF PROOF

Up to this point we have found considerable support for a 'sliding scale' approach to the assessment of capacity (§2), together with a proposal from the Law Commission (§4) about how such a sliding scale might operate for purposes of legal proceedings by combining a single, functionally-defined standard of capacity with a variable, risk-sensitive standard of proof. But not long after the MCA came into force, this strategy for incorporating risk-sensitivity into the assessment of capacity encountered a substantial obstacle – in the form of a landmark legal ruling on standards of proof in civil proceedings.

To understand the ruling in question, we need first to appreciate that the period in which the MCA was drafted and adopted coincided with what, in retrospect, we can recognise as a kind of high-water mark for the idea of a variable civil standard of proof. We have already encountered prominent formulations of this idea in dicta from Lord Donaldson and Dame Elizabeth Butler-Sloss. But the popularity of the idea of a variable civil standard was by no means confined to capacity law. Judges coined a variety of names for the approach, dubbing it variously as the 'heightened civil standard', the 'enhanced civil standard', the 'flexible civil standard', or 'the civil standard, flexibly applied'. The cases in which this idea turned up involved, *inter alia*, anti-social behaviour orders, the sex offender register, deportation, and the nullification of citizenship. One particularly high-profile discussion appeared in the context of Lord Saville's public inquiry into the events known as 'Bloody Sunday'.[48]

In 2008, the issues pertaining to the enhanced civil standard came before the judges of the House of Lords in a case pertaining to the removal of a child from its parents. At issue was the question of the appropriate standard of proof to apply in determining whether a child is at risk with its parents or guardians; the case was heard by a five-judge panel, which was unanimous in its ruling. The main judgment was written by Lady Hale, who memorably wrote:

> My Lords, for that reason I would go further and announce loud and clear that the standard of proof in finding the facts necessary to establish the threshold … is the simple balance of probabilities, neither more nor less. Neither the seriousness of the allegation nor the seriousness of the consequences should make any difference to the standard of proof to be applied in determining the facts.[49]

This is not the place to undertake a detailed analysis of the reasoning that led Hale to her strongly worded conclusion.[50] Much of her reasoning was specific to the context of children's law, involving, *inter alia*, a construction of the relevant statutory language in the Children Act and an unpicking of a rather tangled set of authorities in case law pertaining to removal orders and related proceedings. But one part of Hale's reasoning has particular relevance for the correlative issues pertaining to capacity law. Hale allows that there 'are some proceedings, though civil in form, whose nature is such that it is appropriate to apply the criminal standard of proof'. But she goes on to insist that

> [C]are proceedings are not of that nature. They are not there to punish or to deter anyone. The consequences of breaking a care order are not penal. Care proceedings are there to protect a child from harm.[51]

Elsewhere she describes the relevant statute as establishing a threshold, the purpose of which is 'to protect both the children and their parents from unjustified intervention in their lives'.[52] Although Hale is here describing care proceedings under the Children Act, it is clear that much of her description would apply equally to the MCA. Judgments

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[48] Lord Bingham of Cornhill had invoked the idea of a 'flexible' civil standard in a 2001 case pertaining to a sex offender order, writing: 'The civil standard is a flexible standard to be applied with greater of lesser strictness according to the seriousness of what has to be proved and the implications of proving those matters' (*B v Chief Constable of the Avon and Somerset Constabulary* [2001] WLR 340 [para. 30]). The term 'heightened civil standard' was used, *inter alia*, by Lord Steyn in *Clingham v Royal Borough of Kensington and Chelsea* HL 17 Oct 2002, para 37, a case that concerned anti-social behaviour orders. Lord Saville used the expression 'enhanced civil standard' in his ruling on the standard of proof relevant to his inquiry (A2.41: Ruling, 11th October 2004: 'The Requisite Standard of Proof for Inquiries of this Nature'). The terminology of 'flexible application of the civil standard' dates back at least to the ruling by Lord Fraser of Tullybelton in *R v Secretary of State for the Home Department, Ex p Khawaja* [1984] AC 74 [para. 76] – a case that concerned a deportation order.

[49] *Re B* [2008] UKHL 35 [para 70].

[50] For analysis, see C Bendall 'The Demise of the Enhanced Standard of Proof in Child-Protection Cases' (2009) 31:2 Journal of Social Welfare & Family Law 185-191.

[51] *Re B* [2008] UKHL 35 [para 69].

[52] *Re B* [2008] UKHL 35 [para 54; see also para 59].

as to the presence or absence of capacity are not intended to 'punish or deter'; there are no penal consequences; and the purpose of the relevant legal threshold is to protect the relevant person both from harm and from unjustified intervention. In these respects, there is quite a close analogy between the two legal domains.

Hale's judgment in *re B* pertained specifically to the standard of proof in the Children Act, but Lord Hoffmann, in a concurring opinion, went further:

> [T]he time has come to say, once and for all, that there is only one civil standard of proof and that is proof that the fact in issue more probably occurred than not.[53]

Like Hale, Hoffmann allows that there may be some civil proceedings in which it may be appropriate to rely on the criminal standard of proof. What he disallows is the possibility of some third intermediate standard. And he concurs with Hale in elaborating the civil standard in terms of a straight balance of probabilities.

Hoffmann's concurring opinion is decisive for the MCA for two reasons. First, unlike the Children Act, the MCA is explicit in specifying that the civil standard of proof shall govern proceedings under the Act. As we have seen, those who originally framed the Act may well have had in mind a variable civil standard for purposes of legal proceedings, but Hoffmann's judgment makes it clear that there is only one civil standard of proof. The only alternative standard of proof available would be the criminal standard, and this is clearly ruled out by MCA sec 2(4). Second, this appears to entail that the use of evidence-risk sliding-scale capacity assessments is forbidden by the MCA. If the evidentiary threshold for capacity assessments is set by the civil standard of proof – that is, by the mere balance of probabilities alone – then sliding-scale approaches that modify this threshold in relation to risk are legally impermissible, at least in relation to determinations to be put before the court.

The significance of *re B* for the application of the MCA has been recognised by the Court of Protection. A recent example can be found in a 2020 case:

> The presumption of capacity serves to place the burden of proving incapacity squarely on the shoulders of the applicants. The burden of proof remains the balance of probabilities, nothing more nothing less (see *Re: B* [2008] UKHL 35). In some cases, the evidence will tip the balance significantly in one direction. In other cases, such as this, the balance will be more delicately poised, though still identifiably weighted to one side.[54]

Other examples of reliance on *re B* in the Court of Protection can be found, *inter alia*, in: *LBX v TT & Ors* [2014] EWCOP 24, *PL v Sutton Clinical Commissioning Group & Anor* [2017] EWCOP 22, *A North East Local Authority v AC & Anor* [2018] EWCOP 34 and *Local Authority v SE* [2021] EWCOP 44.

VII. INCORPORATING RISK-SENSITIVITY INTO MCA CAPACITY ASSESSMENTS

At this point it may seem that we have reached a kind of impasse. Despite considerable support in principle for the idea of a risk-sensitive approach in the assessment of

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[53] *Re B* [2008] UKHL 35 [para 13].

[54] *Avon and Wiltshire Mental Health Partnership v WA & Anor* [2020] EWCOP 37 [para 85].

capacity, the twists and turns of legal history may seem to leave little room for one in England and Wales, at least in relation to matters which may go to court. The Law Commission expressed scepticism about a risk-ability sliding scale, and no express provision for such an approach was included in the standard that was adopted by Parliament. As we have seen, there is evidence that the Law Commission understood itself to be proposing a risk-evidence sliding scale, but the legal space required for such an approach subsequently collapsed between the joint pressures of MCA sec 2(4) and Hoffmann's concurring opinion in *re B*. So where does that leave us? In the last analysis we believe that there is scope within the MCA to incorporate sensitivity to information about risk. [55] But its principal legal mechanism for doing so is best understood as neither a risk-ability nor a risk-evidence sliding scale.

In order to make this out in detail, we need to attend to two key provisions of the Act. The first of these comes in the context of the MCA's elaboration of the so-called functional test for decision-making capacity. We have already reviewed the four functional abilities enumerated in MCA sec 3(1): understand, retain, use/weigh, communicate. In its initial elaboration of these abilities, the scope of these abilities is specified quite generically: 'to understand the information relevant to the decision'. But MCA sec 3(4) goes on to elaborate on the matter of scope as follows:

> 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.

