



Human Rights Commission
Te Kāhui Tika Tangata

This is not my home

A collection of perspectives on the provision
of aged residential care without consent

Compiled and published by the Human Rights Commission

Co-editors Dr Mark Fisher and Janet Anderson-Bidois



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1 Foreword

Paula Tesoriero

Disability Rights Commissioner

In July 2017 I commenced my role as Disability Rights Commissioner. As a disabled New Zealander, I have a good understanding of many of the barriers and challenges that disabled people can face when going about their everyday lives. However, even I can still be surprised by the extent of the systemic paternalism within our community. The “we know what’s best for you approach” is still evident in some of our laws and practices. Those who are considered to be “lacking capacity” are particularly vulnerable. Well-meaning families, clinicians and lawyers too frequently step in and make decisions about what they think is best.

This report considers legal and ethical issues associated with residential care for older people when the care is provided in circumstances where the resident concerned has not consented. That is, situations where older people who experience dementia related conditions are “placed” in secure rest home or residential facilities even when they do not want to be there. These individuals live in locked facilities and are prevented from leaving. Even if they are compliant and do not object, they have their liberty and personal choices curtailed.

The current law in this area is complex and some of the contributors to this publication argue that it is outdated and no longer “fit for purpose”. It is also difficult to reconcile common practices with the requirements of the United Nations Convention on the Rights of Persons with Disabilities, which provides that disabled people have a right to live in the community with choices equal to others, including where they live and with whom. Furthermore, there are concerns about the extent of the legal safeguards in place to protect the rights of residents once they are “placed in care”.

Each essay in this publication outlines a particular perspective or concern relevant to this issue. The papers in this compendium represent the views of the authors only. They do not necessarily represent the views of the Commission nor of other contributors. These papers are based on presentations from a series of seminars that took place throughout New Zealand during 2016 and 2017. Over 450 people from a wide range of clinical and professional backgrounds attended the events and participated in workshops to identify and discuss areas of concern and changes that need to be made to provide better legal and human rights protections.

The purpose of this compilation is to generate further discussion and debate about what is a significant, but often invisible, issue for many New Zealanders. Around 5000 older New Zealanders are living in secure aged care residences. What is glaringly absent from this compilation is the perspective of those who live in these facilities. We do not know much about how they feel about the situations they are in or what it is like to be forced, against your will, to live in a place that is not your home and is not where you want to be. It is important that we advocate for these people and do whatever we can to ensure that they are supported to live the best life that they can and that their rights, preferences and wishes are respected. Dementia and cognitive decline are conditions that any one of us might face as we age – we all have a vested interest in ensuring that we “do the right thing” and that the law and practice in this area aligns with international obligations and expectations.

2 This is not my home

Judge Philip Recordon

Ehara tēnei i taku kāinga. He aha au e noho nei ki konei?

He wāhi tiaki taipakeke, kāhore taku noho i whakaaetia e au. Nā wai i whakaae?

This is not my home. What am I doing here? A place for aged residential care, but I didn't authorise my being here. Who consented to it?

Most of us know the elderly lady or gent sitting in the rest home armchair gazing out the window, uncertain why they are not still in their home with all the memories and comforts of what they once knew. My particular lady is my Aunt.

Under no Court orders with two squabbling and loving sons, one with a power of attorney, never properly activated, she lives in a Mt Eden Rest Home. She loves to walk but cannot as the doors of her home are locked for her safety and the safety of many of those she lives with. She remembers who I am, most of the time, and my wife, she associates with me. Typically, for early dementia, she won't recall a visit from earlier in the week, or the day but can detail events from her childhood and her early years as a young adult in New Zealand, fresh from her Scottish Highland home. She appears happy where she is. Her sons (separately) and our family monitor her situation. But there is no valid law to keep her where she is or to stop her walking out the front (or the back) door whenever the outside beckons.

Our travelling seminar "This is not my Home", repeated to full houses six times through the country, was the brainchild of most of those involved, concerned as we are in our own chosen fields with the rights of people having difficulties with capacity, to choose or be involved in choice of home, treatment, welfare decisions, or to have responsible caring others make appropriate and informed decisions on ongoing care with their decisions monitored as to fairness, appropriateness and sustainability. Dr Mark Fisher galvanised me into action as he did a number of the others.

Iris Reuvecamp later took up the baton increasing the tempo, which suited the others involved including the guru of Protection of Personal and Property Rights (PPPR), Alison Douglass. The level of interest the seminar programme attracted served to highlight that DHB and Aged Residential care providers were well aware of this large group of residents lacking the legal protections that they deserve.

Many I see and have seen during my time as a Judge involved in disability law, and earlier, as a district inspector for mental health, with my 'patch' then and now the less affluent suburbs of South Auckland, rely solely on the staff for advocacy and monitoring with very few having a formal basis for care, detention or restraint. As a District Inspector for Mental health I followed those under Mental Health Act orders into the community and into Rest Homes, Boarding Houses and private homes. I was

lucky to see one or two residents of a rest home with 100 residents under an order, whether Mental Health or Protection of Personal and Property Rights (PPPR) Act. The other 98 or 99 had no formal independent monitoring by me or anyone else, no matter their particular frailty. How big this problem is has never been formally assessed. Dr Mark Fisher's 2017 assessment and figures was revealing but, sadly, not surprising, as reported in this seminar series.

A vulnerable population

The elderly population forms a rapidly increasing body of the vulnerable with those in the more impoverished communities in increasing danger of anonymity and exploitation. For those with families, monitoring care is often a time-consuming and thankless task. The basic decency of Kiwi families and individuals has worked pretty well until now but I am increasingly uncomfortable with on-going reliance on their efforts and "necessity" as an untested, unmonitored basis for major invasions of the liberties of vulnerable individuals. There are few people, outside family, prepared to act as Welfare Guardians. Those without families often have no external advocates to ensure their protection. There is currently no system to appoint or pay those willing to be Welfare Guardians as a public duty. In Auckland, only one or two lawyers are able to persuade the court to pay for what is, effectively, Welfare Guardian work. Very much the exception. Ben Gray's invited paper in this series describes the efforts in Wellington to establish public-like Guardians.

That this is a significant issue has been flagged to the government; those of us working in this sector continue to be frustrated by a perceived reluctance from those with power to change recognised inequalities and unfairness in the care and protection of the vulnerable in the land. There are promising signs that the Ardern-led Labour government will take up the issue and address the numerous, obvious and unjust failings in the current situation.

The New Zealand Bill of Rights Act and international conventions, to which we are a party, spell out the illegality of arbitrary detention and deprivation of liberty in all but legally authorised situations. This is reviewed by Michael White in this seminar series. He also shows that illegal deprivation of liberty is common even in those residential facilities that are not "secure". Those residents, like my aunt, who are not allowed to wander, because to wander is dangerous to them and to others, are detained in a legal sense, and need the same protections under law and under international conventions, as those with legally monitored orders in place.

An issue for Dr Mark Fisher and me has been, for some years now, the holdup in the transfer of many patients in hospital and psychogeriatric units to community Rest Homes and Private Hospitals, simply because of delays in the Court PPPR Act process. There are a number of factors here and fingers can be pointed not only at judiciary and court delays, but also at those with responsibility for bringing applications – families, social workers and carers. Improvements in attending to the issue from the Courts has, in Auckland, improved the speed of the Court staff in placing files before Judges. Judges remain guilty, however, of not prioritising PPPR so there are still delays. Recent changes to the PPPR Act appear to have only increased the complexity. Sitting

down with a 90-year-old and trying to explain what is going on with forms or process is a potential nightmare. Andrew Finnie's paper in this series looks at the everyday working of the PPPR Act.

Alternatives under the Law

Are there options we can easily use to provide legal authority for taking someone from the home they love to be in and want to die in? Especially when most people have not made Enduring Powers of Attorney, while still well? The Mental Health Act is one option but can only be a short-term legal fall back and holding process which is often used for inappropriate lengths of time. The Act does not ultimately provide authority for detention in care, nor does it cover all those other aspects of care that fall outside the remit of mental health care. And as a judge sitting in many of the hearings for Compulsory Treatment Orders, many or most of the elderly could struggle to fit under the strict definition of "Mental Disorder".

Can the Code of Health and Disability Services Consumers' Rights be used as an authority? Right 7[4] is based on the English Common law concept of necessity, and does allow for treatment when a person lacks capacity. What about when those deemed incompetent to consent or to make good decisions about their care are placed in a home and situation appropriate to their needs? Does the Code of Rights [not Code of Restrictions] give a provider of services the right to restrain, to sedate, to medicate, transport against express wishes of a person? Especially, when there are few protective mechanisms under the Code, to make sure that the person's best interests are truly being served. This is reviewed in this seminar series by Dr Cordelia Thomas and commented on by others of our authors.

Can the current law be fixed?

Iris Reuvecamp has considered ways in which the current legislation, the Protection of Personal and Property Rights Act 1988, might be improved, adapted or worked around, in the hope of improving the situation for the vulnerable in a short time frame. Many of her solutions will require some legislative change, and also funding, for the structure and personnel to ensure safety for this population. Some of this is underway in small part, with, for example, the proposal that the Ombudsman monitors secure Aged Residential Care facilities for compliance with New Zealand's obligations under the Convention against Torture. But this can only be the beginning, as the size of the problem will likely prove much greater than anticipated.

Protection of the vulnerable

The Protection of Personal and Property Rights Act 1988 is now 30 years old. What was once ahead of its time is now showing itself as no longer fit for purpose. What is the ideal? Where, overseas, are there examples of best practice we could adopt? Will our new government show the will and common sense they have signalled they possess, and categorise, formalise and monitor the caring arrangements of the increasing number of elderly vulnerable citizens? Professor Kate Diesfeld has reviewed

some of the international legal structures and cases. Alison Douglass, who spent a year as a Law Foundation Fellow reviewing this area, has made a case for a significant review of New Zealand's current law in this area, to ensure that those people, lacking capacity and also deprived of liberty, have full legal protection. And the law needs to be consistent with the International conventions that New Zealand is already a signatory to.

Our vulnerable have the right to be safe, to be protected from harm, to be helped to live with dignity and freedom. This will often involve others helping with making decisions in the best interests of individuals. With concerted effort and will we can provide a legal basis for good decision-making and ongoing monitoring.

Ehara tēnei i taku kāinga. He aha au e noho nei ki konei?

He wāhi tiaki taipakeke, kāhore taku noho i whakaaetia e au. Nā wai i whakaae?

3 'This is not my home'

An audit of legal authorities in Aged Residential Care

Dr Mark Fisher

Introduction

There are around 34,000 Aged Residential Care (ARC) beds in New Zealand, and around five percent of the over-65 years old population is in care at any time. This rises to 14% for the over-80's and 50% for those over 95 years old.¹ However, nearly one half of the elderly population will go into an ARC facility towards the end of their life.² The use of residential care is relatively high in New Zealand compared with some equivalent countries.²

Many elderly people in ARC facilities, by virtue of their illnesses or disabilities, have no (or very limited) capacity to make their own health care decisions, including where they should reside. In New Zealand law, those without capacity should have a substitute decision-maker who can consent for them, whether for residence or treatments. However, it is well-known in the sector that many such residents in ARC facilities have no such person appointed to make those care decisions for them. The significance of this grows in recognising that many of these people are effectively restricted or detained, in the sense that they are not permitted to leave.³ This deprivation of liberty of ARC residents can only be justified legally and in terms of international human rights agreements, if appropriate legal authorities are in place.⁴

There has been growing concern amongst managers and clinicians in both District Health Boards (DHBs) and Aged Residential Care (ARC) provider organisations about this scenario. One very public case in Auckland involved a middle-aged woman who continued to be detained in a locked Dementia Unit without legal authority, despite her recovering her capacity and her repeated requests to leave the facility.⁵

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- 1 Organisation for Economic Cooperation and Development. Help Wanted? Providing and Paying for Long-Term Care Paris (2011) OECD www.oecd.org/els/health-systems/47877919.pdf
 - 2 Joanna Broad, Toni Ashton, Merryn Gott, Heather MacLeod, Peter Davis, Martyn Connelly "Likelihood of aged residential care in later life: a simple approach to estimation with international comparison" (2015) 39 Australian and New Zealand Journal of Public Health 374.
 - 3 P (by his litigation friend the Official Solicitor) (Appellant) v Cheshire West and Chester Council and another (Respondents): [2014] UKSC 19; On appeal from: [2011] EWCA Civ 1257; [2011] EWCA Civ 190, (2014).
 - 4 New Zealand Human Rights Commission "He Ara Tika. A pathway forward. The scope and role of the Optional Protocol to the Convention against Torture (OPCAT) in relation to Aged care and disability residences and facilities" (2016) www.hrc.co.nz/files/9314/7251/4226/He_Ara_Tika_Report_2016.pdf

Similar concerns were recognised and addressed in the United Kingdom. In response, legislative changes were made, followed by the implementation of the Deprivation of Liberty Standards processes for residents in long-term care.^{6 7}

There are many reasons for this situation in New Zealand, some of which are considered below. This paper does not address the issues with the legislation itself (which are reviewed elsewhere in this series). Instead, in the first part I have briefly outlined some structural or cultural issues that make it more likely that a person might be detained without there being any form of legal authority in place. The second part of this paper describes a study undertaken to estimate the size of the problem.

Why have we got a problem?

The following summary outlines the obstacles that can hinder care providers or family members in obtaining appropriate legal authority, for the admission into care of an individual who lacks capacity to consent to the type of residential care required.

Demographic changes in New Zealand

New Zealand population structure is ageing (the proportion of those over-65 will double between 2000 and 2050), and, with it, the numbers of people with cognitive issues have escalated. The forecast is for the number of people suffering from dementia to triple between 2011 and 2050.⁸

Living situations of New Zealanders

With increasing age, more and more New Zealanders are living alone. Fifty percent of women aged over 75 live alone. This, combined with the high probability that their children live elsewhere in New Zealand or overseas, means that living in a residential facility is a common solution to increasing need.⁹

Pressure on Hospital Beds

In large general hospitals, the average length of stay (ALOS) in General Medicine is less than 5 days. This is not enough time for hospital clinical teams to organise legal authorities for those that do not already have one existing. Although the ALOS is longer in some other wards, there often remains an unseemly rush to discharge,

5 Health and Disability Commission "Auckland District Health Board, Taikura Trust, Aranui Home and Hospital Ltd (trading as Oak Park Dementia Unit); A Report by the Deputy Health and Disability Commissioner" (2010) www.hdc.org.nz/decisions--case-notes/commissioner's-decisions/2010/08hdc20957

6 Boyle G "Early implementation of the Mental Capacity Act 2005 in health and social care" (2011) 31 *Critical Social Policy* 365.

7 Alison Douglass "Mental Capacity: Updating New Zealand's Law and Practice" (Report for the New Zealand Law Foundation, Dunedin, July 2016) www.lawfoundation.org.nz

8 Alzheimers New Zealand. Dementia Economic Impact Report 2016. March 2017. <http://www.alzheimers.org.nz/getmedia/79f7fd09-93fe-43b0-a837-771027bb23c0/Economic-Impacts-of-Dementia-2017.pdf/>

9 Statistics New Zealand Two's a crowd: Living alone in New Zealand" (2 May 2016) http://archive.stats.govt.nz/browse_for_stats/people_and_communities/Well-being/social-connectedness/social-networks/living-alone/characteristics-people-live-alone.aspx

due to pressure from those waiting to be admitted. Around one third of all hospital admissions are for people over the age of 65.¹⁰

Clinical Teams are not familiar with the law or capacity assessments

There are indications clinicians in both DHBs and ARC providers lack appropriate knowledge about the law relating to capacity and substituted decision-making. Consequently, these issues may not be considered when placements into ARC facilities are made. In particular, there seems to be little appreciation of the need to medically activate Enduring Powers of Attorney (EPOAs).¹¹

Family Court challenges

There are significant delays in obtaining (even interim) orders under the Protection of Personal and Property Rights Act 1988 (PPPRA), due to long delays and pressure on the NZ Family Court system. Currently, the clinical experience is that there are typically waits of up to six months for such orders to be made in larger cities such as Auckland.¹²

Financial costs

Setting up both forms of EPOA may cost an individual up to \$1000. If there is no EPOA, and applications need to be made to the court, the cost to the family may be closer to \$2-3000. These costs prevent many families from seeking legal authorities. The same costs mean that many DHBs are reluctant to take on the responsibility of seeking orders, where the families will not.

Aged Residential Care provider issues

ARC providers range from small family-owned enterprises to large multi-national corporations. Profit margins are generally small, and there are real pressures on providers to fill empty beds quickly. Smaller providers may not have “head office” resources or advice to call upon, in dealing with issues such as legal authorities. Many providers do not have funding to make applications on behalf of their residents, when families are not willing or available.

Cultural Issues

Maori and Pacific families rarely appear to have Enduring Powers of Attorney in place. This may be due to factors such as educational or financial disadvantage, but there also appears to be a cultural reluctance to give decision-making authority to a son or daughter, when families believe that power (mana) within the whānau should reside in the older generations (kaumātua and kuia).

10 Ministry of Health “Publicly funded hospital discharges – 1 July 2014 to 30 June 2015” (2017) www.health.govt.nz/publication/publicly-funded-hospital-discharges-1-july-2014-30-june-2015

11 Heather Astell, Jae-Hyun Lee, Shankar Sankaran “Review of capacity assessments and recommendations for examining capacity” (27 September 2013) 126 New Zealand Medical Journal 1383. <http://journal.nzma.org.nz/journal/126-1383/5844/>

12 Radio New Zealand “Family Court delays at tipping point, lawyers say” (2016) www.radionz.co.nz/news/national/316515/family-court-delays-at-tipping-point,-lawyers-say

How big is the problem?

To date, in New Zealand there has been no published data attempting to identify the size of the problem; that is, how many people are residing permanently in ARC facilities without having either the ability to consent to that residence nor any other person (or order) who can consent on their behalf. Some of these people receive care in a locked facility and may also be physically restrained at times, to provide essential cares. Although there is some clinical awareness that many residents in residential care are there without appropriate legal authority, it has never been established how many residents might be affected.

This audit was undertaken in order to evaluate the size of the problem. The hypotheses were: (1), that a significant proportion of ARC residents would lack capacity to consent to living in a facility; (2), that many of these incapacitated residents would lack any formal legal authority; and (3), that rates of legal authorities would be higher in the secure facilities (Psychogeriatric and Dementia Care units) when compared with the other “open” facilities.

The audit was undertaken in two stages.

The First Audit

I undertook the first stage of the review together with the ARC providers. There was no research funding. The project took the form of an audit, undertaken by staff in the ARC facilities chosen. Ethics approval was not required, in keeping with the Health and Disability Ethics Committees (HDEC) operating protocol.¹³ ARC clinical staff were asked to complete an audit form for every resident in the facility. The audit forms were mostly filled out by the facility Nurse Managers together with the unit Registered Nurse. Information sought included:

- Demographic information including age, gender and ethnicity;
- Information about admission, including year of admission and source of referral;
- Assessment of legal capacity (see below); and
- Whether there were legal authorities in place, including Enduring Powers of Attorney, Court orders, Welfare Guardians, or Mental Health Act Orders. It was also asked whether any EPOA had been activated with a medical certificate.

Each person’s legal capacity for residence, that is, whether a person was able to make the decision about living in the ARC facility, was assessed by asking staff if, in their view, the person could –

- “have a conversation that showed their understanding of what sort of place it is, where they are currently residing”; and
- “can they have a conversation that showed understanding of why they need to be in this sort of care facility.”

¹³ Health and Disability Ethics Committees. Standard Operating Procedures for Health and Disability Ethics Committees, version 2.0. (August 2014) < <https://ethics.health.govt.nz/operating-procedures>>

(For both questions, the nursing staff could record that the person *could have* such a conversation, *could not have* a conversation, or they were *uncertain*. It was the response to the second question which was taken to indicate capacity to consent to living in the facility.) It is recognised that this is not a formal assessment of a person's legal capacity, and at best, represents the views of clinical staff about whether a person could consent to living in residential care. However, for the purposes of the study, this was used as a proxy for or indication of the person's legal capacity. The question posed also limits the person's decision-making to the consideration of where they are living, and not overall care and welfare decision-making.

The audit was completed across five ARC facilities, some of which contained multiple levels of care. There were three Psychogeriatric Private Hospital units, five Private Hospital units and two Rest Home units audited. There were no Dementia Care units in this sample. The sample included 403 residents.

As the audit unfolded, it became apparent that there were serious issues in the methodology. In particular, in some units the clinical staff did not appear to understand the nature of an EPOA or what an Activation medical certificate was. It also became apparent that the legal documentation was not necessarily present in the clinical records; there were many responses such as "*the resident's family said that there was an order, but there was nothing on file...*" These issues raised doubts as to the reliability of the data.

The Second Audit

Because of the uncertainty about the data, a second audit was undertaken. The second audit was completed in mostly the same facilities as the first stage; however, the rural facility was excluded for practical reasons, and two other facilities were included, to ensure that Dementia Care level of care was also audited. In total, the second audit reviewed five Private Hospital units, three Rest Home units, two Dementia Care units and three Psychogeriatric PH units. These are the four main levels of care in New Zealand.

The study was again undertaken as a collaboration between DHB and the ARC providers. The second audit received funding from the ARC providers, which covered the time and expenses of the research assistants (who were independent of the ARC providers). The audit was registered with, and approved by, the Counties Manukau District Health Board Research office. Because the study was seen as an audit using the HDEC protocol, Ethics committee approval was not required.¹³

In the second audit, research assistants went into each facility and unit, and for each resident went through the clinical and administrative files, looking for the following information:

- 1 Year of admission;
- 2 Demographic data;
- 3 Relevant diagnoses that might affect capacity, such as dementia or stroke; and
- 4 Presence of Legal authorities in the files.

The Legal capacity for decision-making regarding place of residence for each resident was taken from the first audit data (where available), or in the new units, was assessed in the same manner as the first audit, by asking the unit nursing staff and manager to consider whether the resident could answer the same two questions as above.