Consider first how this provision applies in the scenario of A and B, the two individuals who face decisions about investing some of their assets. It should be clear that the 'reasonably foreseeable consequences' of the investment decisions vary substantially between the two cases. For A, the range of foreseeable consequences is quite narrow. If the investment proves unsuccessful, then he might end up with a slightly smaller nest egg. If it is successful then he will be very modestly better off. An assessor would need to probe A's understanding of such prospects, but the information about foreseeable consequences that is relevant for A is circumscribed and simple. In B's case, by contrast, the 'reasonably foreseeable consequences' are much more far-reaching, and there is accordingly much more information that B must be able to understand, retain, use and weigh. The foreseeable consequences in B's case encompass a potentially devastating financial setback, which would itself have significant consequences. These consequences notably include his ability to pay for his future care needs. The consequence: B only has the capacity to make the investment decision if he is able to understand information about those needs, their costs, and the impact of an investment loss on his ability to pay for them. There is quite simply *more information* to understand in B's case, and the information itself is considerably *more complex*. The same point applies, *mutatis mutandis*, to the scenario involving C and D.

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[55] We do not discuss here the position in relation to those tests of capacity which remain governed by the common law (see n 2 above), save to note that any court which sought to maintain a sensitivity to risk in this context could not do so by reference to any 'heightened' civil of standard of proof, as this avenue has been eliminated in the way we have discussed above.

Note the consequence for an assessor: applying the provisions of MCA sec. 3(4) to these cases, an assessment of capacity will be *indirectly sensitive* to the degree of risk. Depending on the particular facts of the case, an assessor might well conclude that A has decision-making capacity to make his small investment while B lacks capacity to make the large one – even if their underlying abilities and impairments are identical. This is *not* because the assessor is applying a more stringent legal standard of capacity to B than to A. Nor is it because the assessor demands more evidence concerning B's capacity than concerning A's. We submit that the MCA (in its post-2008 legal configuration) is best understood as articulating a single legal standard of mental capacity and (where a court is involved) a single standard of proof that applies for all the decisions that fall within its scope. The potential for these divergent outcomes ultimately derives from the MCA's principle of decision-specificity in conjunction with the provisions of MCA sec. 3(4). A's investment decision differs from B's, not only in its monetary scale but in the range of foreseeable consequences that it implicates – *and hence in the cognitive load that it imposes*.

The provisions of MCA sec. 3(4) have a rather different significance for the case of E, who faces a decision about a low-risk treatment for a high-risk medical condition. Recall that critics of risk-sensitive sliding scales complained that they threaten to produce an objectionable asymmetry between capacity-to-consent and capacity-to-refuse. Views diverge as to whether such asymmetry is justifiable.[56] But notice the way in which an approach guided by MCA sec. 3(4) steers around this controversy. Firstly, as we have just seen, the MCA standard is not *directly* sensitive to risk; its indirect approach relies on the amount and complexity of the relevant information as a *proxy* for risk. But notice also the way in which it defines the scope of a capacity assessment with reference to the reasonably foreseeable consequences of deciding *one way or another*. Symmetry is thereby preserved, since the scope of the 'relevant information' (and hence the 'ability-load' associated with the decision) is the same regardless of whether E wishes to consent or to refuse. In either case E must be able to understand, retain, use and weigh information about the reasonably foreseeable consequences of *both* consent *and* refusal. This feature of the MCA approach can be seen in a recent High Court ruling, which emphasises that the question addressed by the courts does not separately concern the capacity to accept or to refuse, but *the capacity to make a decision*.[57]

At the outset of this section, we noted that there were two key provisions of the MCA that shape its approach to risk-sensitivity in the assessment of mental capacity. So far we have focused on MCA sec. 3(4). However, given that most cases do not come to

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[56] For two different defences of asymmetry between consent and refusal, see Buchanan & Brock (n 5) and D Brudney & M Siegler, 'A Justifiable Asymmetry' (2015) 26:2 Journal of Clinical Ethics 100-103. For criticism see G Cale 'Continuing the Debate Over Risk-Related Standards of Competence' (1999) 13:2 Bioethics 131-147.

[57] 'In relation to those falling within the scope of the Mental Capacity Act 2005 …, the courts do not examine separately capacity to consent and capacity to refuse medical treatment. Rather, the courts proceed by examining the question of whether the person has the capacity to make a decision in relation to the treatment' (Sir James Munby, writing in *An NHS Trust and X* [2021] EWHC 65 (Fam) [para. 78]). This approach to the framing of the question of capacity has recently been echoed by the Supreme Court in *A Local Authority v JB* [2021] UKSC 52.

court, of equal – if not greater – practical importance is MCA sec. 5, which enacted (in slightly different form) the proposed 'general authority' considered by the Law Commission at the same time as it was considering the knotty questions of standards of proof. In line with the Law Commission's approach, MCA sec. 5 protects any person ('D') from liability for actions undertaken to provide care or treatment – *provided that certain conditions are met*. The key conditions are laid out in MCA sec. 5(1) as follows:

> (a) before doing the act, D takes reasonable steps to establish whether P lacks capacity in relation to the matter in question, and
> (b) when doing the act, D reasonably believes –
>   (i) that P lacks capacity in relation to the matter, and
>   (ii) that it will be in P's best interests for the act to be done.

In principle, any person relying upon the defence in sec.5 should be prepared to defend their conclusions as to capacity before a court, and should therefore be prepared to adduce evidence meeting the civil standard of proof. However, in practice, very few such situations will come to court – by design.[58] It is therefore particularly important to note the reliance in these provisions on the words 'reasonable' and 'reasonably'. D enjoys sec. 5 protection from liability only if D has undertaken *reasonable steps* to address the questions of capacity, and *reasonably believes* that the person lacks capacity in the matter at hand. These concepts are not further elaborated in the statute, leaving open justiciable questions about what constitutes reasonable steps, and when a belief about incapacity is reasonably held. The Court of Appeal has emphasised the extent to which '[a] striking feature of the statutory defence is the extent to which it is pervaded by the concepts of reasonableness, practicability and appropriateness',[59] accepting in so doing that a person may be able to benefit from the defence even if they were not aware of the terms of the terms of the Act but had the 'prescribed state of mind' for purposes of sec.5.[60] So it should not automatically be assumed that a person can only be said to have a reasonable belief in the other's lack of capacity if they have directed themselves by reference to the civil standard of proof. Further, given the time-specific nature of capacity, the fact that a person may not subsequently be able to establish before a court that the other *now* lacks capacity to make a relevant decision does not mean that they did not have, at an earlier time, a reasonable belief that they lacked it.

We have highlighted above the Law Commission's (limited) discussion about the interaction between what is now sec. 5 and what are now secs. 2 and 3. We shall not undertake to address all of the open questions to which the issues highlighted here

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[58] See the description of sec.5 given by Lady Hale (judicially) in terms which unsurprisingly reflect the broad application which the Law Commission had foreseen for it: '[s]ection 5 of the 2005 Act gives a general authority, to act in relation to the care or treatment of P, to those caring for him who reasonably believe both that P lacks capacity in relation to the matter and that it will be in P's best interests for the act to be done. This will usually suffice, unless the decision is so serious that the court itself has said it must be taken to court'. *N v ACCG & Ors* [2017] UKSC 22 [para. 38].

[59] *Commissioner of Police for the Metropolis v ZH* [2013] EWCA Civ 69 at [para 40].

[60] The phrase used by the first instance judge (*ZH v The Commissioner of Police for the Metropolis* [2012] EWHC 604 (QB) [para 40]). The Court of Appeal did not directly address this point, but endorsed his conclusions and thereby can be said to have endorsed this approach.

give rise,[61] but there is one point about which it is important to be clear. Determinations of capacity in the context of sec. 5 are not made in isolation. There are obligations for those who make such determinations that are not to be found within the MCA (or indeed, any equivalent legislation in other jurisdictions). These obligations are found in regional and international human rights conventions which require states to do more than simply refrain (for instance) from taking life, but rather to take active steps to secure life in the presence of a real and immediate risk.[62] Conventionally, at least in the context of physical health, the extent of those steps will be dictated in part by whether the person is said to have capacity to make the decision to accept or refuse the measures proposed.[63] The consequences of this are two-fold.

First, in the context of a high-risk situation – especially one with limited time in which to investigate – the threshold for having 'reasonable grounds to believe' in a lack of capacity will inevitably be set low when the proposed action would secure the vital interests of the person. Second, and conversely, the threshold for proceeding on the basis that the person *has* capacity where respecting that decision will give rise to serious risks will be higher. By way of example, in *Arskaya v Ukraine* the European Court of Human Rights found that there had been a breach of Article 2 ECHR where a person, S, repeatedly refused to accept life-saving treatment in circumstances where

> S, showing symptoms of a mental disorder, the doctors took those refusals at face value without putting in question S.'s capacity to take rational decisions concerning his treatment. Notably, if S. had agreed to undergo the treatment, the outcome might have been different […]. the Court considers that the question of the validity of S.'s refusals to accept vitally important treatment should have been properly answered at the right time, namely before the medical staff refrained from pursuing the proposed treatment in relying on the patient's decision. From the standpoint of Article 2 of the Convention a clear stance on this issue was necessary at that time in order to remove the risk that the patient had made his decision without a full understanding of what was involved.[64]

Otherwise put: there is a *risk-investment sliding scale* in the assessment of capacity: the higher the risk, the more investment (of time, resource, effort, etc.) required in order to arrive at a conclusion that the person's decision is to be respected.