Each resident's hospital (DHB) electronic clinical record was also reviewed by one of the research assistants, looking through the documents and medical letters for copies or reports of legal authorities, and in particular, for evidence of medical certificates which might have activated EPOAs. This step was included because activation medical certificates were so absent in the first audit, and because the legal documentation was frequently absent from the residential facility clinical record.

Second Audit Results

Table 1 presents the demographic information of the sample, including for each type of care. The striking difference is the higher proportion of male residents in Psychogeriatric PH care, compared with the other levels of care. Overall, most residents were admitted into ARC facilities from the DHB hospital. Many of the remainder were transfers within ARC facilities, often from one level of care to another.

Table 1: Second audit sample

	Rest Home	Private Hospital	Dementia Care	Psycho-Geriatric PH
Total (n)	54	229	31	106
Age (average)	82.71	80.07	82.34	78.51
Min (y)	62	50	73	58
Max (y)	101	100	96	96
Male (%)	31%	36%	44%	66%
Maori (%)*	7.3	7.3	3.1	5.7
Pacific (%)*	14.6	17.6	3.1	6.6
Admitted from Hospital (%)	49	69	31	68

* Maori and Pacific percentages are reported. There were few residents identified as Asian or "Other", therefore most of the residual sample is NZ European. The proportion of Maori and Pacific residents varied widely between facilities, largely predicted by ethnicities within the local population.

Table 2 shows the proportion of those lacking legal capacity to consent to living in the facility, as assessed by ARC clinical staff. As expected, those levels of care dedicated to caring for residents with dementia (Dementia Care and Psychogeriatric PH) had very high percentages of residents lacking capacity to decide about their place of residence. Nonetheless, the two other levels of care both showed high proportions of people without capacity, including just over half the residents in Private Hospital care. This is consistent with rates of incapacity in nursing homes internationally.¹⁴

¹⁴ Jennifer Moye, Daniel Marson "Assessment of Decision-Making Capacity in Older Adults: An Emerging Area of Practice and Research" (2007) 62B Journal of Gerontology 3.

Table 2: Assessed legal capacity for second audit sample

	Rest Home	Private Hospital	Dementia Care	Psycho-geriatrics
Total (n)	54	229	31	106
With Capacity (%)	52.7	36.6	0	0.9
Uncertain (%)	7.3	10.6	0	5.6
Without Capacity (%)	40.0	52.9	100	93.5

Table 3 shows the number of residents in each level of care, who were assessed as lacking capacity for residence. It then shows whether or not legal authorities were present for those residents, for each level of care and for the whole group. The table is organised into three parts: (1) those for whom there was a clear legal authority in place, (2) those for whom their legal status was uncertain, largely because of the lack of documentation, and (3) those for whom no legal authority was found or referenced. The footnotes to the table identify and explain the different possibilities or options under each of those headings.

Table 3: Presence of Legal Authorities for those without capacity in second audit sample

Legal Authorities	Rest Home	Private Hospital	Dementia Care	Psycho-geriatrics	Total
Without capacity (n)	22	120	31	100	274
Authority Present: n (%)					
Activated EPOA ⁱ	6 (27.3)	32 (26.7)	15 (46.9)	28 (28.0)	81 (29.6)
Court Order	0 (0.0)	7 (5.8)	1 (3.1)	10 (10.0)	18 (6.6)
Waiting for Court ⁱⁱ	0 (0.0)	1 (0.8)	2 (6.3)	1 (1.0)	4 (1.5)
Uncertain status: n (%)					
Uncertain ⁱⁱⁱ	4 (18.2)	19 (15.8)	1 (3.1)	24 (24.0)	48 (17.5)
No Legal authority found or referenced: n (%)					
No authority ^{iv}	9 (40.9)	36 (30.0)	12 (37.5)	8 (8.0)	65 (23.7)
Unactivated EPOA ^v	3 (13.6)	22 (18.3)	1 (3.1)	24 (24.0)	50 (18.3)
Expired Court Order	0 (0.0)	3 (2.5)	0 (0.0)	5 (5.0)	8 (2.9)

ⁱ Activated EPOAs means that both EPOA documents and the activation medical certificates were found in the clinical records.

ⁱⁱ Waiting group generally had an application submitted to the court, but no reference or evidence that orders had been made.

ⁱⁱⁱ This indicates that the clinical record referenced authorities (often as reported by family) such as an EPOA, or that the activation certificate was referenced but not found.

^{iv} No authorities or references to these were found in the clinical files.

^v This indicates that an EPOA was found in the clinical record, but no activation certificate was found or referenced.

Residents in secure (Psychogeriatric PH or Dementia Care) were compared with residents in non-secure facilities (PH and RH) for presence or absence of legal authorities. Chi-squared statistics were used to check for differences. Although secure facilities tended towards having more legal authorities in place, the difference was not significant ($p=0.074$).

In 10% of the sample, information was found in only the hospital clinical record and had not been present in the residential facility record. However, much of this information fell into the “uncertain” category, where there was a reference to such an authority but no copy of this. (Not all the DHBs have a folder for legal documents in the electronic clinical record; hence there proved to be no easy way to find this information in the DHB files.)

Conclusions

The second audit showed that a considerable portion (65%) of ARC residents lacked capacity to consent to their residence in the ARC facility. This proportion was highest in the specialist locked dementia facilities as might be expected, but was relatively high in both rest home and private hospital residents. Many of these residents had diagnoses of dementia, strokes or cognitive impairment which are often linked with a loss of legal capacity. This confirmed our first hypothesis.

Our second hypothesis was also confirmed, as only 37.1% of residents without capacity to consent to living in that facility, had proper evidence of having a legal authority in place. This situation applied to both locked and open facilities, there being no significant difference between these two types of facility. Thus, our third hypothesis was not confirmed. However, many of the residents in unlocked facilities are effectively also detained, practically and in a legal sense.

Another 17.5% of residents without capacity were being cared for (and most likely detained) without copies of the legal authorities in their clinical files. In this group, care was being provided generally on the basis of references in the clinical notes to the “existence” of such authorities. Some of these references were found in the DHB files, rather than the ARC files. This “uncertain” group was worryingly large. Particularly so, when clinical experience tells us that some families claim to have an EPOA when in fact no such authority exists. The lack of a national register of EPOAs makes it difficult for care providers to check the information given to them by families.

There has been no other published audit of legal authorities of residents in New Zealand, but these findings are consistent with clinical experience and reports from colleagues working in other parts of the country. (We heard the views of clinicians from all over New Zealand while presenting the “This is not my home” seminar series.) A New Zealand study by Boyd and colleagues, looking at deaths in residential care, showed that while most (82%) residents had EPOAs in place, only around 45% of these were medically activated prior to their death (personal communication). However, it was not clear what proportion of these residents had legal capacity for care and welfare decisions. (This study is not yet published).¹⁵

15 Boyd M “Care planning documentation, by region” (2017) Personal communication.

Our findings are also consistent with studies conducted overseas. Redina et al (2009) conducted a small survey in New South Wales looking at whether nursing homes met all the legal requirements for prescription of psychotropic medications for their residents who lacked capacity. They found that only 6.5% fully and a further 6.5% partially met the requirements mandated by the Guardianship Act (1987).¹⁶ Barton et al assessed the legal capacity of 44 residents in a Maryland ARC facility, and also looked to see whether ARC clinicians recognised this incapacity. They also looked for surrogate decision-making orders in those without capacity. They found that 45% of their sample lacked capacity, but that clinicians only recognised this incapacity in two thirds of this group. However, in all 15 patients recognised by staff as lacking capacity, there was no evidence of any of the legal documentation required by law (surrogate decision-makers, advanced directives or court orders).¹⁷

There is a possibility that some of those in our sample who were identified as having no legal authority, do in fact have them in place. Some of those residents may well have a family member who has been appointed as Attorney, or it is possible that medical activation forms may have been completed by a medical practitioner at some stage. However, the fact that there is no documentary proof of these in the ARC clinical file, is an organisational risk for the providers. It also highlights one of the issues with the current legislation, namely that there is no central register of EPOAs.

Many of the resident's files (18.3%) contained a non-activated EPOA. This is a reminder that many medical practitioners do not know the legal requirements for activation of EPOAs, nor the form of the certificate required. This has been made more confusing by recent legal changes, such that "Form 5", the previous activation certificate, has been removed; instead medical certificates now can be in any form but must contain specific information.¹⁸ This requirement is not known to most practitioners. Furthermore, it may also make it more difficult in any future research to identify the activation certificates. On the other hand, there exists the opportunity for ARC providers to make sure that their resident's EPOAs are properly activated, thereby improving the proportion of those with legal authorities by nearly 20%.

These results are likely to be typical for residential facilities around New Zealand. If only 37.7% of incapacitated residents have correct legal authorities in place, the implication for New Zealand is that over 3000 incapacitated residents are detained in secure facilities, and there are nearly 11,000 incapacitated residents overall, without definite legal authorities. The best-case scenario would be that the "Uncertain" residents do in fact have legal authorities, and those with non-activated EPOAs have those activated. Even in this situation, the numbers without appropriate (necessary) authorities would be 1283 in secure facilities and 4693 out of the total New Zealand residential care population.

16 Rendina N, Brodaty H, Draper B, Peisah C, Brugue E. "Substitute consent for nursing home residents prescribed psychotropic medication" (2009) 24 International Journal of Geriatric Psychiatry 226.

17 Dennis Barton, Harminder Mallik, William Orr, Jeffrey Janofsky "Clinicians Judgement of Capacity of Nursing Home Patients to give Informed Consent" (1996) 47 Psychiatric Services 956.

18 Protection of Personal and Property Rights (Enduring Powers of Attorney Forms and Prescribed Information) Amendment Regulations 2017.

Limitations of the research

The main limitation of the study is that the assessment of capacity of the residents was completed on behalf of the researchers by the nursing staff and nurse managers in the ARC facilities. Each resident's legal capacity for decision-making about their place of residence was assessed with reference to their understanding of where they were living and why they needed to be in a residential care facility. This is acknowledged as not being a rigorous assessment of capacity, either in terms of process or by virtue of having different assessors for different groups of residents. It was not practicable to formally assess the capacity of over 400 residents in a rigorous manner in this study, but the results obtained are consistent with levels of incapacity that would be expected in each level of care, and those levels of incapacity found from similar studies. Nonetheless, it remains a question mark.

Another limitation is that, by virtue of the researchers going back to the same facilities that were included in the first audit, those providers may have made efforts to improve their practice in this area. In particular there may have been some effort to complete medical certificates for those that did not have them, or possibly to have sought copies of EPOAs. This might have improved performance between the audits.

Summary

This research has shown that many, if not most, residents lacking legal capacity in all levels of aged residential care, are receiving treatment, and very likely detained, without appropriate legal authorities. This is a significant risk for clinicians and organisations, both in the ARC sector and the DHBs (given that the majority of ARC residents are transferred to there from the general hospital). It also raises significant human rights concerns. It highlights that the vulnerable elderly ARC population has very few independent protections, and that the vast majority, by virtue of their cognitive or physical impairments, are in no position to commence legal actions or make complaints about their incarceration.

As highlighted in the first part of this paper, there are many practical obstacles to making sure that people receiving care have appropriate legal authorities. There are also numerous deficiencies in our current legislation. Both issues need to be addressed in order for this vulnerable population to be properly protected and to ensure proper respect for their human rights.

However, the group of contributors to the "This is not my Home" are hopeful that this issue has been highlighted for both DHB and ARC providers, and that placements into care are proceeding more often with either consent or appropriate legal authorities in place.

Thanks are due to those who collaborated and assisted with this research:
Dr Richard Worrall, Dr John Scott, Kate Matthews, Ruby Maxwell and Anna Perera.

4 Using and working with the PPPR Act – the challenges

Andrew Finnie

This is not my home series

The purpose of this brief commentary is not to provide a detailed outline of the provisions of the Protection of Personal and Property Rights Act (PPPRA) 1988. Rather, the intention is to identify and comment on a range of practical, coal face issues that can be experienced by those seeking to utilise the provisions of the Act.

Through extensive involvement in the Family Court as both Counsel for parties and as Court appointed Counsel over many years, I have had the opportunity to observe first hand the difficulties and frustrations experienced by both lawyers and the people that they represent when participating in proceedings under this Act.

This brief overview is based on my personal observations and is intended to provide an insight into just some of the many practical issues and challenges experienced by legal practitioners working in this area.

Enduring powers of attorney

Although recent reforms to the Act in respect of enduring powers of attorney were intended to increase accessibility and improve the flexibility of processes relating to enduring powers of attorney, the reality is that significant obstacles still remain for many people in respect of enduring powers of attorney. These obstacles include accessibility issues involving cost and knowledge and practical issues involving the exercise and review of enduring powers of attorney.

The recent new forms for enduring powers of attorney appear to have had mixed reviews amongst practitioners. Although intended to be more streamlined and user friendly, some practical concerns remain in respect of the forms.

Cost

Recent attempts to streamline and 'de-complicate' the obtaining of enduring powers of attorney are to be welcomed. Unfortunately for a sizable portion of the population the cost of obtaining enduring powers of attorney is simply outside the range of affordability.

Costs charged by lawyers vary quite markedly in respect of execution of enduring powers of attorney. It is common for lawyers to raise the issue of enduring powers of attorney with their clients in conjunction with other legal matters such as the purchase of a house or the settling of a trust. However, these opportunities do not tend to arise for those with more limited financial resources who do not engage in the sale and purchase of property or seek expert legal advice on other aspects of their day to day lives.

It is thus common in my experience to find many of the families without enduring powers of attorney are from less affluent backgrounds. For many such families, whether its \$180.00 or \$3,000.00 to obtain enduring powers of attorney, the cost obstacle remains, the difference merely being a number. Legal aid is not available for the purposes of drafting enduring powers of attorney.

There is obviously no direct data on how many people do not have enduring powers of attorney due to the cost. In situations where people have difficult financial circumstances however, the execution of such documentation will not be a matter of priority.

Over the years I have worked on many files involving vulnerable adults who had been unable to meet the costs of preparation of an enduring power of attorney and were later the subject of Court proceedings. The irony in this regard in respect of costs is that the cost of preparing enduring powers of attorney is a fraction of the cost of Court proceedings.

Lack of information and knowledge

It is also clear that there is a general lack of knowledge about enduring powers of attorney amongst a wide range of members of the community including what they are and what they can be used for. Recent attempts to publicise information in respect of enduring powers of attorney are to be welcomed, but there still appears to be a widespread lack of knowledge as to both the benefits of having enduring powers of attorney and the consequences in the event of loss of capacity of not having enduring powers of attorney.

Just in recent times in my own practice, I have encountered any number of examples of misconceptions in respect of enduring powers of attorney based on a lack of knowledge. In one a power of attorney document granted in respect of a property transaction to a lawyer was understood by the donor to be an enduring power of attorney as to both welfare and property. The documentation was clearly inadequate and Family Court proceedings were necessary.

In another matter in which I acted, a client had heard of the concept of enduring powers of attorney but thought that she would be able to make decisions for her spouse as of right in the event of his incapacity. Again as a result of this lack of knowledge, an application to the Family Court was eventually necessary.

Confusion as to the pathway to grant enduring powers of attorney and the conditions for doing so is common. I recently encountered a situation where a woman with an

activated and valid enduring power of attorney who suffered from Alzheimers was taken to a lawyer by family members who wanted her to change her enduring power of attorney and thought she could because she said she wanted to do so.

Some people confuse a signing authority at the bank or an agency listing with a government department with an enduring power of attorney.

Lack of central registry for enduring powers of attorney

I have lost count of the number of occasions where I act for family members who can't locate a copy of the enduring powers of attorney of a family member. The potential difficulty in locating previously granted enduring powers of attorney is a very real one for both family members and for legal practitioners.

Recently I had a client instruct me in respect of her father. A very tidy and organised man, he had granted enduring powers of attorney many years ago. His family knew that he had granted them but did not have copies. Nor it turned out did the lawyer who had drafted them. The only person who knew where they were had completely lost capacity. Despite the best of intentions of her father, my client was unable to locate a copy of the enduring powers of attorney. As a result, Family Court proceedings were required.

This is a common issue. The donor has lost capacity. He or she is most unlikely to recall that documents have been executed in the past or may not be able to articulate where they are held. A family member may have lost them or deliberately destroyed them. Alternatively they could be safely filed away in a box that no one can find in a storage facility.

Although sometimes held by Public Trust or the drafting lawyer, this is not always the case and it is simply impossible to be clear how many enduring powers of attorney have been executed but remain inactive due to relevant people not knowing of their existence or their whereabouts.

Likewise, it is impossible to know the number of occasions where enduring powers of attorney have been revoked and/or replaced with further enduring powers of attorney. In some cases this can occur in circumstances where the revocation or replacement remains unknown to those trying to determine whether there is legal documentation in place. It is certainly not uncommon to see multiple enduring powers of attorney executed at different dates emerge in respect of one person.

A national register of enduring powers of attorney would address many of the issues that arise in this respect regarding enduring powers of attorney in this respect. Although there would be an obvious cost in setting up and maintaining such a registry, such a registry could be of major benefit.

Lack of review process and monitoring

Enduring powers of attorney are granted by the donor at a time where the donor has capacity. Once a person has lost capacity the ability of that person to monitor the situation is also obviously lost.

Once activated, the enduring power of attorney operates without a timeframe and without review. Many practitioners working in this area of law would be able to give examples of files where a donee is acting or has acted in a questionable manner as enduring power of attorney in respect of either property or welfare. Such questionable conduct is often made easier by the lack of review mechanisms.

A typical issue often struck in practice is the donee effectively treating the property of the donor as his/her own property. Although family members, or anyone specified by the donor to be consulted or provided with information by the donee may identify an issue in this respect and take steps to challenge it, there is no certainty that such a challenge will occur.

In a recent matter I encountered enduring powers of attorney that had been activated at a time when the donor was in hospital several years ago. No further medical report had been obtained after discharge from hospital and the donee continued to act under the activated enduring power of attorney. This continued until the donor returned to hospital at a later date, was assessed and found to have recovered capacity.

Although the Act permits application to the Family Court for the purpose of reviewing the actions of an enduring power of attorney, this involves cost, delay and often stressful Court processes, particularly if taking place within a context of inter family conflict. There is also litigation risk and uncertainty as to outcome in respect of an application to the Court. In such circumstances many people may choose not to go down the path of Family Court proceedings in this respect.

Although not without difficulties, the part of the Act dealing with enduring powers of attorney has at least recently been partially reformed which has addressed some of the difficulties that arise. However, there remain significant issues in respect of the section of the Act dealing with applications to the Family Court in my view.

Family Court applications

My observations of challenges in respect of applications to the Family Court arise from many angles. As a practitioner with over 20 years' experience in the Family Court, regularly instructed both in a private capacity by individuals and organisations and by the Court as lawyer for subject person, I have had the opportunity to observe first hand the many difficulties encountered with this aspect of the Act. Numerous obstacles exist which complicate proceedings, making it difficult for many individuals to self represent should they wish to do so.

Although the application process itself in theory should be relatively discrete and focused, the reality is that there are considerable potential obstacles and difficulties that can and do arise throughout the application process in the Court.

The required forms

Relevant information and forms are provided on the Justice website for applications under the Protection of Personal and Property Rights Act. However, this requires knowledge that the information and forms are available. It also requires access to

the internet and a printer. Many of those who require assistance under the Act have language or other comprehension barriers precluding them from accessing information from this site.

The Ministry of Justice provides a general helpline but difficulties in accessing information remain.

The forms themselves are not as straightforward as may be thought at first instance and many litigants in person encounter difficulty with these forms as they currently stand. It is common as Counsel for a party or as Court appointed Counsel to be provided with forms incorrectly filled out or covering the wrong application arising from the Applicant having difficulties following the forms.

Although I understand the forms may at some point be the subject of review, in their current form they provide a practical difficulty for many potential litigants in person under the Act.

Costs of representation

Should potential Applicants wish to engage Counsel, then they encounter a further issue, namely the costs of representation. With lawyers generally charging on a time and attendance basis any applications to the Family Court can be an expensive exercise and applications under this Act are no exception. In my experience applications under the Act can vary greatly in cost and for a range of reasons.

Although for family members with a reasonable asset base or income these costs are or may be manageable, for many people in the situation of being on a low income or benefit dependent options may be very limited in respect of funding legal representation.

For those seeking a grant of legal aid to cover the costs of an application, there appears to be limited numbers of practitioners available to undertake this work on legal aid. Although a list of lawyers prepared to do legal aid is available on the justice website, the mere fact that a lawyer is on the approved list of legal aid providers does not mean that lawyer is undertaking legal aid work generally or work under this Act specifically. In my experience given the fixed fee nature of legal aid work and the low return it provides, many practitioners are simply now unavailable to undertake work under the Act on legal aid.

Even if able to find a lawyer prepared to undertake a case under the Act on a grant of legal aid, there can be significant difficulties in securing a grant of legal aid unless there is a dispute involved within the context of the proceedings.

These factors combined seem to have led to an increasing number of people self representing through necessity rather than by choice and also potentially to people simply not making applications when they need to be made.

A reluctance on the part of some family members to take steps may in part be responsible for what appears to be an increasing number of applications by District Health Board staff seeking to act in the interests of a vulnerable adult in circumstances where no protective steps are being taken by family members or others in the community.

Potential difficulties in obtaining evidence for Court applications

Any application requires evidence. Obtaining medical evidence to underpin the application to be filed in the Family Court can be very difficult for family members. Although hospitals often assist in the provision of reports if it relates to a patient in a hospital, for family members with a family member in the community, it can be difficult to obtain access to a suitably detailed medical report.

Often, the medical report obtained is inadequate or brief or doesn't address the issues that need to be covered to address the jurisdictional provisions of the Act. In my experience medical reports can vary widely from a full geriatrician report to a potential two-line report from a GP with all kinds of variations between the two. Given the significant imposition on the human rights of the subject person that result from an order under the Act, an appropriately detailed report is necessary however the potential difficulties in securing one for family members can pose a serious challenge.