A risk-investment sliding scale has received less attention than other types of sliding scales which were widely discussed by bioethicists and legal professionals prior to the MCA. One bioethicist who did touch on this type of sliding scale does so only tentatively and in passing in relation to criticism of one of the more widely discussed scales: 'While the risks related to a decision might be grounds for taking more care in

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[61] And which are perhaps curiously unexplored in the literature, perhaps because of what appears to be a common (if – as noted – incorrect) assumption that all determinations of capacity, whether inside or outside court, are on the balance of probabilities.

[62] See, in the context of Article 2 ECHR: *Lopes de Sousa Fernandez v. Portugal* (2018) 66 EHRR 2.

[63] See, for a neat encapsulation of the position in respect of life-saving medical treatment, *Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80, [2016] COPLR 50.

[64] [2013] ECHR 1235. The ECtHR ruling and the risk-investment scale can be seen as the implicit working out of the principles set out in the MCA. The assumption of capacity (MCA sec.1(2)is maintained; the fact that the decision appears to be unwise is not taken to show that they lack capacity (MCA sec.1(3)), but, rather, emphasis is placed on the correlate duty to investigate (and potentially establish) whether a person lacks capacity and, if they do, what steps to take in their best interests (MCA sec. 1(5)).

assessing a person's competence, they should not provide grounds for increasing the standards by which a person's competence is assessed'. [65] And yet, as noted above, a risk-investment sliding scale has started to gain traction in the European Court of Human Rights. In a case subsequent to *Arskaya,,* which reviewed the circumstances surrounding the death of a woman following her participation in the second-leg of a clinical trial, the court ruled:

> [I]n view of their vulnerability, it is important that mentally ill patients enjoy a heightened protection and that their participation in clinical trials be accompanied by particularly strong safeguards, with due account given to the particularities of their mental condition and its evolution over time. It is *essential*, in particular, that such patients' decision-making capacity be objectively established in order to remove the *risk that they have given their consent without a full understanding of what was involved* (compare Arskaya v. Ukraine, no. 45076/05, §§ 87-90, 5 December 2013). The facts of the case reveal that Ms A.T.'s mental illness worsened during the first clinical trial […]. Yet there is no evidence in the case file that, when inviting her to take part in the second clinical trial and accepting her consent thereto, the doctors in charge duly assessed whether the applicant's daughter was indeed able to take rational decisions regarding her continued participation in the trial.[66] (emphases added)

Noting the serious consequences for the patient following the first clinical trial (her mental illness had worsened), the court criticised the medical team for failing to invest in assessing the patient's capacity to consent to the second trial.[67] The ruling indicates that high levels of investment in assessing a person's decision-making capacity are required when the risks associated with a decision are particularly serious. In light of this ruling, there is a case to be made that the risk-investment sliding scales must be used in determinations of capacity to ensure that states discharge their positive obligations under Article 2 ECHR (or its equivalents at UN treaty level).

VIII. CONCLUSION

We have argued that the MCA adopts a distinctive approach for incorporating information about risk into the assessment of decision-making capacity. Unlike other widely discussed approaches, its approach generates risk-sensitivity without relying on a risk-ability or risk-evidence sliding scale. Under the MCA's principle of decision-specificity, an assessment of capacity is *indirectly sensitive* to risk. Because high risk decisions characteristically have more complex and more far-reaching 'reasonably

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[65] Cale (n 56) [148]. See also Brudney & Siegler (n 56), although it is not clear here if they intend to refer to a risk-evidence or a risk-investment sliding scale: 'The higher the stakes for the patient, the more the physician should be sure that the patient has capacity because the downside of getting that judgement wrong could be the death of an incapacitated patient'.

[66] Traskunova v. Russia [2022] ECHR 631 [para 79].

[67] This touches on a tension between the concept of information disclosure when viewed from a capacity perspective versus a clinical negligence perspective. The latter pushes towards giving the person more and more information (to protect clinicians from charges that they have withheld material information) whereas the former pushes towards stripping back and presenting only the most salient information (to maximise chances that that the person is able to make their own decision). This issue is worthy of further consideration but reaches beyond the scope of this paper. The issue is touched on in E Cave 'Valid consent to medical treatment' (2021) 47 Journal of Medical Ethics; see also T O'Shea:
(2011) Green Paper Report: Consent in History, Theory and Practice. Essex Autonomy Project: <https://autonomy.essex.ac.uk/wp-content/uploads/2016/11/Consent-GPR-June-2012.pdf>
(accessed online 9 May 2023)

foreseeable consequences' than low-risk decisions, both the quantity and complexity of the relevant information will typically be higher with respect to a high-risk decision than with respect to a low-risk one, so the cognitive load required in understanding, retaining, and using/weighing that information will accordingly be higher. In addition, the MCA sustains a *risk-investment* sliding scale, under which a greater investment of resource (whether in staff time, evidence-gathering, consultation, etc.) is justified in cases where risk is high than in cases where risk is low. Finally, the framing of the MCA's liability protections, especially when read by reference to the external obligations upon professionals, are formulated in a way which has the effect of generating risk-sensitivity. But all these principles operate within the MCA's unified overall approach, which adopts a single legal standard of capacity which applies to all decisions that fall within its statutory ambit.

The MCA's approach to risk is not without limitations. Notably, its indirect approach to risk sensitivity effectively tracks risk only insofar as risk varies in proportion to complexity.[68] In circumstances like those of A and B, this proportionality obtains. B has capacity to make the high-risk decision only if he has the ability to understand, retain, use and weigh a large amount of fairly complex information. But it cannot be assumed that risk and complexity always track one another in this way.[69] If circumstances arise where the foreseeable consequences of a high-risk decision are fairly straightforward to understand, the MCA's indirect approach fails to be sensitive to risk.

Balancing this intrinsic limitation, however, we find a number of advantages of the MCA's approach. As we have seen, there has been widespread support among bioethicists and jurists for incorporating information about risk into the assessment of decision-making capacity. The MCA provides indirect, even if imperfect, ways of doing so. Moreover, the MCA's approach manages to steer around the two principal objections that have been laid against the so-called 'sliding scale' approach. Recall that the first objection focused on the asymmetry between capacity-to-consent and capacity-to-refuse that can result from reliance on a risk-sensitive sliding scale of capacity. But as we have seen, the MCA establishes neither a risk-ability nor a risk-evidence sliding scale. MCA secs. 2(1) and 3(1) serve to establish a single standard of capacity, and the framing of MCA sec 3(4) preserves symmetry between capacity-to-consent and capacity-to-refuse. So the MCA's approach avoids the first objection.

What about the second objection, which centred on Saks' insistent question: *Who is to define harm?* Saks objected that risk-sensitive approaches to capacity assessments encroach upon autonomy by requiring the assessor to impose her own values in determining what constitutes harm, and therefore what constitutes risk of harm. Saks' objection raises a number of complex and far-reaching questions that go beyond the scope of the present paper. But Saks' insistent question fails to get traction against the MCA's distinctive approach. This is because the MCA standard of capacity makes

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[68] More exactly: the MCA approach to capacity assessment is sensitive to risk only insofar as the level of risk associated with a decision is proportionate to the quantity and/or complexity of the information about the reasonably foreseeable consequences of deciding one way or the other.

[69] See T Buller, 'Competence and Risk-Relativity' (2001) 15:2 Bioethics 93-109; Owen and others (n 21) [99].

no express reference to harm or risk of harm. In formal terms, assessors should be asking: ‘What are the reasonably foreseeable consequences of deciding one way or another?’ The legally decisive issue is then not so much about whether those foreseeable consequences are *harmful* or not (which is the question that engages Saks’ question), but about whether the person is able to understand information pertaining to those consequences, and to retain, use and weigh that information in making their own choice.[70]

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

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ABSTRACT

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

1. INTRODUCTION

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

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[1] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijerph19106002.

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

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

2. BACKGROUND

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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[19] Brookfield FM. *Waitangi and indigenous rights: Revolution, Law and Legitimisation*. 2023. Auckland: Auckland University Press.

[20] Came H, O'Sullivan D, Kidd J, and McCreanor T. Critical Tiriti Analysis: A prospective policy making tool from Aotearoa New Zealand. 2023 Ethnicities; https://journals.sagepub.com/doi/full/10.1177/14687968231171651.

[21] Te Puni Kōkiri/Ministry of Māori Development. He Tirohanga o Kawa ki te Tiriti o Waitangi. 2001. https://www.tpk.govt.nz/en/o-matou-mohiotanga/crownmaori-relations/he-tirohanga-o-kawa-ki-te-tiriti-o-waitangi.

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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[38] United Nations Declarations on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 13 September 2007, A/RES/61/295, available at: www.refworld.org/docid/471355a82.html [accessed 21 June 2023].

[39] United Nations Declarations on the Rights of Indigenous Peoples: resolution / adopted by the General Assembly, 13 September 2007, A/RES/61/295, available at: www.refworld.org/docid/471355a82.html [accessed 21 June 2023].

[40] New Zealand Health Mental Health and Wellbeing Commission. *Te Huringa: Change and Transformation. Mental Health Service and Addiction Service Monitoring Report* 2022: Wellington: at 9.

[41] Ministry of Health; *Human Rights and the Mental Health (Compulsory Treatment and Assessment) Act 1992;* 2020, Ministry of Health, Wellington.

[42] Ministry of Health; *Transforming our Mental Health Law: A public discussion document*; 2021, Ministry of Health, Wellington.

[43] McDowell M (Health and Disability Commissioner). Consultation: Transforming mental health law in Aotearoa New Zealand. Email to Mental Health Act Review: 19 May 2022; Available at www.hdc.org.nz/media/6209/submission-transforming-mental-health-law-in-aotearoa-new-zealand-final-to-moh.pdf [accessed 23 June 2023].

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

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

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

3. GENESIS OF THE CURRENT PROJECT

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

A. A SDM Approach to Mental Wellbeing

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

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

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

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

[47] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijerph19106002.

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

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

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

B. MAPS and the Approach to Supporting Māori

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

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[49] Every-Palmer, S Kininmonth L, Newton-Howes G, et al. Applying human rights and reducing coercion in psychiatry following service user-led education: A qualitative study. 2021 Health Hum Rights; 23: 239-251.

[50] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002, at 12.

[51] Loosely: 'people of the land' and refers to Māori as the Indigenous peoples of Aotearoa.

[52] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijerph19106002, at 13.

[53] Gordon S, Gardiner T, Gledhill K, et al. From substitute to supported decision making: Practitioner, community and service-user perspectives on privileging will and preferences in mental health care. 2022 Int J Environ Res Public Health; 19:6002 https://doi.org/10.3390/ijerph19106002.

[54] O'Keefe D, Sheridan A, Kelly A, et al. 'Recovery' in the real world: Service user experiences of mental health service use and recommendations for change 20 years on from a first episode of psychosis. 2018 Admin Policy Ment Health Ment Health Serv; 45(4):635-648.

[55] Henderson C, Swanson JW, Smuckler G, et al. A typology of advance statements in mental health care. 2008 Psychiatr Serv; 59(1):63–71.

[56] World Health Organisation. Guidance on Community Mental Health Services: Promoting person-centred and rights based approaches. 2021. Geneva, WHO. https://www.who.int/publications/i/item/9789240025707

[57] Johnson S, Dalton-Locke C, Baker J, et al. Acute psychiatric care: Approaches to increasing the range of services and improving access and quality oc care. 2022 World Psychiatr; 21:200-236.

[58] Tinland A, Loubiére S, Mougeout F, et al. Effect of psychiatric advance directives facilitated by peer workers on compulsory admission among people with mental illness: A randomized trial. 2022 JAMA Psychiatr Online; 79(8):752-759. doi:10.1001/jamapsychiatry.2022.1627.

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

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

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

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[59] Lenagh-Glue J, Thom K, O'Brien A, et al. The content of Mental Health Advance Preference statements (MAPs): an assessment of completed advance directives in one New Zealand health board. 2020 Int J Law Psychiatr; 68:101537.

[60] UNCRPD, Art.12.3.

[61] Lenagh-Glue J, Dawson J, Potiki J, et al. Use of advance directives to promote supported decision-making in mental health care: Implications of international trends for reform in New Zealand. 2022 Australian NZ J Psychiatr; 57(5):636-641.

[62] Farrelly S, Brown G, Rose D, et al. What service users with psychotic disorders want in a mental health crisis or relapse: thematic analysis of joint crisis plans. 2014 Soc Psychiatry Psych Epidemiol; 49:1609-1617.

[63] Bee P, Brooks H, Fraser C, et al. Professional perspectives on service user and carer involvement in mental health care planning: a qualitative study. 2015 Int J Nurs Stud; 52:1834-1845.

[64] Lenagh-Glue J, O'Brien A, Dawson J, et al. A MAP to mental health: the process of creating a collaborative advance preferences instrument. 2018 NZMJ; 131(1486):18-26.

[65] Thom K, Lenagh-Glue J, Potiki J, et al. Service user, whānau and peer support workers' perceptions of advance directives for mental health. 2019 Int J Mental Health Nurs; 28(6):1296-1395.

[66] Lenagh-Glue J Potiki J, O'Brien A, et al. Help and hindrances to the completion of psychiatric advance directives. 2021 Psych Serv; 72(2): 216-218.

[67] Lenagh-Glue J, Dawson J, Potiki J, et al. Use of advance directives to promote supported decision-making in mental health care: Implications of international trends for reform in New Zealand. 2022 Australian NZ J Psychiatr; 57(5):636-641.

[68] Lenagh-Glue J, Thom K, O'Brien A, et al. The content of Mental Health Advance Preference statements (MAPs): an assessment of completed advance directives in one New Zealand health board. 2020 Int J Law Psychiatr; 68:101537.

[69] Lenagh-Glue J, O'Brien A, Dawson J, et al. A MAP to mental health: the process of creating a collaborative advance preferences instrument. 2018 NZMJ; 131(1486):18-26.

[70] Ministry of Health: *Whakamaua: Māori Health Action Plan 2020-2025* (Wellington, NZMoH, 2020).

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

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

4. ENABLING SUPPORTED DECISION-MAKING THROUGH MAPS

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

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

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

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

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

[76] UNDRIP. Article 18: *Indigenous peoples have the right to participate in decision-making in matters which would affect their rights, through representatives chosen by themselves in accordance with their own procedures, as well as to maintain and develop their own decision-making institutions.*

Article 23: …*indigenous peoples have the right to be actively involved in developing and determining health, housing and other economic and social programmes affecting them…*

Article 24.2: *Indigenous peoples have an equal right to the enjoyment of the highest attainable standard of physical and mental health. States shall take the necessary steps with a view to achieving progressively the full realization of this right.*

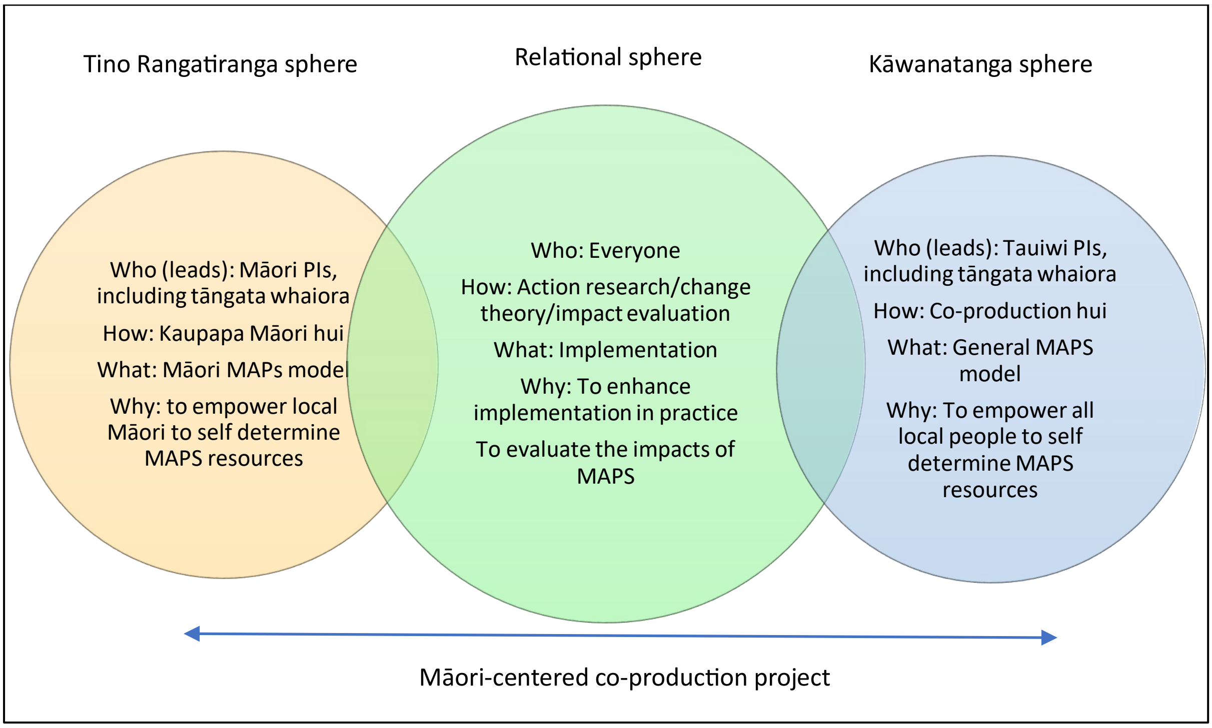
[77] Matike Mai Aotearoa. *He whakaaro here whakaumu mō Aotearoa: The report of Matike Mai Aotearoa.* 2016; New Zealand: Matike Mai Aotearoa. Available at: https://nwo.org.nz/wpcontent/uploads/2018/06/MatikeMaiAotearoa25Jan16.pdf.