Obtaining a medical report can be particularly difficult if there are concerns about the actions of an activated enduring power of attorney holder. Family or friends holding concerns and wanting to make an application to the Court of any kind in such circumstances generally struggle to obtain medical evidence without the consent of the attorney whose actions they are attempting to challenge.

Challenges in sourcing appropriate welfare guardians and property managers

In many situations a suitable welfare guardian candidate and/or property manager candidate is available from within the family. Often however, irrespective of family size, an available candidate cannot be found within the family or there is no one willing to take the role. In other families a person may have family members prepared to take the role of welfare guardian or property manager who are manifestly unsuitable to do so.

In many other situations, a person may have no family or friends who could be appointed in either role. Indeed in my experience it seems increasingly common to encounter situations involving people with no enduring powers of attorney and no family or friends willing, able or suitable to make applications to the Family Court for orders under the Act.

This in turn seems to have resulted in an increasing use of personal orders for both placement and medical treatment (in the absence of a welfare guardian), most typically applications filed by hospital staff. Although obviously not ideal, such orders at least provide a legal framework for placement.

Public Trust

In situations involving personal orders for placement where there will be no welfare guardian or property manager, it has become increasingly common for Public Trust to be involved on a very specific and tailored basis to provide limited assistance to give better effect to the personal order.

This assistance typically involves addressing financial issues such as making application for residential care subsidy, finalising bank accounts and transferring residual benefit payments. The assistance of Public Trust is usually provided in this context under its social responsibility budget.

In circumstances where there is an estate and there is no available and suitable candidate within the family, Public Trust is often appointed to act as property manager. This sometimes occurs on a temporary, urgent basis but also can be long term in nature.

The involvement of Public Trust can itself also potentially lead to further delays with the involvement of a further agency in what can sometimes become a complicated set of arrangements. That said, the assistance of Public Trust in circumstances involving for example alleged elder abuse or when there are simply no alternatives can obviously be of great benefit.

Court delays

Irrespective of whether there are applications for welfare guardian and property manager/order to administer property or a framework of personal orders, the Court process typically involves significant delay. Without the ability to make without notice orders immediately upon application, the Court triaging process commences with the opening of a file and the appointment of lawyer for subject person.

The issue of delay in the Family Court has been an issue for many years. The significant restructuring on an administrative basis of the Family Court Registry in Auckland that took place several years ago appears to have simply worsened those delays. It is appropriate to acknowledge the efforts put into address these issues and in particular the provision of additional resourcing and the hard work of Court staff but significant problems remain in respect of delays in the Court process.

Once filed, a case manager's list can be several weeks down the track to monitor the appointment of lawyer for subject person. Potential delays occur at very many different points in the process including:

- a Initial triaging;
- b The appointment of lawyer for subject person;
- c The report of lawyer for subject person;
- d The referral of the report of lawyer for subject person to a Judge in chambers;
- e The return of the Judge's directions from the Judge's chambers;
- f Delays in allocation of Court judicial conferences;
- g The provision of sealed orders.

These delays can occur on a straightforward unopposed and non-complex application. In matters involving more complexity, the delays also obviously include delays in allocation of Court fixtures.

In the event of a patient who is in hospital but refusing to be placed in care in a private hospital or rest home, difficulties arise in respect of a willingness or otherwise on the part of medical staff to utilise Rule 7(4) of the Code of Health and Disability Services Consumers' Rights. In that context, any delays in the Family Court thus flow on to cause potential delays in the hospital setting including a lack of bed space in respect of any particular ward and a delay in ensuring the discharge of patients who may indeed be clinically ready to leave an acute hospital setting

Many medical and allied practitioners have some understanding of both Right 7(4) and the Protection of Personal and Property Rights Act. Others appear to have limited understanding of both. In a general sense however neither the Code nor the Act appear to be widely understood by medical and allied professionals.

Reviews of Court orders

Once made, welfare and property orders under the Act are typically for a three-year term. A practical frustration for many families involving a family member – perhaps with intellectual disability or brain injury – is the requirement for reviews involving a further application to the Family Court. Although the Act permits on further review an extension of the review period to a five-year term, the reality is that additional applications to the Court are still required, something that has seemed to be a frustration to many family members in such circumstances.

For the purpose of “repeat” applications involving a long term need to be under the Act, the requirement to repeatedly go through the review process does on some level seem onerous.

Any review application requires the preparation and filing of documentation and the appointment of lawyer for subject person with a requirement to report in the usual manner.

Lack of monitoring of Court orders

Balanced against that frustration many might have about needing to seek review is the fact that review on a 3 yearly basis (or whatever timeframe the order otherwise provides) in the Family Court is the only real monitoring process for a welfare guardian order. There is currently no mechanism for any other type of monitoring of welfare guardian orders.

By contrast a property manager is obliged to file yearly statements in the Family Court which are then reviewed by Public Trust. This in itself provides some degree of oversight in respect of property.

Conclusion

The accessibility issue (including accessibility to legal representation) and the systemic delays in the Court process (despite best efforts to improve performance and mitigate delays) together create a significant issue in my view. As Counsel for applicant, as Court appointed Counsel and as Counsel working within the context of the health sector in this arena these issues are significant.

The very brief outline above of some of the challenges posed by the Act is limited in ambit and merely touches on some of the issues with the Act from the practical perspective of a lawyer regularly making applications under the Act and dealing daily with issues arising under the Act. The many challenges presented for vulnerable adults by the Act occur against a backdrop of increasing numbers of applications to the Family Court and an ageing population.

There is no obvious, easy or quick fix to these challenges. In my view the Act is overdue for review itself, to secure better outcomes for the vulnerable adults for whom it is intended to provide protection.

5 The role of Right 7(4) of the Code of Health and Disability Services Consumers' Rights

Cordelia Thomas

Introduction

New Zealand law has a strong focus on the rights of consumers. The Code of Health and Disability Services Consumers' Rights (the Code) gives legally enforceable rights to all consumers of health and disability services, and places corresponding obligations on providers of those services.

The Code came into force in 1996, following an Inquiry led by Judge Dame Silvia Cartwright into unethical cervical cancer research conducted at National Women's Hospital. The research involved withholding treatment from women with significant cervical abnormalities, without their knowledge or consent, in order to study the natural course of their conditions. The publication of the findings of the Inquiry (the Cartwright Report) led to a number of reforms aimed at ensuring the protection of consumers' rights, including the introduction of the Code.

This chapter considers whether Right 7(4) Code of Health and Disability Services Consumers' Rights (the Code) can appropriately be utilised as the legal basis for:

- Transferring a person to a secure unit in a residential care facility and
- The ongoing treatment/detention of a resident in a secure unit.

Right 7(4) Code of Health and Disability Services Consumers' Rights

Right 7(4) provides an exception to the general requirement in the Code that services should only be provided to a person who has made an informed choice and given informed consent. Right 7(4) states:

"Where a consumer is not competent to make an informed choice and give informed consent, and no person entitled to consent on behalf of the consumer is available, the provider may provide services where –

- a It is in the best interests of the consumer; and
- b Reasonable efforts have been taken to ascertain the views of the consumer; and

c Either, –

- If the consumer's views have been ascertained and having regard to those views, the provider believes, on reasonable grounds, that the provision of the services consistent with the informed choice the consumer would make if he or she were competent; or
- If the consumer's views have not been ascertained, the provider takes into account the views of other suitable persons who are interested in the welfare of the consumer and available to advise the provider."

If reasonable efforts to ascertain the views of a person have not been successful Right 7(4) permits "best interests" treatment to be provided, so long as the provider "takes into account" the views of suitable people who are interested in the welfare of the consumer and available to advise the provider. However, there is no requirement that the treatment be consistent with the views of such people, so long as the views are taken into account. In cases of urgency, none of the specified people may be available and in that case a provider may provide urgently required treatment.

There are many situations where a provider may act to preserve the life health or well-being of a person who is unable to make an informed choice and give informed consent. At common law necessity provides a lawful basis for providing services in such a situation. With regard to Code liability, Right 7(4) provides a legal justification for providing services without consent and has been said to reflect the principles of necessity. In addition, clause 3 of the Code states that a provider is not in breach of the Code if they have taken reasonable actions in the circumstances to give effect to the rights and comply with the duties in the Code.

Older people with conditions such as dementia may have previously, while fully competent, expressed a wish that even if they should become incompetent they wanted to remain living in their own home or never wanted to reside in an institution. Right 7(5) States: "Every consumer may use an advance directive in accordance with the common law". An advance directive is a written or oral directive by which a consumer makes a choice about a future health care procedure that is intended to be effective only when he or she is not competent.

The Health and Disability Commissioner Act 1994 (the Act) provides in section 2 that health care procedure means any health treatment, health examination, health teaching, or health research administered to or carried out on or in respect of any person by any health care provider; and includes any provision of health services to any person by any health care provider.

Health services means—

- (i) services to promote health:
- (ii) services to protect health:
- (iii) services to prevent disease or ill health:
- (iv) treatment services:
- (vi) nursing services:

- (vii) rehabilitative services: and
- (viii) diagnostic services;

Thus, it would seem the decision to place a resident in a secure unit would fall within the definition of a health service.

The Right to Refuse Treatment

In English law, competent patients have an absolute right to refuse medical treatment, including life-saving treatment. This principle extends to advance treatment refusals that are made for the time of potential future incompetence. The administration of life-sustaining medical treatment to a competent patient without consent, or to an incompetent patient in disregard of a valid advance refusal, amounts to a battery. However, a treatment refusal is valid only if the patient, when making the decision, was:

- 1 competent;
- 2 informed in broad terms of the nature and purpose of the procedure;
- 3 free from controlling outside influences; and
- 4 intended his/her refusal to apply to the circumstances that subsequently arose.¹

Consequently, in order to make a valid advance directive regarding possible institutionalisation should he or she become incompetent in the future, the consumer must be competent, and understand and anticipate the future trajectory of their illness, including an appreciation of the risks that might arise, for example, from living in their own home when they have lost the ability to care for themselves.

The legal test of whether a person is competent is whether the person understands the nature, purpose, effects and likely consequences of the proposed treatment or of refusing treatment.

Right 7(2) of the Code provides that every person is presumed competent unless there are reasonable grounds for believing that the person is not competent and if a person has diminished competence, they retain the right to make informed choices and give informed consent to the extent appropriate to their level of competence, (Right 7(3)).

Consumers whose competence has diminished as well as those who are incompetent may express (to the extent that they are able) a wish to leave the facility and return to their own home. Right 7(7) of the Code provides the right to refuse the consent to services and Furthermore section 11 of the New Zealand Bill of Rights Act (BORA) states "Everyone has the right to refuse to undergo any medical treatment" and in section 22, "Everyone has the right not to be arbitrarily arrested or detained".

¹ Re T (*Adult: Refusal of Treatment*) [1993] Fam 95 (CA) 103 per Lord Donaldson MR; and *W Healthcare NHS Trust v KH* [2005] 1WLR834, at [15] per Brooke LJ. For a decision in which an advance refusal of life-saving treatment was regarded as valid by an English court see *Re AK (Medical Treatment: Consent)* [2001] 1 FLR129.

Where a person lacks legal capacity to decide about care

It is difficult to argue that if an incompetent person expresses a wish to leave, or attempts to leave, that the provider should discharge them home if it appears that might pose a risk to them. Right 4(4) of the Code states: “every consumer has the right to have services provided in a manner that minimises the potential harm to, and optimises the quality of life of, that consumer”.

Providers who conclude the consumer has insufficient capacity to weigh the risks and make an informed decision might rely on clause 3 of the Code which states: “A provider is not in breach of this code if the provider has taken reasonable actions in the circumstances to give effect to the rights, and comply with the duties, in this Code”. The circumstances include all the relevant circumstances such as the consumer’s clinical circumstances and the provider’s resource constraints.

In a situation where a person who is being treated in hospital refuses a transfer to secure residential care, but clinicians think that such care is necessary in the patient’s best interests, the clinician should assess the person’s competence to make the decision to refuse the transfer. In the English Court of Appeal in *Re T (adult: refusal of treatment)*², Lord Donaldson stated³:

Doctors faced with a refusal of consent have to give very careful and detailed consideration to the patient’s capacity to decide at the time when the decision was made. It may not be the simple case of the patient having no capacity because, for example, at that time he had hallucinations. It may be the more difficult case of a temporarily reduced capacity at the time when his decision was made. What matters is that the doctor should consider whether at that time he had **a capacity that was commensurate with the gravity of the decision which he purported to make**. The more serious the decision, the greater the capacity required.

The Importance of Assessing Capacity

In a report by the Health and Disability Commissioner⁴, a general practitioner (GP) was providing care to a woman with Huntington’s Disease. In 2002 the GP discussed the woman’s future care with her. The woman was adamant she wished to remain living in her own home and the GP promised to ensure the woman would be able to do so. It was agreed that the GP would visit the woman regularly. The woman became increasingly reclusive, refusing home help and other support.

From 2005 she refused to allow the GP into her home and, thereafter, most of the documented contact was by telephone. In 2006, after the woman was admitted to hospital overnight, the GP advised the hospital clinicians that support and cares were in place and took the woman home. No competence assessment was undertaken.

2 [1993] Fam 95; [1992] 4 All ER 649(CA)

3 [1992] 4 All ER 649(CA), 661

4 11HDC00647 (10 June 2013)

During the following four years, the GP had limited contact with the woman although on one occasion she had an hour-long conversation with her through a curtain, but was only able to see her feet.

The GP monitored the woman by visiting the flat to check for signs of life, such as whether the television was on and whether there were flies or smells. In 2010 it was discovered that the woman was living in conditions of extreme squalor and, at that stage, the GP certified that the woman was incompetent with regard to decisions about her care and welfare. The Commissioner stated:

In my view, given the known projectory of patients with [Huntington's disease] and the probability that Mrs A would at some stage lose competence, Dr C's failure to assess Mrs A's competence to make the relevant decisions was suboptimal care and unacceptable.

Secure Residential Care

It is likely that if a person has been treated in hospital and has been assessed as being incompetent and requiring secure residential care, then Right 7(4) could be relied upon as a basis for transferring the person to a secure unit. However, consideration as to whether the particular treatment remains in the resident's best interests should be ongoing throughout the treatment. Although treatment in a secure unit might initially be in the resident's best interests, the resident's condition could change.

It is less clear whether Right 7(4) is a license to continue to treat and/or detain a resident without consent when a court order could reasonably be sought. This issue was considered in a report by the Health and Disability Commissioner⁵.

In that case a 43-year-old woman complained that she was detained in a secure rest home for more than a year without legal authority. The woman had been admitted to hospital in a confused state and her history included depression and alcohol abuse. Following a psychiatric assessment, it was decided that an application should be made to the Family Court for a personal order under the Protection of Personal and Property Rights Act 1988 (PPPR Act) for the woman to be placed in appropriate residential facility. The application was prepared but never filed with the court. Three months later the woman was discharged to a secure rest home caring mostly for older people with dementia. The DHB, needs assessment and service co-ordination agency (NASC) and rest home all believed that an order had been made and she was legally required to remain there.

The woman was reassessed by a NASC twice during the following 10 months. Later the rest home GP referred the woman to the DHB's mental health service and a community alcohol and drug service. The woman was assessed as being too well to be in a secure unit and to be competent in relation to her personal care and welfare. It was then discovered that the PPPR Act order had never been filed and there had been no legal requirement for the woman to remain in the rest home and fourteen months after admission, she left the rest home.

5 08HDC20957

The Commissioner stated:

[The rest home] argued that it was acting under the doctrine of necessity in order to preserve Ms R's life or health. I do not accept that a situation of emergency existed during the 14 months of Ms R's stay at [the rest home]. At most, it may have been appropriate to treat her for the first few days after her admission while clarifying the position with regard to the court order and/or the existence of an enduring power of attorney.

The Commissioner stated that the rest home had a responsibility to verify the woman's legal status and be clear about the legal basis on which it was to provide services. The Commissioner commented: "Surely, any provider in this situation would immediately ask: Who can consent on this person's behalf and who should we therefore be communicating and consulting with?".

Fluctuating capacity

Elderly people may at times have fluctuating capacity to make decisions for themselves, for example, if they are suffering from delirium. In a decision of the Deputy Health and Disability Commissioner⁶ the patient concerned, Mrs A, had some capacity in relation to decisions about her care and treatment. However, she was known to have dementia, which was likely to result in a lessening of her cognitive facilities over time. On admission she was agitated and suffering from short term memory loss and, at times, delirium.

She had previously appointed her daughter as her enduring power of attorney for personal care and welfare (EPOA), however, the EPOA had not been invoked by medical certification that she lacked capacity. She was administered haloperidol. The Deputy Commissioner stated that the clinicians should not have administered the drug to her unless they had a legal basis to do so. In this case, that legal basis could be provided through the application of Right 7(4) of the Code, or through the activation of Mrs A's EPOA.

Under Right 7(4), haloperidol could be provided to Mrs A without her consent if she was not competent to consent to its administration herself and its administration was considered to be in her best interests, and if reasonable steps had been taken to ascertain her views and either, after ascertaining Mrs A's views the treatment of haloperidol was considered to be consistent with the informed choice Mrs A would have made if she were competent or, if it was not possible to ascertain Mrs A's views, clinicians had taken into account the views of other suitable persons interested in her welfare.

Mrs A's daughter was clearly a suitable person who was interested in her mother's welfare and was available to advise the clinicians and, accordingly, she should have been consulted first, and her views carefully considered.

6 13HDC01252

Mrs A did not consent to the administration of haloperidol, nor did the clinicians turn their minds to the issue of substitute decision-making, either through the application of Right 7(4) of the Code or the activation of Mrs A's EPOA.

The Deputy Commissioner said if it was known that Mrs A's competence to consent to her treatment fluctuated, it would have been prudent for the clinicians to have discussed the issue of treatment preferences with her when she was able to understand the information provided and weigh the risks and benefits of the proposed treatment. This would have helped ensure that her clinicians were able to provide treatment consistent with her wishes during any periods of incompetence.

It was found that Mrs A should not have been administered haloperidol without her consent to that treatment, or there being clarity as to the alternative basis on which it was being provided. There was a lack of consideration as to who was able to provide informed consent to the administration of haloperidol to her. As a result, appropriate steps were not taken regarding that administration, either in terms of consent from Mrs A herself (if there were no reasonable grounds for believing she was not competent), or if there were reasonable grounds for believing that she was incompetent, either within the terms of Right 7(4) after appropriate consultation with her daughter or with consent from the daughter if the EPOA had been activated.

Conclusions

Right 7(4) does not make any provision for the length of time for which a provider might rely on that right to continue to treat a person without informed consent. There are some views that consequently Right 7(4) can be the basis for indefinite treatment. However, the Commissioner has indicated that providers have a responsibility to verify the person's legal status and be clear about the legal basis on which services are being provided. As a result the best practice is to obtain an order under the PPPR Act or the Mental Health (Compulsory Assessment and Treatment) Act. Furthermore, a person being detained and treated in reliance on Right 7(4) has limited protections of the type provided under other legislation such as the Mental Health (Compulsory Assessment and Treatment) Act. Therefore, such residents' interests are best served by providers taking steps to obtain appropriate authority for ongoing detention.

6 Plugging the gaps

Strengthening the rights of mentally incapacitated adults pending substantive law reform

Iris Reuvecamp

Introduction

Surprisingly, there has been little substantive change¹ to the primary legislation relating to mentally incapacitated adults, the Protection of Personal and Property Rights Act 1988 (PPPR Act), since it came into effect in 1988. The Code of Health and Disability Services Consumers' Rights² ("the Code of Rights") has also not been substantively amended since it came into force in 1994. Perhaps even more surprisingly, there has been little academic consideration, at least in a formal published sense, about the adequacy of the legal and regulatory framework which applies to mentally incapacitated persons over the course of the last thirty years.³

This is despite significant societal changes which have taken place over this time, including de-institutionalisation of those with mental illness and intellectual disability; advances in medical science and technology which have enabled life and the extension of life in ways not possible previously, and which have changed the way in which we age and the way in which we die; an ageing population;⁴ an increasing proportion of our population developing dementia;⁵ an increased focus on abuse of

1 With the exception of amendments relating to Enduring Powers of Attorney in 2008 pursuant to the Protection of Personal and Property Rights Amendment Act 2013, and further minor amendments to the same provisions pursuant to the Statutes Amendment Act 2016, Part 23.

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

3 See, however, Iris Reuvecamp "Is the New Zealand Legal Framework relating to the making of healthcare decisions on behalf of mentally incapacitated older persons adequate?" MBHL Dissertation, University of Otago, 2012; S Nightingale and I Reuvecamp "Regulating the Detention of Mentally Incapacitated Adults Not Subject to the Mental Health Act" in Dawson and Gledhill, *New Zealand's Mental Health Act in Practice* (VUP, Wellington, 2013) at 163; A Douglass *Mental Capacity: Updating New Zealand's Law and Practice* (Report for the New Zealand Law Foundation, Dunedin, July 2016), www.lawfoundation.org.nz; and the *This is not my home* seminars held across New Zealand in 2016 and 2017. See also, Iris Reuvecamp and Professor John Dawson (eds) *Mental Capacity Law in New Zealand* (Thomson Reuters, Wellington) (forthcoming in 2019).

4 The proportion of people aged 65 years and over is estimated to increase from 15% of New Zealanders in 2016, to 21-26% in 2043, and 24-33% by 2068. Statistics New Zealand National Population Projections: 2014 (base)- 2068 (November 2014) file:///C:/Users/Mic/Downloads/NationalPopulationProjections2014HOTP%20(1).pdf

5 It is estimated that the number of people living with dementia will rise from 62,287 (2016) to 170,212 by 2050. Alzheimer's New Zealand *Dementia Economic Impact Report 2016* (March 2017) at i

vulnerable adults (and in particular, older adults);⁶ and significant developments in international and domestic human rights law.⁷

In light of such changes, it is timely (if not overdue) for there to be a formal review of mental capacity law in New Zealand. However, such a review (which, if comprehensive, would be complex and multi-faceted) is likely to take some time. It is therefore worth considering whether there are steps that can be taken to strengthen the rights of mentally incapacitated adults, and the protective mechanisms currently in place, pending any such review.

Consistent with the focus of the *This is not my home* seminars held in 2016 and 2017, this paper will briefly discuss the legal and regulatory framework which applies to people who lack capacity to make decisions about their long-term placement in residential care, while highlighting gaps in that framework. It will then turn to consider ways in which we may be able to “plug the gaps” in the interim, pending substantive law reform.

The current legal framework

There are, in essence, two components to the current legal framework as it relates to healthcare decision-making where an adult does not have capacity to make decision(s) – where a competent adult has made an advance decision relating to the provision of future healthcare, should particular circumstances arise (an advance directive); and where another individual supports an adult to make a decision, or makes a decision on behalf of that person, if they themselves lack the capacity to do so.

The law in New Zealand only allows certain people to make decisions on behalf of mentally incapacitated adults. These are limited to attorneys appointed under Enduring Powers of Attorney (EPOAs); providers of health and/or disability services (in certain limited circumstances); court appointed welfare guardians or property managers; other persons appointed by the Court for specific purposes; and/or the Court.

EPOAs

Part 9 of the PPPR Act enables a competent adult (“the donor”) to appoint another person to act on their behalf (“an attorney”). An EPOA is not rendered invalid by virtue of the donor’s subsequent mental incapacity.⁸ There is a prescribed process that must be followed when appointing an EPOA.⁹

6 New Zealand Labour, Green Party of Aotearoa New Zealand, in conjunction with Grey Power, New Zealand *A report into Aged Care – What does the future hold for older New Zealanders?* (October 2010); Waldegrave, C., (2015) “Measuring Elder Abuse in New Zealand: Findings from the New Zealand Longitudinal Study of Ageing (NZLSA)”, Technical Paper, Office for Senior Citizens, Ministry of Social Development; New Zealand Labour Party & Green party of Aotearoa New Zealand with Grey Power. *Inquiry into Aged Care* (September 2017)

7 Including, in particular, the New Zealand Bill of Rights Act 1990 and the Human Rights Act 1993

8 Protection of Personal and Property Rights Act 1988, s96.

9 Above n8, s94A.

There are two types of EPOA – a personal care and welfare EPOA, and a property EPOA. Only one person can be appointed as a personal care and welfare EPOA at any one time, and this only comes into effect when the donor becomes mentally incapable.¹⁰ However, more than one person can be appointed as a property EPOA at any one time,¹¹ and the donor may authorise the EPOA to have effect while the donor is mentally capable and to continue to have effect if the donor becomes mentally incapable, or only if the donor becomes mentally incapable.¹²

There is no data available on the number of people who have an EPOA in place, or how many of those have been activated.¹³ This is not helped by the fact that there is no centralised register for EPOAs, which would provide an important safeguard and a useful database for donors, EPOAs and those seeking to rely on an EPOA's status.

There are a number of concerns arising from the operation of the framework which applies to EPOAs. These include a lack of knowledge and understanding of EPOAs by both those working with, and those acting as, EPOAs;¹⁴ a lack of detailed guidance or support available to EPOAs or those working with EPOAs;¹⁵ an absence of a quick and simple mechanism to challenge decisions made or actions taken by an EPOA,¹⁶ and the lack of monitoring of EPOAs.

Providers of health and disability services

The doctrine of necessity is a common law concept derived from English law which provides a lawful basis for providing health and disability services in the absence of consent. In order to be able to rely on the doctrine of necessity, there needs to be a necessity to act when it is not practicable to communicate with the person to whom

10 Above n8, s98(2) and (3)

11 Above n8, s94A(6)(c)(ii)

12 Above n8, s97(4)

13 Note that some data has started to become available via InterRAI, a comprehensive clinical assessment tool for medical, rehabilitation and support needs and abilities such as mobility and self-care. InterRAI has been used in New Zealand for assessing older people's needs for home and community support services since 2012, and in aged residential care since July 2015. For the year 1 July 2016 to 30 June 2017, of the 119,009 assessments which took place, 49,834 recorded EPOAs in place, with 17,461 EPOAs for personal care and welfare having been activated. Email from Uli Trute, Senior Communications and Engagement Adviser, TAS to Iris Reuvecamp in response to an Official Information Act request (29 March 2018)

14 See, for example, Health and Disability Commissioner, Case 08HDC17105 (26 August 2009); and 07HDC17744 (16 February 2009). See also Dr Mark Fisher's audit (chapter 3) which found that of those residents who lacked capacity and had an EPOA in place, 18.3% did not appear to have been formally activated. Dr Fisher concluded "this is a reminder that many medical practitioners do not know the legal requirements for activation of EPOAs, nor the form of the certificate required" (at page 19).

15 Although there are some reference materials available – see for example the website of the Office of the Senior Citizens at <http://www.superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/index.html>. Note also that the Elder Abuse Response Service, a free and confidential 24/7 helpline, was established in July 2017 (phone 0800 32 668 65).

16 Section 103 of the Protection of Personal and Property Rights Act 1988 allows for an application to be made to the court for the review of a decision of an EPOA. However, the number of applications for review of the decisions of EPOAs are few and far between. In 2015, there were 16 such applications, with 12 in 2016 and 10 in 2017. Letter from Jacquelyn Shannon, Group Manager, Courts and Tribunals, Regional Service Delivery to Iris Reuvecamp in response to an Official Information Act request (6 April 2018)

treatment is being provided; the proposed action needs to be one that a reasonable person would take in the circumstances; and it needs to be in the best interests of the patient.¹⁷

Right 7(4) of the Code of Rights effectively incorporates the common law doctrine of necessity in so far as it relates to the provision of health and disability services in New Zealand, and potential liability under the Code of Rights. To this extent, it provides a legal justification for providing health and disability services without consent.

Right 7(4) only applies where a person is not competent to make an informed choice and give informed consent; where there is no valid and applicable advance directive; and where (in relation to adults), there is no personal care and welfare EPOA or welfare guardian available (or they have no power to make the decision in question).

The application of right 7(4) hinges on the requirement that the provision of health and/or disability services is in the best interests of the mentally incapacitated person. In addition, the provider is required to take reasonable steps to ascertain the (competent) views of the mentally incapacitated person, and to act consistently with those views. If it isn't possible to ascertain the person's (competent) views, the provider is required to take into account the views of other suitable persons interested in the person's welfare (if available).

There has been no research into the extent to which health and disability service providers are aware of right 7(4); whether or not they make decisions on behalf of mentally incapable people on the basis of the criteria set out in right 7(4); what kind of decisions are made under right 7(4); and the types of situations in which providers feel that right 7(4) does not provide them with sufficient legal justification to proceed in the absence of consent.

Whilst most District Health Boards (DHBs) refer to right 7(4) in the context of an Informed Consent policy, anecdotally, it appears that large numbers of health practitioners are not aware of right 7(4), and do not routinely apply the criteria set out in right 7(4). This is supported by the Health and Disability Commissioner's (HDC) comments in numerous opinions, in which the HDC has voiced concern about the lack of requirements for consent, and the legal basis for proceeding in the absence of consent.¹⁸

Against that background, it seems likely that, in practice, the current approach to the provision of health and disability services to mentally incapacitated persons generally, is an approach that is consistent with good clinical practice; the best interests of the person; and decision-making by consensus (on both an inter-disciplinary basis, and in terms of the views of family/friends and/or support people of the mentally incapable person).

17 *Re F (Mental Patient Sterilisation)* [1990] 2 AC 1 (HL), cited in the All England Law Reports as *F v West Berkshire Health Authority* [1989] 2 All ER 545.

18 See, for example, Health and Disability Commissioner *General Surgeon, Dr D, A District Health Board – A Report by the Health and Disability Commissioner (Case 13HDC00538)* (16 December 2014) at [89]; and Health and Disability Commissioner *Canterbury District Health Board – A Report by the Health and Disability Commissioner (Case 13HDC01252)* (23 June 2015) at [124] and [125]

Likewise, there is no national consensus about the limits of right 7(4). This is illustrated by the varying approaches adopted across the country by DHBs, Needs Assessment Service Co-ordination Agencies (NASC) and local residential care providers as to whether right 7(4) provides sufficient legal authority to provide long-term care and/or to detain a person in residential care.

This inconsistency in approach is not helped by the fact that, despite its importance as a legal basis for proceeding in the absence of consent, and the widespread reliance on right 7(4) in the provision of health and disability services to incompetent persons, there is no case law on right 7(4), and the HDC has only addressed the use of right 7(4) in a substantive way on one occasion.¹⁹

In practice, it is likely that there are thousands of people who lack capacity to make personal care and welfare decisions and/or to manage their property affairs, without an adult legal guardian, who are provided with long-term care and/or detained (whether in residential care or community) on the legal authority of right 7(4) alone.²⁰

The difficulty with a (conscious or otherwise) reliance on right 7(4) in such circumstances is that there is a lack of independent oversight of the care provided; the degree to which the person's voice is heard is questionable; there is no review or appeal mechanism to ensure that the person's care and/or detention is, and continues to be, appropriate; and there is no monitoring or oversight of the application of right 7(4).²¹

This has resulted in concerns being raised about the extent to which the provision of long-term care and/or detention complies with the New Zealand Bill of Rights Act 1990, our obligations under the International Covenant on Civil and Political Rights (ICCPR), and the United Nations Convention on the Rights of Persons with Disabilities (the UNCRPD).²²

The question that follows is whether relying on right 7(4) as a basis for long-term care/detention would stand up in the face of a human rights based legal challenge – and/or whether further protections are required with respect to decisions made on behalf of mentally incapacitated persons, including (in particular) decisions which impact on a person's liberty.

19 Health and Disability Commissioner *Auckland District Health Board, Taikura Trust, Aranui Home and Hospital Ltd (trading as Oak Park Dementia Unit) – A Report by the Deputy Health and Disability Commissioner (Case 08HDC20957)* (3 November 2010)

20 This is supported by Dr Fisher's study referred to at n14 above, in which he concluded that, assuming the results of the study are typical of residential facilities around New Zealand, over 3,000 mentally incapable residents are likely to be detained in secure facilities, and nearly 11,000 mentally incapable residents in rest home facilities, without legal authority beyond right 7(4).

21 See, by way of comparison, Part 6 of the Mental Health (Compulsory Assessment and Treatment) Act 1992 and Part 2, subpart 5 of the Substance Addiction (Compulsory Assessment and Treatment) Act 2017.

22 J Dawson 'The Law of Emergency Psychiatric Detention' (1999) 2 *New Zealand law Review* 275-303; and above n3.

The Protection of Personal and Property Rights Act 1988

There is no legal requirement to use the PPPR Act in cases where persons are mentally incapacitated and unable to manage their own affairs. However, it provides a mechanism for challenging and/or seeking the Court's judgment regarding the appropriateness of proposed decisions with respect to mentally incapable persons, and to that end, provides an important check on such decision-making.

A critical protection of the PPPR Act process is the appointment by the court of a lawyer to act on behalf of the person who is the subject of the application,²³ and the detailed consideration of an application by the Court.

In considering an application under the PPPR Act in relation to personal rights, the Court is required to consider first, whether it has jurisdiction, and if so, the degree of intervention, if any, that is necessary.²⁴ A Court only has jurisdiction under the PPPR Act in respect of any person who is ordinarily resident in New Zealand and who lacks, wholly or partly, the capacity to understand the nature, and to foresee the consequences, of decisions in respect of matters relating to his or her personal care and welfare; or wholly lacks the capacity to communicate decisions in respect of such matters.²⁵

If the Court determines that a person lacks capacity, it is required to act in accordance with the objectives in section 8, recognising that there may be varying degrees of capacity and that any orders should infringe individual rights as little as possible. It must promote self-reliance and personal capability, designing orders to encourage and assist the person to develop what capacity they have.²⁶

The Court may make a range of orders, including specific personal orders (such as the provision of medical advice or treatment or living arrangements), property administration orders, or the appointment of a welfare guardian or property manager²⁷ (effectively the same as an EPOA, except court appointed).

In 2017, 4,514 PPPR Act applications were filed in the court, 236 of which were for personal orders; 514 for the administration of property; 1,716 for the appointment of welfare guardians; and 1,042 for the appointment of property managers.²⁸

The length of time it takes for a PPPR Act application to be considered and orders made varies considerably across the regions but can take several months even if uncontested (as is the case in the vast majority of applications).²⁹ Delays in the Family Court is not an issue limited to PPPR Act matters, with the Government recently announcing a review of the Family Court because of such delays.³⁰

23 Above n8, s65.

24 Above n8, s9; *Re S (shock treatment)* [1992] NZFLR 208.

25 Above n8, s6.

26 *Re H and H [Protection of personal and property rights]* (1999) 18 FRNZ 297.

27 Above n8, s10.

28 Letter from Jacquelyn Shannon, Group Manager, Courts and Tribunals, Regional Service Delivery to Iris Reuvecamp in response to an Official Information Act request (6 April 2018)

29 Above n28.

30 <https://www.stuff.co.nz/national/crime/103487058/family-court-reforms-a-failure-research-shows>

A further difficulty relates to the lack of monitoring once the orders are made. The court-appointed lawyer's role ends at the time orders are made, and the court has no other involvement other than if a further application is made; or shortly before the orders expire, when the orders are the subject of a review.

In 2017, there were 98 applications for review of personal orders, and 229 applications for review of property orders. These numbers are significantly lower than the number of orders made each year. There are a number of possible explanations for this, including that orders were only necessary temporarily; there was no need for the order to be extended due to the application being made in relation to a particular decision only; the mentally incapacitated person subsequently died; and/or there was a failure to apply for review (resulting in a lapse of the order).³¹

In terms of the use of the Court as a mechanism for reviewing the reasonableness of decisions made by welfare guardians and/or property managers, there were 25 such applications in 2017.³² This suggests that the Court is used infrequently to check the appropriateness of the actions of welfare guardians and/or property managers.

Regulatory controls

There is a complex framework of regulatory controls relating to the provision of health and disability services to mentally incapacitated persons. These include the HDC, the National Advocacy Service, the Retirement Commissioner,³³ the regulation of registered health practitioners by registration authorities,³⁴ the monitoring of health and disability places of detention by the Ombudsman,³⁵ certification and audit requirements,³⁶ contractual obligations under crown funding agreements and contractual agreements,³⁷ and the threat of possible criminal liability for failing to meet duties owed to a vulnerable adult.³⁸

There are, however, gaps in the current regulatory framework, primarily because vulnerable adults are one of the groups of society least likely to assert their rights. This may be for a number of reasons, including ignorance of the processes to raise concerns or complaints; an inability to communicate concerns or complaints; a lack of support in raising concerns or complaints; an age or cultural related reluctance to raise concerns or to complain; a fear of doing so due to their reliance on the people around them; a lack of an accessible and/or appropriate mechanism for raising concerns; and, where complaints or concerns are raised, these being ignored or dismissed.

31 See Dr Fisher's audit (Chapter 3) which found that 2.9% of orders relating to incapacitated residents in residential care had expired (page 17).

32 Above n28.

33 The Retirement Commissioner's role was established under the New Zealand Superannuation and Retirement Income Act 2001. The Retirement Commissioner is appointed by the Minister of Commerce.

34 Pursuant to the Health Practitioners Competence Assurance Act 2003.

35 Pursuant to the Crimes of Torture Act 1989, which provides a regime that enables New Zealand to comply with its obligations under the Option Protocol to the Convention against Torture.

36 Pursuant to the Health and Disability Services (Safety) Act 2001

37 For example, under the Age-related residential care services agreement

38 Pursuant to sections 151, 152, 195 and 195A of the Crimes Act 1961

The regulatory controls in place do not account for this reality, relying, for the most part, on the raising of concerns or complaints by the person themselves, or someone being available to do so on their behalf. This fails to take into account that many people who lack capacity to make decisions do not have people available to advocate on their behalf – making them particularly vulnerable to abuse and neglect in the absence of routine visits and monitoring by their families and/or friends, or, unfortunately, perhaps because of the care (or lack thereof) of their families and/or friends.³⁹

There are some regulatory controls which do not rely on the person themselves, or someone else “blowing the whistle”. Examples of these include the certification requirements in relation to residential care facilities, and the auditing against those certification requirements; as well as the monitoring obligations by DHBs in relation to services provided under various agreements.

Unfortunately, criticisms have been raised about the robustness and effectiveness of such mechanisms to ensure the provision of a reasonable standard of care.⁴⁰ In addition, such mechanisms tend to focus on policies and procedures, rather than on the needs of individuals, and may well miss breaches of individual rights. They also do not address issues faced by the many incompetent persons who may be cared for at home or in the community.

Whilst the threat of potential criminal liability may increase a focus on individual responsibilities to take action where there is a suspicion of abuse and/or neglect, this may have limited effect where there is no mechanism for routinely reviewing such arrangements. They also apply after the fact, and are unlikely, in and of themselves, to dissuade people from abusing and/or neglecting incompetent persons.

Finally, whilst there is a formal monitoring function carried out by the Ombudsmen in relation to the treatment of health and disability places of detention, the Ombudsman’s remit has only recently been extended to monitor and inspect privately run care facilities where there are dementia units, and is yet to be implemented.⁴¹

A call for updating New Zealand’s Mental Capacity Law and Practice

In Mental Capacity – Updating New Zealand’s Law and Practice,⁴² Douglass concludes that New Zealand’s mental capacity law and practice needs updating and reform. Douglass’ conclusion is to be supported, and, it is suggested, insofar as the compre-

39 It has been estimated that 79% of reported elder abuse is at the hands of a family member. See Age Concern New Zealand Incorporated *Elder Neglect: a qualitative study of neglect cases referred to Age Concern Elder Abuse and Neglect Prevention Services during the period 1 July 2002 to 30 June 2006* (July 2009) at 11; see also J Davey and J McKendry *Financial abuse of older people in New Zealand – a working paper* (November 2011) at 2; and T Carney “Civil and social guardianship for intellectually handicapped people” (1982) 8 *Monash Law Review* 199.

40 Office of the Auditor-General *Effectiveness of arrangements to check the standard of services provided by rest homes* (December 2009).

41 Designation of National Preventative Mechanisms (6 June 2018) 2018-go2603 *New Zealand Gazette* <https://gazette.govt.nz/assets/pdf-cache/2018/2018-go2603.pdf?2018-06-06%2009:00:20>

42 Above n3.

hensiveness of a review is concerned, extended beyond the PPPR Act to other legislation where mental capacity is or should be relevant (such as, for example, the Mental Health (Compulsory Assessment and Treatment) Act 1992 (the MHA), which currently does not incorporate incapacity in the legal test for compulsion under the Act).⁴³

Unfortunately, previous calls for a whole-scale review of the PPPR Act, and for the implementation of changes to the current framework (such as a national register for Enduring Powers of Attorney) have not been adopted by past Governments.⁴⁴ It is not yet clear what the approach of the current Government might be with respect to law reform of this nature.

In any event, a review and/or reform of mental capacity law in New Zealand will be a significant undertaking and is likely to take some time. This reality gives rise to the question of whether it is acceptable to allow the current situation to continue pending that review and reform, or whether we should be looking at whether there are short to medium term solutions available which may at least partially address some of the gaps in the meantime.

Plugging the gaps

There are a number of areas where it may be possible to make changes which could strengthen the current framework, pending substantive review and reform.

Accessibility

The costs involved in appointing an EPOA creates a barrier for many people. A trustee corporation will assist with appointing an EPOA at a significantly reduced cost in comparison to many lawyers, but at just under \$300 per EPOA, the cost remains a disincentive for many. One way of addressing this issue may be for the costs associated with the appointment of an EPOA to be subsidised by the government. An alternative is for the government to engage lawyers or legal executives and/or to contract with trustee corporations to run EPOA “clinics” around the country, at which they would advise people who wished to appoint an EPOA, and assist them with the process, at minimal or no cost.

The difficulties experienced by people wishing to make an application under the PPPR Act, both in terms of the accessibility of information on how to make an application under the PPPR Act, and the delays in the progress of an application, also need to be addressed. This can be achieved in a number of ways, including ensuring that there is readily accessible information and guidance available to the public and health professionals on how to make an application, and the forms to be used are modified so that they are easy to understand. In terms of access to the Court, the delays experienced in some parts of the country could be addressed by specialist

43 See Dawson and Gledhill, *New Zealand's Mental Health Act in Practice* (VUP, Wellington, 2013) at 25, where the editors suggest reform of the Mental Health (Compulsory Assessment and Treatment) Act 1992.

44 See Jo Goodhew *Report of the Minister for Senior Citizens on the review of the amendments to the Protection of Personal and Property Rights Act 1988 made by the Protection of Personal and Property Rights Amendment Act 2007* (June 2014).

court registrars, and allocated days to hear applications under the Act (whether on the papers or by way of a full hearing). One option in this regard could be to allocate two days a fortnight to hearings at the local DHB, one being for the purposes of the MHA (as is currently the case), and the other for applications under the PPPR Act.

Advocacy

It is recommended that consideration be given to the development of a specialised advocacy service, independent from the provision of health and disability services, which is designed to facilitate the identification and communication of concerns on the part of persons who lack capacity to some degree to make certain decisions (whether they are cared for in hospital, the community or at home).

It is possible that such a team could sit under the current Advocacy Service established under the Health and Disability Commissioner Act 1994. However, in order to be effective, a dedicated specialist team would need to be established and adequately resourced. Such a team would need to be large enough to enable home visits and/or visits to residential care facilities on a frequent basis (for example, once every so many weeks). Such advocates would also benefit from specialised training on communicating with mentally incapacitated persons.

Understanding

One of the gaps of the current framework is a lack of understanding by the public and health professionals alike about the concept of capacity, EPOAs, the PPPR Act, and the legal basis for the provision of health and disability services in the absence of consent. While larger provider organisations will have organisational policies, procedures and guidelines on these issues, and information on these issues is publicly available, this information tends to come from different sources, is in different formats, and is not readily accessible.⁴⁵

It is suggested that public understanding of these issues could be greatly increased by collating this information and making it readily accessible in one place, whether that is by virtue of a dedicated website and/or by a downloadable easy to read guide.