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

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

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

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



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

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

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

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

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

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

GLOSSARY OF TE REO MĀORI TERMS

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

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

ADVANCE DIRECTIVES ACROSS ASIA: A COMPARATIVE SOCIO-LEGAL ANALYSIS, EDITED BY DAISY CHEUNG AND MICHAEL DUNN (CAMBRIDGE UNIVERSITY PRESS, 2021)

ALEX RUCK KEENE[*]

It is always a joy when a book not only lives up to what it promises in its title, but goes substantially further. This book is just such a one. Daisy Cheung, Assistant Professor at the Centre for Medical Ethics and Law at the University of Hong Kong, and Michael Dunn, Associate Professor at the Centre for Biomedical Ethics, National University of Singapore, have gathered a wide range of contributors to analyse the very different places of advance directives in end of life decision-making in 14 jurisdictions across Asia.[1] Crucially, they have also done the necessary heavy-lifting behind the scenes and on the page to pull together the threads to pose fascinating and important questions both about advance directives specifically but also about the interaction between international consensuses and localised traditions and expectations.

Of particular interest, and importance, is that the editors deliberately sought to cast their net widely in terms of defining 'Asia,' the book taking in countries as diverse as Israel, Saudi Arabia and the Philippines. This has the huge advantage of making clear that it is just as reductionist to talk about an 'Asian' approach to issues around advance directives as it is to talk about a 'Western' approach: and one only needs to compare the chapters about Saudi Arabia and Pakistan to understand that it is equally reductionistic to talk about an Islamic approach to such issues. Further, as it is impossible to talk about advance directives without talking about the framework within which they sit, the book also serves as a fascinating tour d'horizon of end of life decision-making more broadly in each of the jurisdictions.

In the discussion that I did with the editors for my website,[2] they (rightly) squirmed when asked to highlight jurisdictions which they found particularly interesting; they also (and equally rightly) wanted to emphasise that they wanted the book to stand alone, rather than continually to refer back or across to jurisdictions such as England & Wales. So whilst knowing it is perhaps wrong, I cannot help resist highlighting some of the points that particularly struck me in different chapters and some of the reflections that this Anglo-author had in response):

- The discussion in Ilhak Lee's chapter on South Korea of the Boromae Hospital case (page 58), in which the Korean Supreme Court found surgeons guilty as accomplices to murder in a case where a wife obtained the discharge of her

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[1] With limited exceptions, most obviously the chapter in relation to India, the contributors do not address so-called psychiatric advance directives.

[2] Advance directives across Asia – in conversation with Daisy Cheung and Michael Dunn – Mental Capacity Law and Policy – available at https://www.mentalcapacitylawandpolicy.org.uk/advance-directives-across-asia-in-conversation-with-daisy-cheung-and-michael-dunn/.

husband from hospital because she could not continue to pay for his care, [3] the Supreme Court considering that his wife's decision could not be regarded as an authoritative proxy decision, and that the surgeons had not taken proper measures to prevent an anticipated harm;

- Daniel Fu-Chang Tsai's discussion (in the chapter on Taiwan, pages 88-89) of the 2019 Taipei Declaration of Advance Care Planning, which expressly recognises that family members and other care givers have needs that should be attended to as part of the patient's care;

- The observation in Kelly Amal Dhru and Ravindra B Ghooi's chapter on India (pages 116-120) that the introduction of advance directives in the end of life context has been accompanied by far more controversy than their introduction in the psychiatric context by the Mental Healthcare Act 2017 (in complete contrast, it might be noted, to the situation in jurisdictions such as England & Wales). The same chapter also contains a fascinating discussion of the way in which the courts in India appear to view the family as part of the problem, rather than (potentially) as part of the solution, in decision-making;

- The detailed analysis of what Islamic law requires, or is considered to require in Saudi Arabia (by Z. Abbas Syed, E. Shamshi-Gookshi and A. Parsapoor) and Pakistan (by Mohammed Asim Beg, Erfan Hussain, Noshin Khan, Asma Hamid and Muhammad Atif Waqar), albeit that this is one area where it would have been very interesting had the authors of the respective chapters expressly commented on the interpretations advanced in the other, as this would have been a conversation I would very much liked to have been privy to;

- The relevance of resignation to uncertainty within Filipino culture analysed by L.D. de Castro, R.B. Manaloto, and A.A.L. Lopez (pages 192-5), a cultural phenomenon which it might be thought is more widely spread than just within the Philippines (and the Filipino diaspora), and might well be thought to play at least some part in the universally low uptake of advance decisions in every jurisdiction;

- The (tantalisingly brief) discussion in Bo Chen's chapter (at pages 240-1) of the role of voluntary guardianship amongst the LGBT community in mainland China as a way in which to seek to secure recognition of the place of a partner within decision-making;

- The emphasis placed in Japan (discussed by Reina Ozei-Hayashi, Futoshi Iwata, Satoshi Kodama and Miho Tanaka, at pages 248-249) on consensus in healthcare decision-making, including the family as part of the consensus group. Whilst this might be thought to sit at odds with the focus on the patient

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[3] Linked, in some ways, to the observation in Thitanant Tengaumuay's chapter on Thailand (page 91) that the concept of wishing to refuse medical treatment was barely considered before 2002 and the introduction of Universal Health Coverage; before then, the primary concern was even access health care services at all, regarded as a matter of "luck."

> in 'Western' systems, one might ask how often decisions to honour advance decisions to refuse treatment are honoured where (at the point that the decision is 'active') there is a mismatch between any indications that the patient may be able to give, the view of the family and the view of the medical team.

What is set out above are but a few of the points at which I found myself reaching for a Post-It note to put on the (curiously shiny) pages of the hardback, but hopefully serve to indicate just how many different directions it would be possible to jump from the springboard of the book's chapters.

Structurally, the editors have divided the jurisdictions that are covered into three categories: (1) well-regulated; (2) semi-regulated; and (3) non-regulated. However, as the editors make clear (page 13), "well-regulated" simply means that there is a clear set of rules, rather than that those rules actually work effectively. Miriam Ethel Bentwich (for instance) making a powerful case in relation to Israel (a supposedly "well-regulated" jurisdiction) that "the restrictive nature and supposed strict regulation of Israeli advance directives have actually led to their under-regulation" (page 19). As developed in the final chapter, the differences in approach represent different aspects of "generative accommodation" to "an emerging international consensus in healthcare practice and regulation regarding the value of an AD and its underlying ethical principle of respect for patient autonomy" (page 332). Cheung and Dunn's view, one which appears amply borne out on the evidence in the preceding pages, is that this a better way to explain the growing place of advance directives in different shapes in the jurisdictions they examine than indigenous development. The concept of generative accommodation, with its requirement for acute sensitivity to local traditions, is a helpful explanatory and descriptive tool for other areas where change is afoot: an obvious one being in relation to the Convention on the Rights of Persons with Disabilities. It is also one which is helpful in prompting reflection as to whether a failure to respond to the asserted consensus in the 'required' fashion simply because of wrong-headedness or bias, or is it because the accommodation reached actually represents the 'right' result for that particular jurisdiction at that point in time.

The only, minor, reservation that I have about this book is that, whilst the editors are at pains (page 14) to make clear that they did not seek to encourage their contributors to advance a case that advance directives are 'a good thing,'[4] the tenor of each of the chapters suggests that the contributors did, in fact, appear to consider this to be the case. It would have been interesting, if only to give shade to the light, to have had a chapter written by a contributor who appeared to have reservations about them, as it is clear that many people, in many of the jurisdictions covered, do indeed have reservations. However, I anticipate that it might well have proven challenging to find contributors with such views to take part in such a project, and even those contributors who are clearly most concerned to advance the cause of advance directives within

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[4] To be clear, I think that they are, although with caveats: see the advance planning discussion document I wrote for the Law Society of Scotland's 2022 report on Advance Choices and Medical Decision-Making in Intensive Care Situations, available at https://www.lawscot.org.uk/news-and-events/law-society-news/advance-choices-and-medical-decision-making/.

their own jurisdiction give more than enough material relating to that jurisdiction to enable the reader to gain what appears to be a rounded picture of the position.

Overall, therefore, this book comes highly recommended, and, as a real bonus, it is open access in its electronic form, thereby making its insights readily available to all.[5]

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[5] Full disclosure: I was involved in the conference in 2020 from which the book took its genesis.

THE MEDICO-LEGAL DEVELOPMENT OF NEUROLOGICAL DEATH IN THE UK, BY KARTINA A CHOONG (SPRINGER, 2023, c£44 PB/EBOOK)

ALEX RUCK KEENE[*]

This crisp (75 page) book by Kartina A. Choong, Reader in Medical Law and Ethics at the University of Central Lancashire, provides an extremely useful overview of how death has become to be understood not only as a cardio-respiratory matter, but also as a neurological matter, and an examination of the consequences of this within the United Kingdom. It also develops a thesis that the role of the courts in formalising and endorsing the clinical understanding of neurological death has been unhelpful, and that the definition of death should be a matter for Parliament.

The opening chapter, "Death Revisited," outlines how the traditional understanding of death (i.e. that respiration and circulation has stopped) started to be accompanied in the mid-20th century by a parallel understanding of death as the cessation of brain function. Choong sketches out how this understanding arose as a result of the increasing use of mechanical ventilation in modern intensive care units, enabling – often – respiration and circulation to be maintained indefinitely, and raising the question of the point at which it could or should be said that the person was nonetheless dead. As she identifies, this question was also tangled up with the development of approaches to organ donation – organs from those who have died from cardiac failure, for instance, will have been starved of blood and oxygen for a period of time, and will therefore not necessarily be in the best condition for transplantation. The ethical dilemma to which this gives rise in terms of the incentive to classify a ventilator-dependent patient as dead in order to obtain high quality organs is a clear one, and Choong traces its unfolding in the international context in concise and clear fashion.

In the second chapter, "The Emergence of Neurological Death in the United Kingdom," Choong turns to the UK context, and the role of the Conference of Medical Royal Colleges and Their Faculties (now the Academy of Medical Royal Colleges (AOMRC)). Interestingly, as she identifies, in the Conference's first statement on the matter (in 1976), it did not follow the approach taken in the United States in equating brain death with the demise of the person. Rather, the statement identified that a diagnosis of brain death was an indicator of futility; ventilation and other life-sustaining treatment could be withdrawn, not because the patient was dead, but because they had no chance of recovery. Three years later, in an addendum, the Conference made the shift to brain death as equating to the death of the person. Choong is critical of this addendum for having identified no basis for its "glaring leap in interpretation" (page 17); she is also critical more generally of the guidance for the fact that it did not make clear what role those with an interest in securing organ donations had played in it. She then traces through the development of guidance, both as to the diagnosis of what was (by 1995) being identified as "brain stem death", rather than "brain death,"

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and as to the relevance of brain stem death for organ donation, leading to the most recent (at the time of writing) guidance, the AOMRC's 2008 *Code of Practice for the Diagnosis and Confirmation of Death*, and the Royal College of Paediatrics and Child Health (RCPH)'s 2015 recommendations in relation to children aged under 2 months old. As Choong notes (page 23), the 2008 Code of Practice "*made a conscious and deliberate effort to decouple the diagnosis and confirmation of death from organ donation and transplantation. This was to presumably ward off criticism that the diagnosis of brain stem death is inextricably linked to the desire to obtain organs for transplantation*." No doubt reflecting when work started upon them, and in what is otherwise a work which is otherwise admirably up-to-date (ncluding as it does detailed discussion of the 2022 case of Archie Battersbee) the chapter does not note that the AOMRC is currently undertaking an update of the 2015 guidance, and the RCPCH are also updating an update of their 2015 recommendations.[1]

In Chapter 3, Choong turns to law's response to the introduction and development of death by neurological criteria in clinical practice. She highlights through a careful and comprehensive review of the case-law both how and why these criteria came before the courts, and how the dialogue between the courts and the clinicians unfolded. Foreshadowing her argument in Chapter 4, she is at pains to emphasise the extent to which it was the courts, rather than Parliament, which have given legitimacy to the clinical criteria enshrined in the guidance. One consequence of this, she argues, is that very short shrift has been given to arguments based upon religious conceptions of the point of death which, in the United States, have found their way into legislation such as the New Jersey's Declaration of Death Act 1991. This Act provides that death cannot be declared on the basis of neurological criteria "*when the licenced physician authorised to declare death, has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs that such a declaration would violate the personal religious beliefs of the individual*." In such circumstances, death can be declared only on the basis of cardio-respiratory criteria. Attempts to run such arguments have failed before the English courts in cases such as *Re A (A Child)* [2015] EWHC 443 (Fam), as have arguments based upon the diagnostic criteria used in other jurisdictions. Rather, as Choong highlights, the Court of Appeal has made clear that "*it is impossible for this court now to embark upon an assessment of whether a different test…should replace the long established UK criteria represented in modern times by the 2008 Code and the 2015 Guidance*."[2]

In Chapter 4, Choong develops the argument that Parliament should be involved in the consideration of what constitutes death. The heart of her argument (at page 53) is that judges have only been:

> invited to adjudicate on a narrow set of circumstances. In the situations discussed, it was clear that the agenda also dictates how the decision was made. The question posed to the judges was whether a ventilated patient in ICU was dead and whether it would be lawful to withdraw their

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[1] Details of the latter can be found at https://www.rcpch.ac.uk/resources/diagnosis-death-neurological-criteria-infants-less-two-months-old-clinical-guideline (accessed 31 March 2023).

[2] *Re M (Declaration of Death of Child)* [2020] EWCA Civ 164

> ventilation. Judges in turn perceived and framed their task as one to find out what are the criteria used by doctors to determine death, and whether these were satisfied in the circumstances. Thus rather than asking how should death be determined, or whether the definition and criteria used by the medical profession are sufficiently robust, their angle of inquiry saw to it that the diagnosis and criteria used by the Conference, and later the Academy, received legal endorsement. It also led to the exclusion of other alternative definitions and determinations of death. In this way, ventilators can be removed from patients who are brain stem dead even if they are considered still alive in other jurisdictions and from a religious perspective. Such an uncompromising stance is taken without being preceded or informed by its own independent research or of wider consultation or debate—as these are not, as mentioned above, within the scope of judicial decision-making. Neither would the making of exceptions or reasonable accommodation be fitting, as they have a responsibility to ensure that the law is clear and consistent.

At the same time, however, Choong observes that:

> By recognising that brain stem dead patients are legally dead, the judiciary indirectly legitimised heart-beating organ donation since vital organs are retrieved from patients who are considered to have died.

Demonstrating perhaps a slightly rose-tinted perspective on Parliamentary processes, Choong considers that, whilst Parliamentary intervention would not be to consider the acceptability of the idea of diagnosing death by neurological criteria, it would provide an opportunity to debate and deliberate upon the robustness of the existing formulation and criteria of death; and the feasibility and significance of religious exemption in relation to the withdrawal of artificial ventilation. I say slightly "rose-tinted" perspective because, with honourable exceptions (most often to be found in the House of Lords) Parliamentarians have not, perhaps, always shown itself at their best when it comes to debating issues relating to life and death. If there were to be a move towards codifying the definition of death in statute, I would certainly make a (biased[3]) plea towards involving the Law Commission as an intermediary step to maximise the chances of making a law which works.[4]

A final chapter pulls the threads together, leaving the reader well equipped to understand both the history of where we have come from and to interrogate the updating guidelines forthcoming from the AORMC and the RCPH. I look forward to the next edition of this book in which Choong casts her expert eye over them.

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[3] As a former secondee there.

[4] As to which, see the fascinating recent book by David Goddard, Making Laws That Work: How Laws Fail and How We Can Do Better (Hart, 2022).