Further ongoing education and training of health professionals is also necessary.

EPOA/advance directives/wills register

A national register for EPOAs (and perhaps also advance directives and wills) would provide a centralised source of information for people with EPOAs, and those seeking

45 See, for example, the SuperSeniors website run by the Office for Seniors, which sits within the Ministry of Social Development. The website provides information on Finance and Planning, Health and Wellbeing, Elder Abuse and Age-friendly Communities. In particular, it provides detailed information (both written and by video clip) about setting up an EPOA. It also advertises the Elder Abuse helpline (a free and confidential 24/7 helpline) – <http://www.superseniors.msd.govt.nz/finance-planning/enduring-power-of-attorney/index.html>; Community Law Wellington and Hutt Valley and Age Concern New Zealand *Planning your Future – the role of enduring powers of attorney* (July 2015) at <http://www.ageconcern.org.nz/files/PlanningYourFuture.pdf>; Bupa Care Services NZ *Understanding dementia. A guide for carers and support people*. <http://www.bupa.co.nz/media/277668/dementia-book.pdf>; Care Publications Ltd *Where from here – He ara whakamua* (2017) – available for order online at <http://www.carepublications.co.nz>

to rely on them. It would enable those involved in appointing EPOAs (i.e. lawyers and legal executives) to check whether a person already has an EPOA, and for EPOAs themselves to obtain a copy of the documentation as and when required.

Ideally, such a register would be administered by an independent agency charged with a range of functions relating to the protection of mentally incapacitated persons. However, in the absence of such an agency, consideration could be given to a government department establishing such a register (for example, the Ministry of Social Development). An alternative may be the New Zealand Law Society in light of the fact that lawyers or legal executives are always involved in the appointment of an EPOA. A further option is for a trustee corporation such as the Public Trust to manage such a register.

Development of further clinical and legal standards

Capacity is the gatekeeper of decision-making autonomy. That being the case, it is important that those assessing capacity are provided with evidence-based guidance on how to conduct a capacity assessment, and that they do so in a considered and consistent way. To that end, Douglass, Young and McMillan have developed *A Toolkit for Assessing Capacity*⁴⁶ – a clinical, legal and practical guide for health practitioners when assessing an adult’s capacity to make decisions. Ongoing education and training about capacity assessments is required if health practitioners are to become comfortable with this form of assessment.

In her report *Mental Capacity: updating New Zealand’s Law and Practice*, Douglass advocates for the development of a Code of Practice which provides guidance on the interface between the revised legislation and the notion of capacity or competence as used in the Code of Rights, and explains, and makes provision for, supported decision-making as a form of best practice. Douglass suggests that such a Code of Practice be developed by the relevant government agency responsible for the revised incapacity legislation, in consultation with the health and disability, social development and justice sectors, to commence concurrently with a review of the PPPR Act, so it can be in place on the commencement of revised legislation.⁴⁷

It is suggested here that consideration should be given to the immediate development and implementation of a Code of Practice, or at the least, some form of guidance relating to the interface between the various aspects of the legal framework relating to decision-making by mentally incapable persons. This could be led by one of the three Ministries with responsibilities for mentally incapacitated persons (that is, Health, Social Development or Justice), and could still be developed in conjunction with the HDC, the relevant health practitioner registration authorities, Colleges and allied social work organisations as proposed by Douglass.

46 A Douglass, G Young and J McMillan *A Toolkit for Assessing Capacity* in A Douglass “Mental Capacity: updating New Zealand’s Law and Practice” (Report for the New Zealand Law Foundation, July 2016) www.lawfoundation.org.nz/

47 Above n3 at pg 170.

Such a Code of Practice could be given legal status by virtue of right 4(2) of the Code of Rights (which provides that every consumer has the right to have services provided that comply with legal, professional, ethical, and other relevant standards) if it was endorsed by the relevant health practitioner registration authorities, Colleges and allied social work organisations; if it was referred to in the Health and Disability Services Standards; and/or if it formed part of the certification and audit framework for providers of health and disability services certified under the Health and Disability Services (Safety) Act 2001.

Legal Safeguards

One of the most significant gaps within the current legal framework is the lack of clarity around the boundaries of right 7(4) of the Code of Rights, and the corresponding absence of a requirement to apply to the Court for orders under the PPPR Act in certain circumstances (such as, for example, where a person is going to be provided with long-term care and/or detained for this purpose).

However, this issue could be addressed pending a review and/or law reform by the adoption of a requirement for a person to have an EPOA or to be subject to court orders (or for these to be pending) if the person is mentally incapacitated at the time of admission to a residential care facility. This is already the approach of a number of District Health Boards, Needs Assessment Service Co-ordination agencies (NASCs) and health and disability service providers in different parts of New Zealand when arranging for admission of a person to secure dementia level care, although it is not a nationally consistent approach.

In addition, or as an alternative, the requirement could be incorporated into guidance or a Code of Practice as set out in further detail above.

It may also be possible to incorporate this as a requirement by specifying the parameters of right 7(4) in the Code of Rights, although this would require a change to the regulations.

Abuse and neglect/poor decision-making by EPOA

The introduction of an Elder Abuse hotline and increased funding for Age Concern and a number of new organisations for the provision of elder abuse prevention services⁴⁸ has resulted in a clearer way forward for reporting concerns about abuse and/or neglect of a mentally incapacitated older person, including situations where such concerns extend to an EPOA.

The extension of the Elder Abuse line, and the provision of elder abuse prevention services to all mentally incapacitated persons (not just older persons), would also be of significant benefit.

Changes should also be made in terms of accessibility of the Court where there are concerns about the decision-making of an EPOA (whether or not this involves alleged abuse or neglect). Such concerns should be able to be escalated to the Court easily

48 <https://www.beehive.govt.nz/release/new-elder-abuse-intervention-services>

and quickly, both in terms of the way in which such concerns can be raised (i.e. the forms that need to be completed and the nature of evidence to be filed), and the time taken by the court to consider those concerns.

Monitoring and Oversight

A further significant gap in the current legal framework is the lack of monitoring or oversight of EPOAs, their court-appointed equivalents or other personal and property orders.⁴⁹

It is suggested that there are several options available to ensure that there is appropriate monitoring and oversight of decisions made with or on behalf of a mentally incapacitated person.

A straight forward option is the extension of the brief of the court-appointed lawyer for the person who is the subject of an application under the PPPR Act to include a requirement that the lawyer meet with the subject person at least once a year throughout the currency of the order, and at the time the order is due for review (regardless of whether an application for review has been made) and reports back to the court.

A slightly more complicated option (as it would require legislative change) would be for the role of the District Inspector to be extended to residential care facilities (and perhaps, in the longer term, accommodation in the community). This could be achieved by amendment of the PPPR Act to include provisions relating to District Inspectors in a similar way to the MHA and the Substance Addiction (Compulsory Assessment and Treatment) Act 2017.

Some of the recommendations of White, as set out in the Human Rights Commission's report *He Ara Tika – A pathway forward* have recently been progressed, with the Office of the Ombudsman having been designated to monitor and inspect privately run care facilities where there are dementia units in June 2018⁵⁰. It is, however, important that the Office of the Ombudsman is properly resourced to enable frequent visits; and that a framework for preventative monitoring of these facilities is developed which is fit for purpose and complements the existing oversight mechanisms.

Establishment of independent agency

There has been a call for some years for the establishment of an independent agency such as an Aged Care Commissioner,⁵¹ or more broadly, an independent agency charged

49 Noting that a Property Manager is required to file annual statements of account which are checked by the Public Trust.

50 Above n41.

51 New Zealand Labour, Green Party of Aotearoa New Zealand, in conjunction with Grey Power, New Zealand *A report into Aged Care – What does the future hold for older New Zealanders?* (October 2010); New Zealand Aged Care Association and Grey Power *An Aged Care Commissioner in New Zealand* <https://nzcz.org.nz/assets/Documents/The-Aged-Care-Commissioner-in-New-Zealand-Embargued-Doc-For-Release.doc>; New Zealand Labour Party & Green party of Aotearoa New Zealand with Grey Power. *Inquiry into Aged Care* (September 2017)

with the protection of all vulnerable adults, such as, for example, the Office of the Public Guardian in the UK.⁵²

The Office of the Public Guardian in the UK is involved in the registration of EPOAs, supervising the equivalent of welfare guardians and property managers appointed by the Court, assisting EPOAs and welfare guardians in carrying out their duties, and protecting people who lack the mental capacity to make decisions for themselves. It works closely with other organisations to ensure that any allegations of abuse are fully investigated and acted on and has responsibility for mental capacity policy. It provides guidance to the public and both legal and health professionals.⁵³

In a New Zealand context, there are currently a number of agencies who are carrying out components of the role of the Office of the Public Guardian (for example, the Office for Seniors in providing guidance, Age Concern and other NGOs in providing elder abuse and prevention services, and the Family Court in relation to applications under the PPPR Act). It is suggested that, while further resource would, of course, be required to facilitate the establishment and ongoing operational costs of such an agency, to a significant extent, many aspects of the role of such an agency are already funded and in place.

Conclusion

The call for a wholesale review of mental capacity law in New Zealand is supported. However, such a review will take time. It is suggested that, in the meantime, there are a range of actions that could be taken pending such a review and/or any consequent law reform, which would significantly strengthen the rights of mentally incapacitated adults.

52 Michael J V White He Ara Tika A pathway forward – the scope and role of the Optional protocol to the Convention against Torture (OPCAT) in related to aged care and disability residences and facilities (Human Rights Commission, June 2016)

53 <http://www.gov.uk/government/organisations.office-of-the-public-guardian>

7 Aged residential care without consent

A human rights perspective

Michael J V White

This paper sets out the international human rights applicable to aged residential care with a particular focus on those who may find themselves in care without their informed consent. It highlights some areas of concern where the existing domestic legal framework is arguably inconsistent with New Zealand's human rights obligations, and suggests a mechanism to ensure compliance with those obligations.

The right to liberty and freedom of movement is a fundamental human right. However, it is not absolute. States can deprive people of their liberty through a variety of means where the reasons for deprivation of liberty are prescribed by law. Deprivation of liberty in a broad sense means the placement of a person in a setting which that person is not free to leave. Traditionally this has referred to situations in which people have been arrested, are in detention, imprisonment or interred in psychiatric facilities. However, there is growing recognition that there are other places, such as residences and facilities, where a person may effectively be deprived of their liberty. These include aged residential care facilities.

Human rights obligations apply to these facilities under the International Covenant on Civil and Political Rights (ICCPR), the Convention against Torture and other Cruel, Inhuman or Degrading Treatment (CAT) and the Convention on the Rights of Persons with Disabilities (CRPD). These international instruments encourage States to limit deprivation of liberty. They also acknowledge that people deprived of their liberty are vulnerable and particularly at risk of other human rights violations. Monitoring places where people are deprived of their liberty is an integral part of the measures that States must take to fulfil their international human rights obligations.

New Zealand has ratified 7 of the 9 core International human rights treaties including the ICCPR, CAT and the CRPD. The Government has a responsibility to ensure that the rights of those in residential care are protected in accordance with the binding international obligations it has signed up to. Many of these obligations are also codified domestically in legislation including the New Zealand Bill of Rights Act 1990 (BORA) and the Human Rights Act 1993.

Deprivation of liberty

Article 9(1) of the ICCPR provides:

Everyone has the right to liberty and security of person. No one shall be subjected to arbitrary arrest or detention. No one shall be deprived of his liberty except on such grounds and in accordance with such procedure as are established by law.

Article 9 is complemented by the positive requirements in Article 10 (1), which provide:

All persons deprived of their liberty shall be treated with humanity and with respect for the inherent dignity of the human person.

The United Nations Human Rights Committee (HRC) has confirmed that persons deprived of their liberty in Article 10(1) of the ICCPR includes:¹

Anyone deprived of liberty under the laws and authority of the State who is held in prisons, hospitals (particularly psychiatric hospitals), detention camps or correctional institutions, or elsewhere. States parties should ensure that the principle stipulated therein is observed in all institutions and establishments within their jurisdiction where persons are being held.

Lines can become blurred however, when considering deprivation of liberty on an involuntary basis in the health or care sector. The Optional Protocol to the Convention against Torture and other Cruel, Inhuman and Degrading Treatment (OPCAT) is an international human rights treaty designed to strengthen the protection of people deprived of their liberty. The OPCAT embodies the idea that prevention of ill-treatment in places where people are deprived of their liberty can best be achieved by a system of independent, regular visits that monitor conditions and treatment.

Article 4 of the OPCAT states:

- 1 Each State party shall allow visits by the mechanisms referred to in Articles 2 and 3 to any place under its jurisdiction and control where persons are or may be deprived of their liberty, either by virtue of an order given by a public authority or at its instigation or with its consent or acquiescence (hereinafter referred to as places of detention)
- 2 For the purposes of the present Protocol, deprivation of liberty means any form of detention or imprisonment or the placement of a person in a public or private custodial setting which that person is not permitted to leave at will by order of any judicial administrative or other authority.

Article 4 does not provide a list of places that should be subject to visits. During the drafting of the Protocol many delegations pointed out that “deprivation of liberty” was commonly used in the human rights arena and that “detained” could be a too narrow definition.² Article 4(1) as finally drafted suggests that the OPCAT extends

1 Human Rights Committee, General Comment 21, Humane treatment of persons deprived of their liberty (1992), at [4].

2 Nowak, M and McArthurr, E, *The United Nations Convention Against Torture: A Commentary* (Oxford: Oxford University Press, 2008), at 889.

to detention by non-state actors but only if the State is aware of this and does not prevent it. Nowak and McArthur therefore believe that the OPCAT could cover private hospitals and care homes.³

Article 4(2) expands the coverage of the OPCAT to places that persons are not permitted to leave at will by order of a public authority.

The United Nations Sub-Committee on the Prevention of Torture has also grappled with defining the scope of deprivation of liberty in Article 4. It has stated:⁴

Article 4 contains two sub paragraphs which need to be read consistently together and which places within the scope of the OPCAT any public or private custodial setting under the jurisdiction and control of the State party, where persons may be deprived of their liberty and are not permitted to leave, either by an order given by any judicial, administrative or other authority or at its instigation or with its consent or acquiescence.

It is inevitable that there will be a degree of opaqueness about the precise parameters of the definition when translated into operational practice. However, the preventive approach which underpins the OPCAT means that as expansive an interpretation as possible should be taken in order to maximise the preventive impact of the work of the NPM.

The SPT therefore takes the view that any place in which a person is deprived of liberty (in the sense of not being free to leave), or where it considers that a person might be being deprived of their liberty, should fall within the scope of its visiting mandate – and, in consequence, under the visiting mandate of a National Preventive Mechanism – if it relates to a situation in which the State either exercises, or might be expected to exercise a regulatory function.

As a tool of prevention, the NPM ought therefore to be able to access as broad a range of potential places of deprivation of liberty as possible in order to determine whether the State ought to be exercising such a regulatory function, as well as to examine the manner in which existing detention powers and regulatory functions are being exercised. In so doing, the NPM ought to be mindful of the principle of proportionality when determining its priorities and the focus of its work.

Drawing on the SPT'S conclusion, any place where people may not be free to leave that is subject to the regulation or oversight of the State – or should be the subject of the State's regulatory functions – could potentially fall within the scope of Article 4. This would include facilities and residences which are subject to national standards, rules or guidelines administered by the State, such as residential aged care facilities.

3 Ibid at 931.

4 Sub Committee on the Prevention of Torture, Response to the New Zealand Human Rights Commission's request for interpretative guidance on Article 4.2 of the OPCAT (2015).

The Convention on the Rights of Persons with Disabilities

The CRPD does not create any new rights. It can, however, be a powerful instrument in interpreting a State's obligations. One area of particular importance in this regard relates to involuntary or coercive treatment.

The CRPD clarifies what constitutes improper coercion. "[R]espect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons"⁵ is at the core of the CRPD. Accordingly, in the health care context, care must be provided on the basis of free and informed consent.⁶ The existence of a disability cannot be used to deny this right.

Article 12 of the CRPD provides special protections to ensure that people with disabilities enjoy legal capacity, including the right to make legal decisions. The CRPD requires States to provide disabled people with access to support to exercise their legal capacity. A corollary of this is that a failure to do so – in other words adopting a substituted decision-making process – removes a disabled person's autonomy which can, in some circumstances, amount to a deprivation of their liberty.

In its General Comment 1 the CRPD Committee states:⁷

Respecting the right to legal capacity of persons with disabilities on an equal basis with others includes respecting the right of persons with disabilities to liberty and security of the person. The denial of the legal capacity of persons with disabilities and their detention in institutions against their will, either without their consent or with the consent of a substitute decision-maker, is an ongoing problem. This practice constitutes arbitrary deprivation of liberty and violates articles 12 and 14 of the Convention. States parties must refrain from such practices and establish a mechanism to review cases whereby persons with disabilities have been placed in a residential setting without their specific consent.

Article 14(1) reiterates the formulation of the right to liberty and security of the person found in the ICCPR and clearly states that the deprivation of liberty based on the existence of a disability would be contrary to the CRPD and discriminatory. The Office of the High Commissioner for Human Rights suggests the following interpretation of Article 14:⁸

[Article 14] should not be interpreted to say that persons with disabilities cannot be lawfully subject to detention for care and treatment or to preventive detention, but that the legal grounds upon which restriction of liberty is determined must be de-linked from the disability and neutrally defined so as to apply to all persons on an equal basis.

5 CRPD, Preamble.

6 CRPD, Article 25.

7 Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014), CRPD/C/GC/1 at [40].

8 Office of the United Nations High Commissioner for Human Rights, Thematic study on enhancing awareness and understanding of the Convention on the Rights of Persons with Disabilities, UNDoc. A/HRC/10/48 (2009).

The United Nations Committee on the Rights of Persons with Disabilities has also developed guidelines on interpreting Article 14, in which it states:⁹

Involuntary commitment of persons with disabilities on health care grounds contradicts the absolute ban on deprivation of liberty on the basis of impairments (article 14(1)(b)) and the principle of free and informed consent of the person concerned for health care (article 25). The Committee has repeatedly stated that States parties should repeal provisions which allow for involuntary commitment of persons with disabilities in mental health institutions based on actual or perceived impairments. Involuntary commitment in mental health facilities carries with it the denial of the person's legal capacity to decide about care, treatment, and admission to a hospital or institution, and therefore violates article 12 in conjunction with article 14.

The Committee makes similar comments in relation to persons with disabilities who are deprived of their liberty on the basis of care needs.

In relation to monitoring, the Committee has stated:¹⁰

Article 16(3) of the Convention explicitly requires monitoring of all facilities and programmes that serve persons with disabilities in order to prevent all forms of exploitation, violence and abuse.

Prohibition of torture and other cruel, inhuman and degrading treatment

Placing someone in a place in which they are deprived of their liberty inevitably puts that person in a vulnerable situation, one in which they are reliant on others for their basic needs and in some cases, dependent on others for decisions about their care, wellbeing and safety. Many people who end up in these situations, however, are vulnerable even before they lose their liberty. For example, people with disabilities and older people.

The ICCPR was the first universal human rights treaty to expressly include a prohibition on torture and other cruel, inhuman or degrading treatment or punishment (thereafter referred to as ill-treatment). Article 7 of the ICCPR states:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

This is one of the few absolute rights in the ICCPR, with no restrictions permitted. It is also a non-derogable right, which means that States can never derogate from it, even in times of public emergency that threatens the life of the nation.¹¹

9 Committee on the Rights of Persons with Disabilities, Guidelines on article 14 of the Convention on the Rights of Persons with Disabilities; The right to liberty and security of persons with disabilities, 2015, at [10].

10 Ibid at [19].

11 See ICCPR, Article 4.

The UN Human Rights Committee¹² interprets Article 7 broadly. In the Human Rights Committee's view the ill-treatment prohibition extends to chastisement or disciplining of children, and to individuals in educational and medical institutions, as well as arrested or imprisoned individuals.¹³

Article 10(1) of the ICCPR complements Article 7. The Committee has interpreted Article 10 to mean that detainees may not be "subjected to any hardship or constraint other than that resulting from the deprivation of liberty; respect for the dignity of such persons must be guaranteed under the same conditions as for that of free persons".¹⁴ Therefore Article 10 imposes a lower threshold of severity than Article 7; in other words it covers treatment that may not be sufficiently severe to qualify as cruel, inhuman or degrading.

The UN Human Rights Committee has also stated that Article 10, paragraph 1 "imposes on State parties a positive obligation towards persons who are particularly vulnerable because of their status as vulnerable persons deprived of their liberty".¹⁵

Article 15 of the CRPD reflects the ICCPR in prohibiting torture and ill-treatment. It adds however, that States must take action to protect persons with disabilities "on an equal basis with others".

The CAT makes a distinction between torture on the one hand, and ill-treatment on the other. Article 2(1) requires State Parties to take effective legislative, administrative, judicial and other measures to prevent torture in any territory under their jurisdiction. Article 16 creates a corresponding duty on State Parties to prevent ill-treatment.

Both torture and ill-treatment under the CAT require the involvement of a public official or someone acting in an official capacity or the acquiescence of such a person. However, the CAT does not further provide a definition of acts of cruel, inhuman or degrading treatment and the definitional threshold between cruel inhuman and degrading treatment and torture can be unclear.

In 2005 the UN Special Rapporteur on Torture took the position that:¹⁶

A thorough analysis of the travaux preparatoires¹⁷ of articles 1 and 16 of [CAT] as well as a systematic interpretation of both provisions in light of the practice of the Committee against Torture leads one to conclude that the decisive criteria for distinguishing torture from [cruel, inhuman or degrading treatment] may best be understood to be the purpose of the conduct and the powerlessness of the victim rather than the intensity of the pain or suffering inflicted.