SUICIDE AND THE LAW, BY ELIZABETH WICKS (HART, 2023, HARDBACK, £76.50; PAPERBACK/EBOOK £61.20)

ALEX RUCK KEENE*

This book by Elizabeth Wicks, Professor of Human Rights Law at the University of Leicester, stands in fascinating contra-distinction to Jonathan Herring's recently published "The Right to be Protected from Committing Suicide" (Hart, 2022).[1] Herring sought to develop a sustained argument for a more assertive interpretation of Article 2 ECHR. Wicks argues, if not exactly for the contrary, but for an approach within the law which is considerably more open to the concept of autonomous decision-making about the end of life. Whilst Wicks does not downplay the need for preventative interventions in the case of what she describes as "incapacitated self-caused risks to life," the tenor of her work is very different to that of that of Herring's (and, helpfully, the timing of the two publications means that she is able to engage with it directly at a number of points).

Given these different approaches, how the reader responds to the respective works is likely, in part, to be a reflection of how they feel about the underlying arguments being advanced. To show my hand, I am instinctively considerably closer to Herring than Wicks. It was also perhaps unfortunate that I came back to completing this review of Wicks' book having just read a further excellent, and disturbing, blog about the 'capacity for suicide phenomenon.'[2] It is doubly unfortunate that I started reading her book having just finished listening to a BBC Radio 4 documentary about the 'Serenity Integrated Mentoring' approach.[3] This approach enjoyed a dangerous vogue amongst police and mental health services in relation to 'high intensity users', at least part of the approach apparently having been based upon criminalising suicidal behaviour on the part of such users, and resting in significant part to rest upon the concept that such users have capacity to take their own life.

Wicks clearly agrees that there is such a concept (indeed, as she identifies in her conclusion, the law's "proper ambit" should be defined by reference to whether a person has capacity to choose to die). I am certainly not arguing against this concept; however, I did have the feeling that Wicks' book – and her arguments – would have benefited from what could crudely be called a 'reality check' of engagement with the issues that have been thrown up by SIM and/or (earlier) by the Independent Review of the Mental Health Act, which pointed to the dangers of people being denied care

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[1] Reviewed at [2022] IJMHCL 83.

[2] Jane Fisher, *The 'capacity for suicide phenomenon' and the Mental Capacity Act*, available at https://www.madintheuk.com/2023/04/capacity-suicide-phenomenon/. See also here Wren Aves: *"If you are not a patient they like, then you have capacity"*: Exploring Mental Health Patient and Survivor Experiences of being told "You Have the Capacity to End Your Life". Psychiatry is Driving Me Mad. 2022. DOI:10.13140/RG.2.2.34386.84163, available at https://www.psychiatryisdrivingmemad.co.uk/post/if-you-are-not-a-patient-they-like-then-you-have-capacity.

[3] File on Four, 'Punished for being Mentally Ill' (last broadcast 19 March 2023): available via https://www.bbc.co.uk/programmes/m001k0qx.

on the basis that they are said to have capacity to take their own life.[4] There are also a number of points at which the focus on case-law and legal academic commentary did leave me missing the equivalent engagement in Herring's book with clinical and sociological literature.

It is certainly not that Wicks is not capable of placing the law in context. She does so in a very strong, and fascinating, chapter (3) on the legalisation of suicide in the United Kingdom, drawing on archival research and offering penetrating insights into the way in which the Suicide Act 1961 was, in effect, smuggled through Parliament by the then-Home Secretary 'Rab' Butler.

It is perhaps important, though, to note that Wicks has chosen to write a book primarily of legal scholarship, rather than of socio-legal scholarship. And on its own terms, it provides a very clear overview of the numerous ways in which law interacts with the idea of suicide. Particularly helpful is the way in which Wicks develops these interactions in a range of contexts, from suicide in detention, to the suicide of children and young people, to suicide and refusal of treatment at the end of life, before finishing with the debates around assisted suicide. Too often, suicide is 'silo-ed' off from discussions around (say) refusal of life-sustaining treatment: Wicks makes clear just how problematic this is conceptually in her excellent chapter (7) on this issue.

Conversely, the chapter on suicide in detention did seem to me to move onto very abstract terrain in its defence of a proposition that the focus on mental capacity would be "entirely suitable" for the prison context as the touchstone for determining whether or not intervention is justified. Wicks had previously in chapter 4 sought to develop a concept of mental capacity bolstered by diachronic continuity,[5] and suggests (page 119) the "challenges posed by the prison environment mean that most attempts at suicide would not meet this standard." However, having acted in inquests following suicides in prison detention, I, for one, left the chapter not entirely convinced that the answer to the "unique" challenges of prison suicide "can better be resolved by means of a stringent application of the standards [of capacity outlined above]" (page 120). Further, here and elsewhere, I did keep coming back to the question of whether (even a 'heightened') capacity-based approach is really sufficient, as opposed to just necessary. Or is this based upon an unduly 'thin' version of autonomy which does not pay sufficient attention to the contexts within which choices are made, and the extent to which choices reflect the options which are or are not put forward to the person?[6]

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[4] See also in this regard, from a clinical perspective, the work of Dr Chloe Beale, including Beale, C. (2022). Magical thinking and moral injury: Exclusion culture in psychiatry. BJPsych Bulletin, 46(1), 16-19. doi:10.1192/bjb.2021.86 and, more recently her article co-authored (inter alia with me), Beale, C., Lee-Davey, J., Lee, T., & Ruck Keene, A. (2023). Mental capacity in practice part 2: Capacity and the suicidal patient. BJPsych Advances, 1-10. doi:10.1192/bja.2022.82. For a discussion between Chloe and I about these issues, see: Alex Ruck Keens, *Suicide and the (mis)use of capacity – in conversation with Dr Chloe Beale*, available at https://www.mentalcapacitylawandpolicy.org.uk/suicide-and-the-misuse-of-capacity-in-conversation-with-dr-chloe-beale/.

[5] I.e. that a person's decision to take one's own life is consistent with the person's identity and the story of their life, looking also to their future (see pages 88-89).

[6] I did repeatedly think whilst reading Wicks' book of the work of Jonas-Sebastian Beaudry in the context of the rapidly evolving context of medical assistance in dying in Canada. See in particular, his 2018

Overall, however, and whether or not one agrees with the thrust of Wicks' thesis – and the arguments she develops in the final chapter for law reform – the book is a stimulating and elegantly written work, covering a very wide range within a relatively short (221 page) compass. It will certainly be taking its place on the reading list for my Law at the End of Life course at King's College London next year, as I suspect it will – and should – on the reading list of equivalent courses; it is also a work that will challenge practising lawyers who have any involvement in these areas, and will hopefully also make its way before the Health and Social Care Select Committee of the Westminster Parliament as it grapples at the moment with its inquiry into assisted dying/assisted suicide.[7]

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article, *The Way Forward For Medical Aid in Dying: Protecting Deliberative Autonomy Is Not Enough,* Supreme Court Law Review, Second Series, 85, available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3189417.

[7] UK Parliament, Health and Social Care Committee; see https://committees.parliament.uk/work/6906/assisted-dyingassisted-suicide/.

THE FUTURE OF MENTAL HEALTH, DISABILITY AND CRIMINAL LAW, EDITED BY KAY WILSON, YVETTE MAKER, PIERS GOODING AND JAMIE WALVISCH (ROUTLEDGE, 2023, HARDBACK/EBOOK)

ALEX RUCK KEENE[*]

This collection of essays is subtitled: 'Essays in Honour of Emeritus Professor Bernadette McSherry,' on the occasion of her retirement following an academic career spanning over 30 years. Crucially, the book serves to reflect the fact that McSherry's contribution was limited neither to her home country of Australia, nor to academia, but extended much further, both geographically and 'operationally,' including – most recently, as a Commissioner on the Royal Commission into Victoria's Mental Health System,[1] the subject of several of the essays in the book.

The editors were all (at one stage or another) doctoral students or post-doctoral researchers working with McSherry at the University of Melbourne or Monash University. Their stated goal in the introduction (page xxix) was two-fold: (1) to acknowledge the contribution that McSherry has made to the fields of law and policy covered by the title, especially to promoting interdisciplinary approaches; and (2) to recognise the influences that McSherry has had on the Academy and wider community, including, in particular a determination that those who draw on services[2] are central to research and law reform.

The headline of the review is that they have succeeded in both aims, curating chapters from 23 international contributors (although, notably, none from the Global South[3]), across four broad themes: (1) reforming mental health and disability law; (2) regulating coercion; (3) improving access to justice and the criminal law; and (4) transforming mental health law.

For someone involved in law reform – in the English context – I must confess having found the opening section of particular interest. The chapter by Mary Donnelly on 'Making the Future Happen: Law Reform Lessons from the Victorian Royal Commission' examines the Victorian Royal Commission by reference to the history of law reform

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[1] Available at https://finalreport.rcvmhs.vic.gov.au.

[2] Reflecting the standard language in Australia, the term 'consumer' is used by the editors for those who would most often be called in England & Wales 'service users.'