12 The Committee is established under Article 28 of the ICCPR.

13 Human Rights Committee, General Comment No. 7: Article 7 (Prohibition of torture or cruel, inhuman or degrading treatment or punishment), 1982.

14 Supra note 1 at [3].

15 Ibid.

16 Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, Manfred Nowak, UN Doc. E/CN.4/2006/6 (23 December 2005), at [39].

17 Travaux Preparatoires are the official record of a negotiation. When interpreting treaties the Vienna Convention on the Law of Treaties notes that the travaux are useful in clarifying the intentions of a treaty.

If this interpretation is followed, while torture is absolutely prohibited, the circumstances in which other forms of treatment are perpetrated will determine whether they qualify as ill-treatment. Accordingly, Nowak and McArthur consider that if force is used legally and for a lawful purpose, and the force applied is not excessive and is necessary to meet the purpose, then it will generally not qualify as cruel, inhuman or degrading treatment. However, in circumstances where someone is deprived of their liberty no such test of proportionality applies. In their opinion, any form of physical or mental pressure or coercion in such a case constitutes at least ill treatment.¹⁸

Aged Residential Care, consent and coercion in Aotearoa New Zealand

New Zealand has a fairly well developed regulatory framework governing the placement of individuals in aged residential care. Where an individual is deemed to lack legal capacity a legally appointed attorney may be able to make decisions on their behalf about care options. In other cases such decisions may be determined by other mechanisms such as an advanced directive. This framework would broadly meet the requirements of New Zealand's International human rights obligations.

However, in many cases individuals may not have an enduring power of attorney, a Court-appointed attorney or an advanced directive. In these cases decisions about their care are often made by a clinician or provider under the auspices of Right 7(4) of the Health and Disability Code of Health and Disability Consumer Rights (Code).¹⁹

Right 7(4) provides an exception to the requirement for informed consent. It gives decision-making powers to the clinician or provider so long as they have taken steps to ascertain the patient's views (or the views of other suitable people) to reach the conclusion that placement in residential care will be in the "best interests" of the patient. In other words, it provides a legal justification for placing someone in residential care without consent in some circumstances.

Right 7(4) anticipates supported decision making where the circumstances allow making it consistent with the purpose of the CRPD. However, its application can be less consistent with the spirit and letter of the CRPD and other human rights obligations including those in BORA. In some cases individuals remain in residential care indefinitely on the basis of Right 7(4) without any apparent review of their ability to provide informed consent or any legal formalisation of the placement.

In order to ensure compliance with New Zealand's international obligations there needs to be a robust mechanism to enable supported decision in as many circumstances as possible before resorting to a "best interests" assessment. This already exists to some degree within Right 7(4) but needs to be accompanied by strong operational guidelines to ensure that in practice:

18 Manfred Nowak and Elizabeth McArthur, "The distinction between torture and cruel, inhuman or degrading treatment", *Torture*, Vol. 16, No. 3 2006, pp 147 -151.

19 For a detailed analysis of Right 7(4) refer to (Cross Reference to Cordelia's paper)

- a supported decision-making is available to everyone regardless of their level of support needs;
- b support is based on the will and preferences of the person;
- c people have a right to be have support in communicating their will and preferences, even if this communication is unconventional;
- d people have the right to be supported in a range of ways, formally and informally. They also have a right to refuse support; and
- e safeguards are set up, with the goal of ensuring the person's will and preferences are respected as far as possible in the circumstances.

Furthermore, Article 12 of the CRPD expressly requires the establishment of effective safeguards for the exercise of legal capacity. The absence of such safeguards – including periodic review of an individual's ability to provide informed consent and the continued need for residential care – or any independent monitoring or oversight is concerning. The OPCAT could potentially be one mechanism that could provide independent preventive monitoring.²⁰

20 For a more detailed discussion on the role of OPCAT in residential care settings see: White, *He Ara Tika; a pathway forward*, New Zealand Human Rights Commission (2016). https://www.hrc.co.nz/files/9314/7251/4226/He_Ara_Tika_Report_2016.pdf

8 International developments on deprivation of liberty

Professor Kate Diesfeld

Introduction

This chapter will highlight the context in which the influential case from England, *P v Cheshire West and Chester Council* (Cheshire West),¹ was decided. It will highlight subsequent developments in England and Wales, Australia and more specifically Victoria. Lessons and initiatives from abroad may provide fertile ground for us to design optimum safeguards for older people who are subject to coercive residential care in Aotearoa New Zealand.

Within the last two decades, England and Wales introduced a range of legal reforms to protect the thousands of people who lack capacity and are deprived of their freedom, in a range of residential settings. In response to increasing concerns regarding the liberties of people who lack capacity and reside in coercive settings, the United Kingdom Parliament amended the *Mental Capacity Act 2005* to introduce the Deprivation of Liberty Safeguards (DoLS). The well-known “Bournewood gap” identified in England illuminated the problematic legal status of people lacking capacity to consent or object to detention.² Subsequent legislative reform and cases inspired scholarly debate and analysis.^{3 4 5 6} Similarly, the government of Victoria is exploring the optimum means to safeguard people in similar situations. Their insights may fruitfully contribute to reforms in New Zealand.

1 *P v Cheshire West and Chester Council* [2014] UKSC 19 [46] (*Cheshire West*)

2 Gledhill, K. The filling of the ‘Bournewood gap’: coercive care and the statutory mechanisms in England and Wales. In B. McSherry and I. Freckelton (Eds) *Coercive Care: Rights, Law and Policy* (London and New York: Routledge, 2013), 114-134.

3 *Ibid.*

4 Douglass, A. *Mental Capacity: Updating New Zealand’s Law and Practice* (Wellington: New Zealand Law Foundation, 2016).

5 White, M. *He Ara Tika; A Pathway Forward: The Scope and Role of the Optional Protocol to the Convention Against Torture in Relation to Aged Care and Disability Residences and Services* (Wellington: New Zealand Human Rights Commission, 2016).

6 Diesfeld, K. Aged care and liberty deprivation. In I. Freckelton and K. Petersen (Eds) *Tensions and Traumas in Health Law* (Arrandale, NSW: The Federation Press, 2017), 36-50.

England and Wales

The recent historical progression of legislation relating to deprivation of liberty in England and Wales is detailed in scholarship by Professor Gledhill.⁷ Of interest to advocates for New Zealand's ageing population, essentially the Mental Health Act 2005 was reformed to protect people who are contained in hospitals and rest homes and do not have the capacity to consent to this arrangement. Section 50 of the Mental Health Act 2007 added sections to the 2005 Act, and with corresponding Schedules, created a framework for safeguarding those who experience such restrictions in England and Wales.

The original regime made it lawful to deprive a person of liberty in hospitals or care homes in prescribed circumstances and under specific authorisation.⁸ The Deprivation of Liberty Safeguards (DoLS) require that six assessments must be completed before an authorisation can be given. The providers apply to the local authority for DoLS authorisation. The local authority scrutinises whether requests are appropriate and, to avoid unnecessary deprivations, advises facilities on least restrictive practices. Up to six assessments are undertaken by professionals to determine whether the deprivation is justified and the potential duration is 12 months. Additionally, the local authority appoints the person's representative (usually a family member or friend) and offers the support of an Independent Mental Capacity Advocate. The person or representative may challenge the decision in the Court of Protection.

The DoLS system attracted considerable critique. For example, by March 2013 a House of Lords Select Committee report claimed that the safeguards were frequently not used and deprived some qualified individuals of the protections that Parliament intended.⁹ Criticisms multiplied and were magnified after publication of the judgment in *Cheshire West*.

Cheshire West

In a nutshell, the *Cheshire West* judgment expanded the boundaries of what historically qualified as a deprivation of liberty. The case scrutinised the living situations of three people. Their conditions included learning disabilities, Down's syndrome and cerebral palsy. One person lived in a foster home and two people lived in residential facilities. All were subject to close surveillance and two were occasionally restrained for their safety. Two people attended education programmes but none were permitted to leave their residences at will.

By majority, the United Kingdom Supreme Court concluded that these circumstances qualified as a deprivation of liberty. Dame Hale referred to the universal character of human rights, founded on the inherent human dignity of all people and confirmed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

7 *Supra* n 2.

8 Department of Health. Briefing on Mental Health Act Deprivation of Liberty Safeguards – April 2010 Gateway Reference: 14353 (London: Department of Health, 2010).

9 Ministry of Health. Mental Health and Deprivation of Liberty (London: Ministry of Health, 2015). www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty. Accessed 8.11.17

Her Honour observed that the CRPD was ratified by the United Kingdom in 2009 and is recognised by the Supreme Court as integral to the international context within which the Convention on the Protection of Human Rights and Fundamental Freedoms (European Convention) is to be interpreted.

Of relevance to many older people with compromised capacity, the judgment defined the State's duties to people with disabilities:

Far from disability entitling the State to **deny** such people human rights, rather it places the State (and upon others) the **duty** to make reasonable accommodation to cater for the special needs of those with disabilities (emphasis added).¹⁰

Her Honour reminded of us of the impact of containment, through a memorable comparison:

... (W)hat it means to be deprived of liberty must be the same for everyone, whether or not they have physical or mental disabilities. If it would be a deprivation of my liberty to be obliged to live in a particular place, subject to constant monitoring and control, only allowed out with close supervision, and unable to move away without permission even if such opportunity became available, then it must also be a deprivation of the liberty of a disabled person. The fact that my living arrangements are comfortable, and indeed make my life as enjoyable as possible, should make no difference. A gilded cage is still a cage.¹¹

Her Honour evocatively reminds us that benevolent care within a coercive setting, no matter how well intentioned, is still is a deprivation of liberty. This is true for many older people who reside in rest homes and hospitals, in New Zealand and in other jurisdictions. According to the judgment, wherever the deprivation exists, even in foster homes and other domestic situations, safeguards must be established.

The impact was swift and debates fierce. The judgment had grave repercussions and wreaked "significant damage" to the DoLS, according to leading lawyer Tim Spencer-Lane, who featured in a Law Commission video.¹² In the wake of *Cheshire West*, the government asked the Law Commission to review the scheme, after local authorities reported a tenfold increase in DoLS applications in England and a 16-fold increase in Wales.¹³ Law Commissioner Nicholas Paines QC observed:

The deprivation of liberty safeguards were designed at a time when considerably fewer people were considered deprived of their liberty. Now they are failing those they were set up to protect. The current system needs to be scrapped and replaced right away.¹⁴

10 Supra n 1 [45].

11 Supra n 1 [46].

12 Ministry of Health. Mental Capacity and Deprivation of Liberty <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/> Accessed 8.11.17

13 Fouzder, M. Law Commission seeks to overhaul deprivation of liberty safeguards (London: Law Gazette, 13 March 2017). <https://www.lawgazette.co.uk/law/law-commission-seeks-to-overhaul-deprivation-of-liberty-safeguards/5060213.article>. Accessed 8.11.17.

14 Ibid.

In his view, the resulting cost savings can be “directly reinvested to support those most in need”.¹⁵ The Commission’s 2015 consultation concluded that the regime was deeply flawed, excessively complex and bureaucratic with enormous costs to the local authorities and the National Health Service.

On a positive note, the Social Care Institute for Excellence (SCIE)¹⁶ detected benefits from the current system. The scrutiny that accompanies DoLS sometimes produces creative, supportive, constructive care plans. Also, the Independent Mental Capacity Advocates and Best Interest Assessors have important roles in ensuring that people’s rights and quality of life are protected.

However, the momentum for reform quickened. In March 2017, the Law Commission published a review of DoLS. It recommended amendments to the Mental Capacity Act and replacement of the DoLS with Liberty Protection Safeguards (LPS) to strengthen people’s rights in areas such as best interests. If adopted, the new broader regime would apply to people 16 years of age and older, plus extend beyond care homes and hospitals to include health and social care settings. A person would not be deprived of his or her liberty until the appropriate arrangements have been authorised. Scrutiny would be magnified regarding whether a deprivation of liberty is necessary and proportionate.

Two protection tiers would be established. For the first, usually the “responsible body” would complete a capacity assessment, a medical assessment, and an assessment of whether the planned care arrangements are “necessary and proportionate”. The assessments would be undertaken by the local authority for social care situations and by the National Health Service for hospital patients. An independent reviewer (employed by the responsible body) who is involved in the person’s care would review, and have the power to approve the assessments. For the second tier, an Approved Mental Capacity Professional (replacing the Best Interests Assessor) would only be involved when the person was objecting to his or her care arrangements, or previously indicated a likely objection to those arrangements.

This proposal for a streamlined, but potent, regime was supported by Law Society President Robert Bourns.¹⁷ He recommended that the framework should allow people to challenge practices that are overly restrictive or abusive. For those who are responsible for care, the process must be straightforward. For those who do not comply, penalties should be enforced.

These recommendations were included in the Commission’s final report and draft bill 13 October 2017.¹⁸ The Commission reiterated the “widespread agreement that the DoLS are overly technical and legalistic, and too often fail to achieve any positive outcomes for the person concerned or their families”. Symptoms of the crisis included DoLS referrals that were not actioned and breach of statutory deadlines.

15 Ibid.

16 Social Care Institute for Excellence Deprivation of Liberty Safeguards (DOLS)(London: Social Care Institute for Excellence, 2017). <https://www.scie.org.uk/mca/dols/at-a-glance>. Accessed 8.11.17

17 Supra n 13.

18 Law Commission. Mental Capacity and Deprivation of Liberty (London: Law Commission, 2017). <http://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/> Accessed 8.11.17.

The Government's interim response was published on 30 October 2017 and the Law Commission is awaiting the Government's final response. It remains to be seen whether the proposed regime will significantly reduce complexity and bureaucracy, and whether it will be accompanied by adequate resources.

Australia

Australia, like many other countries, has examined the use and lawful limits of restrictive practices, including for older people in residential care. In Australia, “restrictive practices” are defined as interventions that limit the rights or freedom of movement for person's protection.¹⁹ Concerns have arisen regarding the unregulated or excessive use of such practice in diverse Australian contexts.

While regulation currently occurs primarily at the State and Territory level, Australia has attempted to create a consistent national framework. This may have relevance for aged care facilities. In 2014, the Commonwealth, State and Territory ministers endorsed the National Framework for Reducing and Eliminating the Use of Restrictive Practices In the Disability Service Sector.²⁰ A key principle is that decisions about restrictions should be made by the person who is subject to them, to the extent possible. For example, a positive behavioural plan would include the support required for the person to make decision about restrictive practices. Of particular relevance, the ALRC advised that the government should create a similar strategy for aged care in its National Framework, at Recommendation 8-2.

More recently, the ALRC proposed greater protections against abuse and exploitation for older people.²¹ The 43 recommendations prioritised autonomy. The review of Commonwealth law included more robust prevention and responses to elder abuse in aged care services. Importantly, it recommended closer scrutiny of restrictive practices in aged care.

Victoria

The momentum for reform has increased. A select example demonstrates how one Australian State has responded. Victoria's government grappled with the legal status of people who lack capacity but are subject to coercive care. In August 2017, the Office of the Public Advocate (OPA) published a discussion paper entitled “Designing

19 Senate Community Affairs Inquiry into the Indefinite Detention of Persons with Cognitive and Psychiatric Impairments (Canberra: Parliament of Australia, no date). http://aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Indefinite_detention. Accessed 8.11.17.

20 Australian Government Department of Social Services. National Framework for Reducing and Eliminating the Use of Restrictive Practices In the Disability Service Sector (National Framework) (Canberra: Australian Government Department of Social Services, 2014). <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/national-framework-for-reducing-and-eliminating-the-use-of-restrictive-practices-in-the-disability-service-sector>. Accessed 8.11.17.

21 Australian Law Reform Commission. Elder Abuse—A National Legal Response (ALRC Report 131) (Sydney: Australian Law Reform Commission, 2017.) <https://www.alrc.gov.au/publications/elder-abuse-report>. Accessed 8.11.17.

a deprivation of liberty authorisation and regulatory framework".²² As documented in other countries, the OPA acknowledged that thousands of people with cognitive disabilities, mental illness and/or age-related disabilities reside in social care facilities. Many are subject to very high levels of supervision and restrictions, including complete and continuous deprivation of liberty. Commonly, decisions are made by family members, or by staff members who believe that a duty of care allows (or requires) them to make the decisions.

The proposal prioritises concepts from the CRPD, such as supported decision-making. Also, it requires precise explanation of: the duration and scope of powers that are authorised and periodic review. Of significance, there must be a documented plan to reduce those restrictions.

Examination of the detail of this most recent strategy from New Zealand's close geographic neighbour is informative and inspiring. In brief, the Public Advocate's proposed framework would require the following whenever arrangements are being considered that would give rise to a deprivation of liberty:

- Alternative options need to be identified and explored;
- The subject person must be engaged and supported to make her or his own decisions wherever possible, including through the provision of relevant information and other decision-making supports;
- The subject person can nominate her or his own advocate or an independent advocate must be arranged;
- The substantive criteria for a deprivation of liberty must be examined. These should be that:
 - The person is unable to be supported to make her or his own decision;
 - The threshold harm criterion (to be determined) applies;
 - The proposed arrangements are necessary and proportionate; and
 - There is no less restrictive alternative.
- The person's wishes and preference must be identified and considered and the relevant people must be consulted;
- The appropriate decision-maker must be engaged. If the proposed arrangements are intended to address a risk of harm to the person, and are consistent with the person's wishes, the service seeking to implement the arrangements may determine whether the criteria are met. In any other case, the service must apply to the Victorian Civil and Administrative Tribunal's ('VCAT') Human Rights List for a determination;
- An authorisation record must be produced, which must specify the precise arrangements that are to be authorised, the decision-making process and

²² Office of the Public Advocate. Designing a deprivation of liberty authorisation and regulatory framework (Melbourne: Office of the Public Advocate, 2017). <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/restrictive-interventions/438-discussion-paper-designing-a-deprivation-of-liberty-authorisation-and-regulation-framework>. Accessed 8.11.17

reasons, the maximum duration for the authorisation and the timeframe for periodic reviews. It must also include a plan to reduce restrictions over time;

- The authorisation record must be registered with the registration authority, which will review any record produced by a service.

In addition, the Public Advocate included these protections.

- Empowerment of the registration authority to refer a matter to VCAT or for investigation;
- Required periodic reviews;
- A right to merits review, appeals and judicial oversight;
- Provision for advance directives and second opinions;
- Ongoing rights to independent legal and non-legal advocacy;
- A complaints body; and
- Strengthened civil and criminal sanctions.

The Public Advocate's proposed framework is presented as a flowchart in the Appendix.²³

According to the Public Advocate, this strategy is only one element of a matrix of required reforms to create a potent system that protects the rights and dignity of people in social care settings.

In some respects, this scheme seems more streamlined than the LPS proposal from England and Wales. However, the precise scope and mechanics of the framework remains to be determined. One of its merits is the integration of the principles of the CRPD, such as an emphasis on supported decision-making, with access to independent advocacy and a dedicated complaints body.

Additional options for New Zealand

While we await the Victorian government's response to this detail discussion paper, there is an opportunity to examine a proposal made by Professor Gledhill²⁴ prior to the *Cheshire West* judgment. Although his recommendation was in the context of the jurisprudence of England and Wales in 2013, it may have currency and gain traction in New Zealand. Professor Gledhill inquired whether a guardianship regime is the solution. A guardianship framework might avoid the pitfalls and complexity of the DoLS. This would not involve transfer of *all* decision-making to the guardian, but only select decisions, including admission to residential facilities. The guardian would be appointed prior to admission.

23 The flowchart is located in the Appendix at p 88 in this document. Office of the Public Advocate. Designing a deprivation of liberty authorisation and regulatory framework (Melbourne: Office of the Public Advocate, August 2017). <http://www.publicadvocate.vic.gov.au/our-services/publications-forms/research-reports/disability/restrictive-interventions/438-discussion-paper-designing-a-deprivation-of-liberty-authorisation-and-regulation-framework> . Accessed 8.11.17.

24 *Supra* n 2.

According to Professor Gledhill, one virtue is its simplicity. An audit would simply inquire whether a guardianship exists. Rather than scrutinise whether deprivations existed, the manager would determine whether the person had the capacity to make a voluntary decision regarding residence and a guardian. Professor Gledhill's analysis includes robust consideration of how this might operate, within a human rights framework.

The nuances of how this form of guardianship might be implemented in New Zealand's context awaits analysis. A number of possibilities emerge. One is the creation of an Office of the Public Advocate. However, this may create a bureaucratic labyrinth and may de-personalise the role, which ideally involves a close relationship between the vulnerable individual and her or his guardian. Another possibility is the creation of paid "private" guardians, but this also poses a raft of issues regarding funding, monitoring and professionalisation of the role. A third option is payment of interested family members but this alternative poses similar issues, as well as the potential for undue influence or conflicts of interest.

Conclusion

Aotearoa New Zealand is poised to erect the most modern, and rights-protecting, regime for people who cannot consent to their residential arrangements. New Zealand has a strong and long tradition of human rights safeguards, from the New Zealand Bill of Rights Act 1990, the Human Rights Act 1993 and the Code of Health and Disability Services Consumers' Rights. Our role in creating, and commitment to, the CRPD adds greater potency to our efforts.

Part of our challenge is to decide whether we will take up the challenge: how far will we throw the net to protect all people in diverse settings who are de facto detained, often across their lifespans?

We share an agenda with our international colleagues and advocates: identifying the least restrictive alternative, promoting supported decision-making and protecting human rights. We also have a significant opportunity, and perhaps an obligation, to design an effective and sustainable human rights framework for all those who are rendered vulnerable to deprivation of their liberties. From abroad, we may learn lessons from recent experiments. No doubt we will make innovative contributions, in the New Zealand tradition.