[3] In passing, it might be thought that this reflects a continuing problem in relation to the CRPD, which forms a central spine to the book: "[f]*or a document that is extremely futuristic and representative of the needs of persons with disabilities, the General Comment on Article 12 is not robust in terms of representation from ultra-vulnerable populations or those from the Global South. This leads to a silencing or abstraction of practical issues faced by the aforementioned population and treatment responses of those states that have ratified it*" (pp122-3): Mrinalini Ravi et al, *Contextualising legal capacity and supported decision-making in the Global South: Experiences of Homeless Women with Mental Health Issues from Chennai, India*, in Mental Health, Legal Capacity and Human Rights (Michael Ashley Stein, Faraaz Mahomed, Vikram Patel and Charlene Sunkel, eds, Cambridge, 2021).

efforts in the mental health zone in England & Wales,[4] and – in my view entirely rightly – suggests that the way in which the Royal Commission proceeded "show[ed] ways in which to think about law reform which expand and reinterpret the telos of mental health law and the kind of legal interventions which might be considered in the mental health sphere" (page 29). Importantly, the editors then counterpose this chapter with a chapter by Penelope Weller examining the ways in which the high hopes of the Royal Commission have not been translated – to date – into the legislative response in Victoria, the Mental Health and Wellbeing Act 2022 (Vic), looking, in particular at the Commission's recommendation that legislation should make the right to health its primary objective. One striking feature of that legislation, which came into force in September 2023, is that combines many of the 'systems' drivers recommended by the Royal Commission to move matters forward, but at the same time very traditional looking provisions relating to compulsory treatment, seclusion, restraint, and advance directives. The mismatch is explicable by the fact that "[w]hen the new [Act] was being written, there were many different ideas about how to change the compulsory assessment and treatment criteria. Ultimately, it was not possible to decide on the best way to change compulsory treatment laws in the limited time available,"[5] such that the Victorian Government commissioned an independent review to examine these areas. If nothing else, Weller's chapter provides an idea of the stakes at play – and can be very usefully read alongside the questions posed in the (now closed) consultation of the independent review.[6]

Peter Bartlett's chapter on the implementation of the Mental Capacity Act 2005 in England & Wales poses important challenges for those seeking to implement the 2022 Act, any further amendments to it, and – more broadly – the CRPD, focusing on four themes: (1) as fundamental rights of those with disabilities are involved, there will need to be judicial oversight, but 'courts behave like courts' (page 55); (2) implementation relies upon professionals; (3) meaningful remedies in the field of social and economic rights require actions by governments often hesitant to take them (and in the context of judicial reluctance to push); and (4) changing the law does not change practice. This last point echoes that made in the foreword by Duncan Cameron, a community member of the Mental Health Tribunal in Victoria, who, noting that a new law is on the horizon in Victoria, asks "what shall we put in it?", but answers:

> To be honest, I don't think it really matters. Having lived through the most recent change [legislation passed in 2014], I've come to the conclusion that that it's not what's *in* the law matters. It's more about people and the attitudes of those who administer the law. If various provisions of *the Act* are routinely ignored with no consequences, then those provisions may well as not be there. If we are to say 'but those provisions are aspirational,' then around we go again – the same parts of the mental health infrastructure comply while the rogue element goes up the river (page xxvii, emphases in the original)

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[4] Including the 2017 review led by Sir Simon Wessely, to which I was the legal adviser, and during the course of which I regularly myself continually returning to McSherry's work, such as the book she edited with Ian Freckleton on Coercive Care: Rights and Policy (Routledge, 2013).

[5] As the introduction to the consultation document published by the independent review puts it: https://engage.vic.gov.au/download/document/31331.

[6] https://engage.vic.gov.au/download/document/31331.

Cameron's salutary reminder also provides important context for – to me – one of the most concretely 'useful' chapters in the book, that by Simon Katterl and Sharon Friel in Part III – on developing a human rights and mental health regulatory framework; it also provides context for the chapters in Part II, on regulating coercion and restrictive practice. The chapters in this section are (at one level) more narrowly jurisdiction-specific, to Australia and New Zealand, but Ian Freckleton's chapter, in particular, on reforming the use of chemical restraint in health care and disability settings has wider resonance given how often recourse is had to this, and, as he identifies, how often it is tangled up with questions of whether the medication in question is serving a therapeutic purpose.

McSherry is well known for her work straddling both the civil and criminal fields of mental health law, strands of thinking which sometimes sit too much in their own silos. To this end, it is particularly good that the book contains three chapters in part III specifically thinking about criminal law in this context, one (by Jamie Walvisch and others) on causal explanations in sentencing offenders with mental health problems (primarily focused on Australia); one (by Christopher Slobogin) thinking about finetuning a jurisprudence of risk;[7] and the third a particularly stimulating chapter by Lisa Waddington and Paul Harpur on a rather different aspect of the right to equal access to justice contained in Article 13 CRPD, namely the rights of persons with sensory disabilities to participate in juries.

Part IV of the book opens with a chapter by Anna Arstein-Kerslake on using Articles 12 and 14 of the CRPD as a framework to deconstruct and reimagine mental health law. As Donnelly had noted in her chapter earlier in the book, whilst many states have taken steps to reduce the use of compulsion, no State Party to the CRPD "has (yet) entirely repealed all aspects of compulsion under mental health law" (page 14). In characteristically elegant and forthright terms, Arstein-Kerslake restates the position that the CRPD does not permit of substitute decision-making or of involuntary treatment/detention. For those reading the book in sequence, however, it is striking how in the chapters between those of Donnelly and Arstein-Kerslake the majority of the contributors have simply side-stepped these issues, for instance acknowledging that there remains an 'unresolved debate' (Weller, at page 40) or that 'views differ' (Walvisch and colleagues in relation to the criminal aspect at page 182). That side-stepping could be simply pragmatic, on the basis that it is necessary to engage with systems as they are, and to nudge them into a slightly better place whilst working for further reforms. It could also be a recognition that the ethical arguments in favour of the hardest-edge interpretations of the CRPD are not clear-cut. In this regard, and whilst not wanting to rehash arguments of 'naysayers' (as Arstein-Kerslake puts it at page 238), I did find myself looking in vain in her chapter for a discussion of the duty on the State to secure the right to life, which applies equally to those with disabilities

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[7] When I saw his name in the contributor list, I was, I should say, perhaps expecting – and in some ways hoping – to see a contribution building on his previous work such as his article *Eliminating mental disability as a legal criterion in deprivation of liberty cases: The impact of the Convention on the Rights of Persons with Disabilities on the insanity defense, civil commitment, and competency law*. (2015) 40 International Journal of Law and Psychiatry, 36-42. That is not to downplay how stimulating (if, I must confess, to me at least not entirely convincing) his chapter in the current volume is.

as it does to those without.[8] And, as so often,[9] I did find myself wondering whether the solutions proposed to address situations of mental ill-health are equally well-fitted to address situations of, for instance, dementia.

Any consideration of the future of the law – in any area – cannot ignore the seemingly irresistible rise, if not of the robots, then of AI, and the chapter by Piers Gooding and Yvette Maker on the digital turn in mental health law sounds a number of important warnings about the use of AI in risk assessment in the forensic mental health setting.

Importantly placed within the section on transforming the future of mental health law, the last substantive chapter is a powerful examination by Erandathie Jayakody and Malitha Perera of how to move beyond the 'deficit' lived experience narrative in the mental health context.

The book is broadly conceived: whilst most of the chapters focus primarily on situations of mental ill-health, some strayed very much more into what I would call 'capacity law' territory; most obviously those by Bartlett, but also those by Kate Diesfeld about safeguarding residents in aged care facilities in New Zealand from abuse in neglect and by John Dawson and Frances Matthews, about the potential for arbitrary detention of elderly people in secure rest home care (again in New Zealand). In this light, it is interesting to this reader, close as I am to the 'fusion' land of Northern Ireland,[10] that there appears to be no place in the future envisaged by this book at least for the elimination of separate mental health legislation – or 'mental health law' as a discipline.

In conclusion, this very stimulating book serves as a fitting tribute to a person whose influence has been and continues to be hugely significant, and who we hear from directly in an afterword giving her reflections on her work prompted by the contents of the book.

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[8] See further Alex Ruck Keene, *Deprivation of liberty and disability- its meaning and (il)legitimacy?*, available at https://www.mentalcapacitylawandpolicy.org.uk/deprivation-of-liberty-and-disability-its-meaning-and-illegitimacy/.

[9] See further Ruck Keene et al., *Mental Capacity – why look for a paradigm shift*, (2023) 31 Medical Law Review 340–357, https://doi.org/10.1093/medlaw/fwac052.

[10] Albeit that it is somewhat stalled, with the Mental Capacity Act (Northern Ireland) 2016 only partially implemented.