9 Filling the gap

Liberty safeguards for people with impaired capacity

Alison Douglass

Introduction

Liberty and freedom of movement are values of fundamental importance in our society, yet currently in New Zealand there is no legal process governing loss of liberty for some people who lack decision-making capacity. In a broad range of settings, people with impaired capacity are detained, and under the continuous supervision and control of those caring for them, and not free to leave. Yet, in many cases – such as where a person is not under the authority of the Mental Health (Compulsory Treatment and Assessment) Act 1992, or an order is made under the adult guardianship law, the Protection of Personal and Property Rights Act 1988 (PPPR Act), they are detained. Moreover, in most cases, the PPPR Act does not provide an ongoing process for reviewing the detention of people who lack capacity where their detention has been authorised by a person holding an enduring power of attorney (EPOA) or a welfare guardian appointed by the Family Court.

This paper is based on the writer’s law reform report, *Mental Capacity: Updating New Zealand’s Law and Practice* (Report), published in July 2016. The findings of the Report were first presented at the “This is not my home” seminar,¹ and need for reform regarding this gap in the law has subsequently been published in a medical law journal.² This paper begins with a precis of the key findings of the Report. There follows a discussion of the legal concept of capacity and the impact of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on capacity law and policy in New Zealand. It highlights the lessons to be learned from the English experience of developing deprivation of liberty safeguards, identifies the so-called “Bournewood gap” in New Zealand, and provides recommendations for reform in New Zealand with liberty safeguards.

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- 1 A. Douglass, *Mental Capacity: Updating New Zealand’s Law and Practice* (New Zealand Law Foundation, 2016), www.alisondouglass.co.nz. ISBN 978-0-473-40993-7. Presentation to “This is not my home” Aged Residential Care Without Consent, 27th September 2016, Auckland.
 - 2 A Douglass “Rethinking necessity and best interests in New Zealand mental capacity law” (2018) 18 *Medical Law International* 3.

Mental Capacity Report

The Report is the result of a legal research project undertaken by the writer as the 2014 recipient of the New Zealand Law Foundation International Research Fellowship. The project has involved analysis of relevant New Zealand law plus analysis of the legislative framework provided by the Mental Capacity Act 2005 (for England and Wales) and its associated Code of Practice. Key informants for this research include leading experts, academics and members of the judiciary in the United Kingdom, as well as a wide range of people working in the health and disability sector in New Zealand, including contributors to this publication.³ The Report is also based on the writer's own experience as a lawyer practising in this field and representing people with disabilities and impaired capacity in the Family and appellate Courts.

The key finding of the Report is the need to modernise the law and in particular New Zealand's adult guardianship law, the Protection of Personal and Property Rights Act 1988 (PPPR Act). The range of people to whom the legislation applies and the social environment in which it operates are now very different from when it was passed at the peak of the era of deinstitutionalisation of large psychiatric facilities. The United Nations Convention on the Rights of Persons with Disabilities (CRPD), and its paradigm shift towards supported decision-making, requires State parties to rethink domestic laws and engage with the key concepts of this important human rights convention.

The Report provides a template for law reform with specific recommendations. It tackles the challenge of how to provide a workable law that best protects and promotes the autonomy of people with impaired capacity. These recommendations include: incorporating "front-end" supported decisionmaking as a legal principle, taking into account tikanga Māori; defining capacity with a single legal test; providing for an accountable process for assessing "best interests" as a standard for decisionmaking; and, a Code of Practice to inform professionals of best practice standards within New Zealand law. There is also guidance to health practitioners who are involved in assessing people's capacity, in the form of a toolkit, co-authored with a psychiatrist and an ethicist.⁴ The report highlights that in contrast to comparable countries, New Zealand does not have a national register for enduring powers of attorney (EPOA) (and for advance directives and organ donation) or a public body that champions this area of the law. These measures are now recognised in the United Kingdom as instruments of support and safeguards against abuse that are compliant with article 12 of the CRPD. Another measure is supporting effective access to independent advocates for people with impaired decision-making capacity.

The Report identifies two major gaps in New Zealand's law; firstly, the focus of this seminar, the lack of legal safeguards for people who lack capacity and who are unable to consent or object to their healthcare and living arrangements.⁵ Secondly, the lack of a facility in law to allow participation in research by adults incapable of

3 Above n 1, Douglass Report, Appendix E.

4 Above n 1, Douglass Report, Appendix D A Toolkit for Assessing Capacity. www.alisondouglass.co.nz

5 Above n1.

giving informed consent.⁶ The most significant development in English law that New Zealand can learn from, has been the realisation that the doctrine of necessity under the common law – the principle that necessary treatment and care can be provided to a person that lacks capacity in their best interests – which is expressed through Right 7(4) of the HDC Code, provides inadequate legal safeguards in these situations.

This is the so-called “Bournewood gap” and the decision in the European Court of Human Rights (ECtHR)⁷ following a decision of the House of Lords under the Mental Capacity Act 2005 (England and Wales) (MCA). This case has led to major developments in English law, including the establishment of “deprivation of liberty safeguards” (DoLS), to fill the gap. The reform of these safeguards is ongoing in the UK⁸ and steps are being taken in other comparable countries to address the need to have a responsive legal framework. More recently, the Office of the Public Advocate in Victoria, Australia, (where there is a similar adult guardianship law to that in New Zealand) has described the situation as “an acute legal and moral problem”,⁹ warranting reform to clarify when a “social care” practice may constitute a deprivation of liberty. The Victorian proposal aims to design an authorisation process in circumstances where people are detained so as to contribute tangible benefits to people’s lives.¹⁰ A crucial aspect in designing these safeguards is that they are a “check and balance” in the system, regardless of whether or not the person is compliant or objects to their detention or placement in care. They are not concerned with the quality or standard of care provided but to ensure there is an independent means to check upon the person’s liberty rights.

At the same time as publication of the Report, in 2016, the Human Right Commission issued a report on the detention of people in aged care facilities under the OPCAT.¹¹ More than any other issue, the detention of people in aged care facilities in this context drew feedback and comment on the Report from the public and those working in the health and disability sector.

6 Douglass Report, Ch. 6 Research on People who Lack Capacity.

7 *HL v United Kingdom* (2005) EHHR 32 at para 799.

8 Law Commission, *Mental Capacity and Deprivation of Liberty: A Consultation Paper No. 222* (London, TSO 2015). The final report and draft Bill were published on 13 March 2017. The UK Government’s final response was published on 14 March 2018. <https://www.lawcom.gov.uk/project/mental-capacity-and-deprivation-of-liberty/>. The UK government is poised to implement these changes and the Joint Committee on Human Rights has issued a report on the proposed reforms: <http://www.mentalcapacitylawandpolicy.org.uk/joint-committee-on-human-rights-reform-of-dols-report-published/>

9 J Chesterman, “Designing a Deprivation of Liberty Authorisation and Regulation Framework” Discussion paper, August 2017 Office of the Public Advocate www.publicadvocate.vic.gov.au

10 Ibid.

11 Human Rights Commission He Ara Tika A pathway forward: the scope and role of the Optional Protocol to the Convention against Torture (OPCAT) in relation to aged care and disability residences and facilities. https://www.hrc.co.nz/files/9314/7251/4226/He_Ara_Tika_Report_2016.pdf/

Capacity, Right 7(4) of the HDC Code and 'best interests'

Decision-making capacity (or simply "capacity") refers to individuals' ability to make particular decisions or take actions that influence their lives. It focuses on whether the person retains that ability and, if not, who should decide on their behalf and on what basis.

Decision-making capacity can affect people of all ages and arises in a variety of social environments in healthcare settings. The law affects a wide range of adults with impaired decision-making capacity, who are vulnerable for reasons such as dementia, learning disabilities, mental illness or acquired brain injury. The decisions in question may involve, for example, a younger adult with learning disabilities negotiating choices about their living arrangements; or, an older adult experiencing the onset of dementia who needs to work out their next steps. The increasing prevalence of dementia and Alzheimer's disease means there are now more people with impaired capacity in the community, and, there is a greater need to support them within the health system. The prevalence of patients who lack capacity in New Zealand hospitals and care facilities is unknown. A review of 58 international studies of capacity found 45% of patients in psychiatric settings and 34% of patients in general medical settings lack decision-making capacity.¹² Dementia is a leading cause of incapacity and is expected to affect over 78,000 New Zealanders by 2026.

In New Zealand, the law governing issues of capacity and decision-making is largely found in two distinct pieces of legislation. The first is the PPPR Act, the guardianship law for adults aged 18 or over who lack capacity to make financial, care and welfare decisions. The second is the Health and Disability Commissioner Act 1994, which in turn authorises the making of a legally enforceable Code, the Code of Health and Disability Services Consumers' Rights (HDC Code).¹³ The interface between the PPPR Act and the HDC Code is not well understood. The Health and Disability Commissioner does not, for example, have any oversight of the implementation or monitoring of court orders under the PPPR Act. The Commissioner's opinions are limited to breaches of the Code. Further it is a reactive, not a proactive, process, and does not provide prospective mechanisms for those who lack capacity and are especially vulnerable in the health system. The HDC Code does not define "competence" or codify a legal test for capacity to consent to medical treatment or health care. The competence of a consumer (patient) to make an informed choice, and give or refuse informed consent to healthcare procedures or disability services, is a key component to ensuring that the rights of consumers are protected under this Code. In the exercise of a person's legal capacity to make an informed decision, Right 7 (3) of the HDC Code recognises that where a person has "diminished competence", they retain the right to make informed choices and give informed consent, to the extent appropriate to his or her level of competence.

12 P Lepping, T Stanly and J Turner "Systematic review on the prevalence of lack of capacity in medical and psychiatric settings" (2015) 15 Clin Med (JRCF) 337.

13 Code of Health and Disability Services Consumers' Rights Regulations 1996.

It is within the context of the informed consent rights in the HDC Code (Rights 5, 6 and 7) that the doctrine of necessity under the common law is expressed as an exception in Right 7(4) of the HDC Code. While some refinements have been added, including express requirements to consider the patient's known prior views before providing health or disability services, and to consult other persons, where possible. Provided those requirements are met, the text of Right 7(4), like the common law doctrine, provides both a justification for the provision of health and disability services without consent, where the person lacks capacity, and a defence to Code liability (under the HDC Code) for the health provider provides a "health and disability service" in the person's "best interests".¹⁴

There is however, no guaranteed process for reviewing situations where Right 7(4) may be relied upon for people who lack capacity to consent or object to their detention in a range of healthcare and living environments, and who are not subject to involuntary treatment under the mental health legislation, thereby maintaining the Bournemouth gap. In contrast, this gap has been filled in England, albeit controversially, by enactment of the Deprivation of Liberty safeguards (DOLS) regime and ongoing reform is under consideration by the Law Commission for England and Wales (Law Commission).¹⁵

In addition, New Zealand's legal framework in the HDC Code and the PPPR Act does not provide statutory guidance on the meaning of a person's 'best interests', an essential component of implementing the necessary safeguards, or how to assess these interests in difficult clinical situations. Nor is there guidance about how these interests should be determined in accordance with the person's "will and preferences" or support for the exercise of a person's legal capacity might be implemented to better reflect the principles of the CRPD.

Article 12 of the CRPD

Article 12 of the CRPD has added new impetus towards understanding legal capacity and the concept of supported decision-making. Although New Zealand was one of the first countries to ratify this Convention in 2008, the consistency of the PPPR Act with the CRPD is now under scrutiny, especially in relation to how the concept of supported decision-making can be incorporated into the PPPR Act, the scheme of which provides the substitute decision-making within the adult guardianship regime.¹⁶ The General Comment released in 2014 casts doubt on New Zealand's compliance with the CRPD as does the subsequent report on New Zealand's position from the UN Committee.¹⁷

14 Above n 2 A Douglass Rethinking necessity and best interest; Refer C Thomas Right 7(4) paper.

15 Above n8 Law Commission for England and Wales reports.

16 United Nations Committee on the Rights of Persons with Disabilities General Comment Number 1 Article 12: Equal recognition before the law, CRPD/C/GC/1 (2014). The Convention itself does not actually mention "supported decision-making" or "substitute decision-making" or define these terms.

17 Office for Disability Issues Government response to the United Nations Committee on the Rights of Persons with Disabilities Concluding Observations on New Zealand (Ministry of Social Development, Wellington, 2015).

In addition to the general principles and obligations contained in the CRPD, art 12 and the right to equal recognition before the law are of central importance in understanding how the CRPD applies to capacity law and practice. The CRPD has arguably had the greatest impact on State parties having to rethink domestic laws and review best practice standards in this area of the law and practice. Its aim is that people with disabilities, including those with impaired capacity, should enjoy rights on the same basis as everyone else. Particularly important in this context is the right of people with disabilities to make decisions about significant matters affecting their lives based on their free and informed consent. Article 12 of the CRPD emphasises the concept of universal legal capacity. Legal capacity comprises both legal standing – being recognised as a person before the law, and legal agency – the ability to act within the framework of the legal system.¹⁸ There is an obligation on States to provide support to achieve equal capacity, for persons with disabilities who broadly include those who have “long-term physical, mental, intellectual or sensory impairments”.

In summary, art 12 recognises the following rights and obligations on state parties:

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

By ratifying the CRPD, New Zealand undertook to adopt all appropriate legislative, administrative and other measures for the implementation of the rights recognised in it. These obligations necessitate the critical review of the capacity laws in New Zealand, their interface with involuntary treatment legislation¹⁹ and a careful assessment of the applicability of human rights law in this context.²⁰ As poignantly stated by Jackson J, in the Court of Protection in England:²¹

a conclusion that a person lacks decision-making capacity is not an ‘off-switch’ for his rights and freedoms. To state the obvious, the wishes and feelings, beliefs and values of people with a mental disability are as important to them as they are to anyone else, and may even be more important.

18 M Bach and L Kerzner “A new paradigm for protecting autonomy” (2014) Ontario Law Commission <http://repositoriocdpd.net:8080/handle/123456789/449> at 16. See also B McSherry “Legal issues: legal capacity under the convention on the rights of persons with disabilities” (2012) 20 J Law Med 22.

19 Relevant to this discussion is the interface of the PPPR Act with involuntary treatment/mental health laws including the Mental Health (Compulsory Treatment and Assessment) Act 1992, Intellectual Disability (Compulsory Care and Rehabilitation) Act 2003 and the recently introduced Substance Addiction (Compulsory Treatment and Assessment) Act 2017 where incapacity to consent to treatment to severe substance addiction is a criterion for compulsory status.

20 Above n 2 A Douglass, Rethinking necessity and best interests at 5-6.

21 Wye Valley NHS Trust v Mr B [2015] EWCOP 60, at [38] Jackson J affirmed the right of an individual to refuse life-saving treatment, even though Mr B lacked capacity as a result of mental illness marked by religious delusions.

Learning from the English experience

The House of Lords' decision in the *Bournewood* case in 1999,²² and the decision of the European Court of Human Rights (ECtHR) in *HL v United Kingdom* in 2004,²³ exposed a gap in the legal protections that cover the detention of compliant people who lack the capacity to object which became known as the "Bournewood gap". This gap in the law was exposed after a 48 year old man with severe autism was informally admitted to Bournewood Hospital in England and he was detained there. He had been deprived of his liberty when the staff exercised complete control over his freedom of movement. This deprivation of liberty was a breach of Article 5(1) of the ECHR as there was inadequate protection against the arbitrariness of his informal admission. Article 5(4) of the ECHR therefore required that he had guaranteed access to an independent review process concerning the lawfulness of his detention.

Subsequently amendments were made to the Mental Capacity Act (England and Wales) 2005 (MCA),²⁴ including the implementation of the Deprivation of Liberty Safeguards (DoLs), and a broadened interpretation that was then given to "deprivation of liberty" and it was extended to people with impaired capacity who are "detained" in community settings by the UK Supreme Court in the judgment known as *Cheshire West*.²⁵ At the same time, a House of Lords Committee decreed that the safeguards as enacted through the MCA were no longer "fit for purpose" and called for a substantial overhaul of this regime.²⁶

The review of the English law by the Law Commission for England and Wales proposes simplified "liberty protection safeguards" and is ongoing. The onerous Deprivation of Liberty Safeguards became unworkable in practice and in turn has been the subject of criticism. In March 2017 however, the Law Commission for England and Wales released its review of the Scheme along with a draft Bill which proposed replacing the Deprivation of Liberty Safeguards with a new Scheme called the "Liberty Protection Safeguards".²⁷

The *Bournewood* case and developments are highly relevant to New Zealand. There are many similarities between English and New Zealand mental capacity law. In common with the UK, New Zealand is a party to the main international human rights instruments relevant to mental capacity law and the New Zealand Bill of Rights Act 1990 (NZBORA), s 22 protects the right to liberty or the right not to be arbitrarily detained. Such liberty rights are also guaranteed by the International Covenant on

22 *R v Bournewood Community and Mental Health NHS Trust*, Ex p. L [1998] All ER 289 at 299

23 Above n 7, *HL v United Kingdom*.

24 MCA 2005 ss 4A and 4B, Schedules 1A and A1. The new legislative scheme was inserted into the Mental Capacity Act by the Mental Health Act 2007, which came into effect in 2009.

25 *P v Cheshire West and Chester Council and P v Surrey County Council* [2014] UKSC 19, [2014] AC 896.

26 House of Lords Select Committee Mental Capacity Act 2005: post-legislative scrutiny (TSO, London, 13 March 2014).

27 Above fn9. Law Commission for England and Wales, *Mental Capacity and Deprivation of Liberty*, No. 372 (2017).

Civil and Political Rights 1966 (ICCPR),²⁸ the United Nations Convention on the Rights of Persons with Disabilities (CRPD).²⁹ Although New Zealand is not a party to the European Convention on Human Rights (ECHR)³⁰ decisions of the Strasbourg Court in the European Court of Human Rights, Article 5 of the ECHR is similar to the rights expressed in the NZBORA. Therefore, the case law from the English Courts and the Strasbourg Court will be influential in New Zealand.³¹

In view of the significant developments in England and comparable countries, it is surprising how little attention has been given to the issue of the Bournemouth gap in New Zealand. The English experience is that the common law doctrine of necessity provides an inadequate procedural safeguard for people with impaired capacity who are unable to consent or object to their healthcare and living arrangements. Yet there has been no policy discussion in New Zealand about how “deprivation of liberty” safeguards should or could be implemented along with the PPPR Act, the adult guardianship law that has remained static over thirty years.

Identifying the Bournemouth gap in New Zealand

The Bournemouth gap exists in New Zealand because there are no specific legal safeguards that apply to these situations of detention. Many people who lack capacity to make decisions about their accommodation arrangements – either those in residential care or those who are about to be discharged from hospital and admitted into care – have no legal provisions anticipating their loss of capacity.³² They do not have a legally authorised person appointed under an Enduring Power of Attorney (EPOA) or an appointed welfare guardian, who has the power to consent or object to decisions authorising their detention in relation to their living arrangements. Even if they do, or if Court orders are obtained, the PPPR Act is not designed to provide ongoing oversight of their detention or restrictions on their liberty.

Where in such situations, there is no-one to act on behalf of a person who lacks capacity, healthcare providers in New Zealand are often reliant on the common law doctrine of necessity, expressed through Right 7(4) of the HDC Code, to provide a legal justification for their confinement. This justification is based on the assumption that decisions about the effective detention of the person who lacks capacity can simply be made in their best interests by healthcare professionals, without any independent oversight of those decisions being required – an assumption that was rejected by the ECtHR, where it described the problems of relying on the doctrine of necessity and said.³³

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

29 CRPD, art 14.

30 European Convention on Human Rights (opened for signature 4 November 1950, entered into force 3 September 1953), art 5.

31 Gledhill K, “A Rights Audit of the Mental Health Act” in Dawson J and K Gledhill (eds) *New Zealand’s Mental Health Act in Practice* (VUP, Wellington, 2013) at 286.

32 See Chapter 3 M Fisher.

33 Above fn 9 HL v United Kingdom ECHR [2004] 471 at [120]-[121].

The Court observes that, as a result of the lack of procedural regulation and limits, the hospital's health care professionals assumed full control of the liberty and treatment of a vulnerable incapacitated individual solely on the basis of their own clinical assessments completed as and when they considered fit: as Lord Steyn remarked, this left "effective and unqualified control" in their hands. While the Court does not question the good faith of those professionals or that they acted in what they considered to be the applicant's best interests, the very purpose of procedural safeguards is to protect individuals against any "misjudgments and professional lapses".

The closest reported example to date that illustrates the Bournemouth gap in New Zealand concerned the informal detention of a woman in a dementia unit against her wishes that arose as a complaint under the HDC Code.³⁴ There will be many instances where the lawfulness of a person's initial detention in care would be clearly justified under the doctrine of necessity (and Right 7(4)) but the original reasons for their detention may cease to be valid if their condition changes. Their ongoing detention may then become a disproportionate response to the situation, and a breach of s 22 of the New Zealand Bill of Rights Act 1990.³⁵ Moreover, under New Zealand law, the precise situations in which providers may rely on Right 7(4) or must indeed seek a court order, are not fully clear. In practice, it seems that providers tend not to risk relying on Right 7(4) alone in more contentious cases, such as where a family dispute exists about where to place an older family member, where the person strenuously objects to the proposed arrangements (particularly their admission to a secure dementia unit), or where there is no obvious family member or friend available who is concerned about the person's long-term interests.³⁶ There is a risk therefore that there are inconsistent and idiosyncratic approaches undertaken in New Zealand.

The Bournemouth gap exists in New Zealand because there are no specific legal safeguards that apply to these situations of detention. Reliance on the doctrine of necessity in these situations was rejected by the ECHR (*HL v United Kingdom*) as an inadequate basis for the ongoing detention or monitoring of situations where people are deprived of their liberty. In these circumstances, the people concerned are under the continuous supervision and control of those who care for them and are not free to leave. Therefore, they meet the "acid test" for when safeguards are needed as described by Lady Hale in *Cheshire West*.³⁷

34 HDC Opinion 08HDC20957 Auckland District Health Board, Taikura Trust, Aranui Home and Hospital Ltd (Trading as Oak Park Dementia Unit) (3 November 2010). The Commissioner's opinion and the case before the Human Rights Review Tribunal did not expressly address the right not to be arbitrarily detained under s 22 of the New Zealand Bill of Rights Act (NZBORA) 1990 Taikura Trust; Cordelia Thomas Right 7(4).

35 *Zaoui v Attorney General* [2005] 1 NZLR 577.

36 Above n 1 Douglass report, ch 3, 3.64-3.85, interviews with providers and case examples based on real situations "Current problems and practice".

37 HRC Ara Tika A Pathway Forward, the Scope and Role of the Optional Protocol to the Convention Against Torture (OPCAT) in Relation to Age Care and Disability Residences and Facilities, Michael J V White, June 2016, New Zealand Human Rights Commission.

In New Zealand, neither the court procedures currently available under the PPPR Act (personal orders or the appointment of a welfare guardian) nor Right 7(4) of the HDC Code are designed to be effective in identifying deprivations of liberty in advance of a person's detention. Nor do they provide ongoing monitoring of a person's detention to ensure that decisions are the least restrictive option available and are in their best interests. There remains a lack of transparency around the decisionmaking process itself and the standard required to be met. Most family members and service providers are unaware of the legal uncertainty surrounding restrictions on liberty or their lack of authority to implement such arrangements. Sometimes this may simply be assumed, especially if the person may wish to make a decision that others disagree with. As there is no public body that champions this area of the law and practice, people with impaired capacity and their families are not provided with access to relevant information and supports they may require to make their own decision. The legal landscape of mental capacity law is fragmented: a review of law requires a coordinated Government approach.³⁸

There are also legal risks for those working in the health and disability sector. These concern the extent to which providers of health and disability services might breach their duty of care to people by detaining them without legal authority or, indeed, for not detaining them when it is required to provide them with adequate care (including potential breach of statutory objectives or duties).³⁹ The objectives and functions of the District Health Boards include: "to promote effective care or support for those in need of personal health or disability support services" and "to promote the inclusion of participation in society and independence to people with disabilities", and "to monitor the delivery and performance of services", the prospect of criminal liability for insufficient care,⁴⁰ and the potential for breach of professional standards. Importantly, the lack of legal safeguards against deprivation of liberty poses practical and ethical challenges for people who work with this vulnerable group and recognise that the current legal framework is inadequate to best promote and protect the autonomy of those for whom they care.

Liberty safeguards

The English experience demonstrates that the key concern is not *whether*, but *how* deprivation of liberty safeguards are provided and how far the revised scheme should extend. The expanded interpretation of the concept of deprivation of liberty by the UK Supreme Court in *Cheshire West* means that under the English law these safeguards are needed for many more people in care homes and hospitals, as well as community settings such as foster care placements, than had previously been understood. The

38 Currently, mental capacity law and policy in New Zealand stretches across four government departments: The PPPR Act is administered by the Ministry of Justice and the Ministry of Social Development (Office of Senior Citizens); the Office of Disability Issues is responsible for the CRPD; the Ministry of Health has no specific role yet the Code of Practice under equivalent legislation in England, Mental Capacity Act 2005 has significant input from the Department of Health.

39 See for example ss 22 and 23 of the New Zealand Public Health and Disability Act 2000.

40 See for example, Crimes Act 1962 offences: s 151 – a duty in respect of vulnerable adults to provide necessities and protect from injury; s 195 – ill-treatment or neglect of child or vulnerable adults; and s 195A – a failure to protect a child or vulnerable adult.

starting point for policy makers in New Zealand, however, is to accept the need, in principle, to fill the Bournemouth gap, and then to consider how widely detention should be interpreted and to respond appropriately within the New Zealand context.

The number of people in supported residential or hospital care is likely to grow quite substantially in New Zealand as the community ages and life expectancy increases. It is an ongoing challenge to devise sufficiently flexible and efficient care as well as practical legal safeguards for people likely to need support in deciding where they will live, especially where restrictions are placed on their liberty, even if for their own welfare.

Along with better provision for supported decision-making, clear procedural safeguards for people who lack capacity and are deprived of their liberty are urgently required for New Zealand to comply with its obligations under arts 12 and 14 of the CRPD, and in accordance with international and domestic human rights law – the right not to be arbitrarily detained. Moreover, as this seminar has demonstrated, those working in the health and disability sector including health professionals, social workers and lawyers, recognise the gap in the law and the moral obligation to fill it.

Recommendations for liberty safeguards are as follows.⁴¹

- 1 Revised mental capacity legislation should provide legal mechanisms, criteria, and procedures, to govern decisions involving the deprivation of liberty of people who lack capacity, referred to as “Liberty safeguards”,⁴² including:
 - b a two-step authorisation process to, initially, identify a deprivation of liberty, and then to monitor an ongoing deprivation of liberty;
 - c rules governing how such decisions are to be made, by whom, and under what process; when the liberty safeguards are to be used; their duration and discharge;
 - d a standard stating that decisions should be made in the best interests (and according to the known will and preferences) of the person, when the liberty safeguards apply;
 - e a speedy mechanism for the designated decision-maker, whether an independent individual (for example, the equivalent of the District Inspector under the MH(CAT) Act) or a public body that can provide independent oversight to authorise a deprivation of liberty, with ready access thereafter to review of the decision by a Tribunal or the Family Court;
 - f a Code of Practice for health and social service providers to operationalise the liberty safeguards;

41 Above n 1. These recommendations are set out in Ch 3 “Liberty Safeguards”

42 The term “liberty safeguards” is suggested as preferable to “deprivation of liberty safeguards”. According to the English Law Commission, the naming of the proposed new safeguards has provoked the most debate in the Law Commissions proposals to date. This is because some consultees understood the phrase “deprivation of liberty safeguards” to mean that people were being denied access to legal rights. They now propose to call these “Liberty Protection Safeguards”.

- g a publicly appointed and independent person or body to be available to act an advocate for people who lack capacity and who have no other suitable person to support and represent them in the liberty safeguarding process; and
 - h options for ensuring the oversight and monitoring of compliance of these liberty safeguards by a public body or agency (such as a Public Guardian or Office of the Public Advocate) established under the legislation.
- 2 A comprehensive review should be undertaken of legislative schemes regulating deprivation of liberty in comparable jurisdictions, including the proposed legislation and changes to the Mental Capacity Act as recommended by the English Law Commission and comparable jurisdictions to New Zealand.
 - 3 Consultation with the health and disability sector in the development of the liberty safeguards that could be enacted and would have sufficient flexibility to cover the range of environments where deprivations of liberty occur, and could operate in the most effective and cost-efficient way.

10 The Welfare Guardianship Trust as a strategy to support people without capacity

Dr Ben Gray

Alison Douglass¹ summarises the legal framework that we have for making decisions for people who lack capacity.

The PPPR Act permits a person with capacity to appoint an Enduring Power of Attorney (EPOA), to make financial, health and welfare decisions should they later lose their capacity and it confers statutory jurisdiction on the Family Court to make substitute decisions concerning the welfare and property of people lacking capacity or to appoint a welfare guardian or property manager (a Deputy under the MCA) to make decisions on their behalf. Decisions for individuals who lack capacity are ideally made by an enduring power of attorney, a Court-appointed Welfare Guardian or guided by an advance directive.

Douglass further discusses how Right 7(4) from the code of rights² is used controversially for making decisions in the absence of any of the mechanisms above and the significant issues that are raised by that approach.

A not uncommon scenario is that a person is admitted from the community acutely to hospital and is found to lack capacity. In the event that they do not have an EPOA, or a Welfare Guardian in place and have no family or friends willing to take on that role, clinicians wishing to transfer their care to residential care, are placed in a difficult position. The ideal option is to find someone willing to act as a Welfare Guardian but there are significant numbers of people who do not have anyone willing to do this for them. A court order can be applied for to approve the initial decision of the Subject Person's transfer to residential care but that does nothing to allow for their ongoing care, and there can also be significant delays in getting such an order through the court. In the context of acute public hospital beds being in high demand there is anecdotally increasing reliance on Right 7(4). In the past this has been managed informally in some centres by the clinicians or courts being aware of suitable individuals who are willing to volunteer as a Welfare Guardian. This approach has proved to be inadequate to resolve the problem in Wellington.

1 A Douglass "Rethinking necessity and best interests in New Zealand mental capacity law' .(2018) 18 Medical Law International 3, Chapter 3 Liberty Safeguards.

2 Health and Disability Commissioner (Code of Health and Disability Services Consumers' Rights) Regulations 1996 <http://www.hdc.org.nz/your-rights/about-the-code/code-of-health-and-disability-services-consumers-rights/>

The Wellington Welfare Guardianship Trust is a charitable trust established to recruit, approve and train suitable volunteers to apply to be Court-appointed Welfare Guardians for people who are unable to make, or communicate, decisions for themselves. Once appointed the Trust provides on-going support for the volunteers.

The Trust consists of a Board who bring various fields of expertise and experience to ensure the Trust's aims are met. The current Trustees have expertise in social work, general practice, family law practice, family court processes and health and disability issues.

The Trust Co-ordinator receives requests for volunteers from a range of people including lawyers; rest home managers and family members who live outside the local area or are unable/unwilling to act as a Welfare Guardian themselves.

Most requests for the appointment of a volunteer Welfare Guardian occurs when the Subject Person has no known relatives; when their relatives live in another part of New Zealand or overseas or when the person's family cannot agree on which of them should be appointed.

The Coordinator matches the needs of the subject person to a suitable volunteer and supports the volunteer to apply to the Court for an Order appointing them the Welfare Guardian.

Once appointed by the Family Court the Welfare Guardian is the only person legally able to make decisions about the day-to-day care and welfare of their Subject Person, subject to the limitation on their powers prescribed by law.³ These may include decisions about non-urgent medical treatments and accommodation. The court orders may be tailored to specify what kinds of care and welfare decisions the welfare guardian make as the appointed decision-maker for the subject person.

The trustees meet monthly and as needed to interview prospective volunteers and provide support/education sessions for volunteers. We have a volunteer administrator. The major costs we face are the costs of preparing and submitting applications to the court on behalf of our volunteers to become Welfare Guardians. All the other work is done on a voluntary basis. In particular, we are currently unable to provide any Volunteer Welfare Guardian costs, such as travel costs.

Welfare Guardians are appointed for three years so any volunteer needs to be prepared to take on this length of commitment, limiting the pool of people who may be suitable. Each volunteer has a board member assigned to him or her as a first point of contact in case of any queries.

We were established in 2015 modelled on the successful Otago Welfare Guardianship Trust, which has been operating since 2011. We appointed our first Volunteer Welfare Guardians in April 2018. To date we have had one application on behalf of a subject person that we were unable to match with a volunteer willing to be their Welfare

3 Limits on the powers of welfare guardians include, for example, they cannot refuse life-saving treatment or consent to brain surgery on the person's behalf: Protection of Personal and Property Rights Act 1988, s 18.

Guardian. Otago developed the website <https://welfareguardians.nz/> that has the public site providing information about the function of the trust and importantly the confidential site which enables the storage of all the relevant documents and the recording of details of visits to Subject Persons by Volunteers. This has been designed so that future regional Trusts can be added to the site easily.

To date we are the only two regional trusts, although groups are being developed in Timaru, Christchurch, Hamilton and Palmerston North with enquiries from other centres. The work of the trusts to meet the need of people who lack capacity having no person able to be their Welfare Guardian can only ever be a stop gap. Clearly, there is no national coverage or public body that fulfils this role. Even within our region, our volunteers live too far away from some of the subject persons for it to be viable for them to offer assistance. There is no obligation to provide a volunteer. There may also be situations where the Trust cannot offer a volunteer due to being unable to find a suitable volunteer to match the request for a welfare guardian or, in some situations, not wishing to expose a volunteer to a family in conflict. With increasing population and language diversity there will be more people who as they age either lose their fluency in English or were not fluent in the first place., thereby compromising their ability to communicate and to have culturally appropriate support through a welfare guardian. With aging baby boomers the small pool of volunteer welfare guardians will be a growing problem for the elderly. It is also a significant issue for people with intellectual disabilities who have been cared for solely by their parents who may well die before their children Parents may face cognitive impairments themselves and difficulties in fulfilling the guardian role for their adult children.

The current arrangements are not satisfactory. In her mental capacity report, Douglass highlights the shortage of welfare guardians and the lack of a public body that champions this area of the law, as is common in similar countries. She recommends consideration be given to having an “advocate of the last resort” who is a publicly appointed person or body to be available to act as an advocate for people who lack capacity and who have no other suitable person to support and represent them.⁴ The option of expanding Welfare Guardianship Trusts to cover the country is unlikely to ever happen. An alternative is legislative reform to ensure that these most vulnerable people in our community are not left without anyone authorised to speak up for them.

4 A. Douglass, *Mental Capacity: Updating New Zealand's Law and Practice* (New Zealand Law Foundation, 2016), www.alisondouglass.co.nz

11 Concluding thoughts

Dr Mark Fisher and Janet Anderson-Bidois

Large numbers of residents in aged residential care lack the capacity to make decisions about where they would prefer to live. Instead, other people make those decisions for them: sometimes the decisions are made by a family member, but sometimes decisions appear to have been made by clinicians, anxious to clear a hospital bed. In some cases there will be legal orders in place authorising admission, or an attorney with decision-making power may have been properly appointed under the provisions of the Protection of Personal and Property Rights Act. However, as is clear from the audit reported in this collection, in many situations there appears to be no clear lawful basis for detaining individuals in secure care facilities. The deprivation of liberty in these circumstances is a significant human rights issue for New Zealand.

Many residents in these circumstances experience dementia, sometimes compounded by a range of other age-related illnesses or disabilities. As a result of these conditions, they are unlikely to be able to obtain legal advice, make a formal complaint or seek review of their situation from agencies such as the Health and Disability Commissioner's office. Some will be without family. This population is highly vulnerable, and they are not infrequently the subject of abuse, sometimes from their family members and others close to them.

Care and accommodation in the aged residential care sector is mostly professional and aimed at meeting individual needs. However, these best intentions can be undermined by pressures on private facilities to keep their beds occupied, low profit margins, and the need for DHBs to discharge people from acute care. People can be transferred into private secure care facilities or across DHB borders without adequate clinical consideration or investigation of capacity. Needs assessment may be undertaken as a cross-sectional snapshot, when the person concerned may not have fully recovered from an acute clinical episode. Subsequent formal review or confirmation of ongoing care needs can be absent.

Where legal authorities do exist for the person, the nominated attorney is likely to be a family member or friend, and they may have had little guidance or assistance about how to appropriately discharge their legal responsibilities in the manner expected. Many families and friends have limited understanding of supported decision-making and how to assist individuals to give best effect to their expressed will and preferences, even if they do not have a full ability to make decisions about all aspects of their lives.

The authors in this collection have highlighted the problems that arise from this unsatisfactory state of affairs. The inadequacies of both the Protection of Personal and Property Rights Act 1988, and of Right 7(4) of the HDC Code in providing for true participation and protection of incapacitated individuals are described. There are practical and financial barriers preventing effective legal authority being put into place. Supported decision-making is not required at the “front-end” of the legislation and there are practical barriers that prevent supported decision-making frameworks being fully utilised even when there are good intentions to do so. Legislative changes that have been implemented in overseas jurisdictions highlight that our legislation is now out of date and no longer fit for purpose. We have large numbers of people deprived of their liberty without clear authority.

New Zealand needs a new legislative framework covering the area of legal competency for everyday decision-making. This framework might seek to replace the Protection of Personal and Property Rights Act 1988, but ideally would also incorporate areas currently covered by the Mental Health (Compulsory Assessment and Treatment) Act 1992. The latter currently lacks reference to decision-making capacity in its terms, but (lack of) capacity is one of the significant unspoken drivers for employment of the Act in treating those with a mental disorder who may also have impaired capacity for decision-making. Any changes that are contemplated must accord with the United Nations Convention on the Rights of Persons with Disabilities and other international human rights frameworks.

In our view, New Zealand needs a system which:

- 1 enhances the community's understanding of the issues and creates incentives for people to put Enduring Powers of Attorney in place without financial penalty;
- 2 enhances the clinical workforce's understanding about issues of capacity and its expertise in both assessment and documentation;
- 3 implements a framework that enhances supported decision-making and ensures that supported decision-making is the default position;
- 4 provides support, training and oversight for those who have decision-making authority on behalf of another person;
- 5 provides for a Code of Practice for health and social service providers to operationalise the necessary safeguards;
- 6 has the ability to provide for those lacking capacity, where there is no available or suitable family or friend who can act as a Welfare Guardian or Attorney, such as a system or public agency with a Public Advocate or a Public Guardian;
- 7 requires a central register of EPOAs and Court orders;

- 8 reconsiders the jurisdiction of the Family Court and the need for speedy access to a specialised tribunal or equivalent, such as the English Court of Protection;
- 9 provides for rapid appointment of welfare guardians (or an equivalent role with a less paternalistic title) and making of court orders, especially where there is no contest or dispute;
- 10 appropriately addresses the current issues around different tests or thresholds for capacity in different situations;
- 11 ensures oversight of ARC facilities to ensure that people are not being detained arbitrarily. This should be extended to all facilities, recognising that detention (deprivation of liberty) occurs without a locked door and where people are compliant;
- 12 enhances the current legal safeguards for this vulnerable population who lack capacity, for example, introducing District Inspector-type roles or some “check and balance” in the legal system; and
- 13 ensures regular inspection and review of places or situations in which people might be deprived of their liberty, whether Aged Residential Care, community placements or even a person’s own home (noting that the issues arise for people of all ages with a wide range of disabilities and is not confined to ARC).

There are ways in which the current legislation might be improved, as outlined in Iris Reuvecamp’s paper, and some of these may be able to be implemented relatively efficiently and quickly. However, we consider that a formal review by the Law Commission in consultation with consumers and the health and disability sector is required, in anticipation of revised “fit for purpose” and human rights-compliant legislation. However, legislative change alone is not sufficient to remedy the deficiencies in the current situation and to properly safeguard the rights of vulnerable older adults. It is important that the clinical workforce, other professionals and the broader community receive the education, training and resources they require to address these issues. The “This is not my Home” seminar has shown that the health and disability sector are looking for leadership to address the clear gaps in law and practice.

Biographies

Alison Douglass

Alison Douglass is a Dunedin barrister with 30 years' experience, specialising in health and disability law and she is an honorary senior lecturer with the Bioethics Centre, University of Otago. Alison is appointed by the Family Court for people with impaired capacity as counsel for the "subject person" under the PPPR Act and for the care recipient under the Intellectual Disability (CCR) Act; and has represented people with disabilities and their families in the appellate courts. Alison was the 2014 recipient of the New Zealand Law Foundation International Research Fellowship. Her legal research project involved a comparative analysis of the English Mental Capacity Act and developments in the UK. Alison's report proposing law reform of the PPPR Act is entitled: *Mental Capacity: updating New Zealand's Law and Practice*, www.alisondouglass.co.nz.

Andrew Finnie

Andrew Finnie is a senior family court practitioner working in Auckland. He specialises in elder law and frequently receives appointments from the Family Court as Lawyer for Child, Lawyer for Care Recipient and Lawyer for Subject Person. He also acts as a mental health roster lawyer. Andrew receives instructions from a number of health providers in the area of elder law.

Dr Ben Gray

Dr Ben Gray works as a GP at Newtown Union Health Service and lecturer in Primary Health Care and General Practice and Otago University Wellington, where he convenes the course in Professional Development and Ethics. He has a Masters in Bioethics and Health and is particularly interested in how health law and ethics applies to diverse populations. He is the Chair of the Wellington Welfare Guardianship Trust.

Dr Cordelia Thomas

Dr Cordelia Thomas has a PhD in law. She is currently Associate Commissioner at the office of the Health and Disability Commissioner. She has had a number of other roles at HDC and was previously the senior legal advisor at the Bioethics Council and a senior law lecturer at Massey University.

Iris Reuvecamp

Iris Reuvecamp is a practising lawyer specialising in health and disability law, with a particular interest in capacity law. She is co-editor of the book *Mental Capacity Law in New Zealand*, to be published by Thomson Reuters in mid-2019. Iris acts as court-appointed lawyer with respect to applications under the Protection of Personal and Property Rights Act 1988; and has expertise in the law relating to mental health, disability and older persons.

Janet Anderson-Bidois

Janet Anderson-Bidois is the Chief Legal Adviser at the Human Rights Commission. Janet has a particular interest in issues relating to informed consent, mental health and capacity. She spent 15 years as an in-house medico legal adviser for several district health boards in the Auckland region and worked previously as an investigator for the Health and Disability Commissioner's office and as a general litigator in private practice. Janet has a Master of Laws degree from Auckland University.

Kate Diesfeld

Kate Diesfeld, JD is Professor of Law at Auckland University of Technology. She practiced disability and mental health law in California and the United Kingdom. She has held academic roles at the University of Kent in England and Te Piringa Faculty of Law in New Zealand. Her fields include elder law and she Chairs AUT's Ethics Committee.

Dr Mark Fisher

Dr Mark Fisher is Service Clinical Director for Liaison Psychiatry and Mental Health Services for Older People at Auckland DHB. He has worked as a Consultant Psychiatrist and in Mental Health leadership roles for over twenty years. His clinical and research interests are in dementia, mental health service delivery, mental health-related law including capacity, and electroconvulsive therapy.

Michael White

Michael White is a human rights lawyer and advocate. He has a Masters in Law and has worked in private practice, government organisations, international organisations and NGOs. He is currently Chief Executive of Inclusive NZ, a human rights NGO based in Wellington. Prior to taking up his current role Michael was a Senior Legal Adviser at the New Zealand Human Rights Commission.

Paula Tesoriero MNZM

Paula Tesoriero is New Zealand's Disability Rights Commissioner and she is responsible for protecting and promoting the rights of disabled New Zealanders. She is also a Paralympian cycling gold medallist, a former lawyer and a mum. Her previous roles include general manager at Stats NZ and at the Ministry of Justice; and she has held a range of governance roles on various Boards.

Judge Philip Recordan

Phil Recordon has a history of working with people with disabilities. He was district Inspector for mental health for many years and is currently Mental Health liaison judge for the Auckland region. He has spoken nationally and internationally in the area and in related areas such as addiction. He works currently from the Manukau District Court.



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