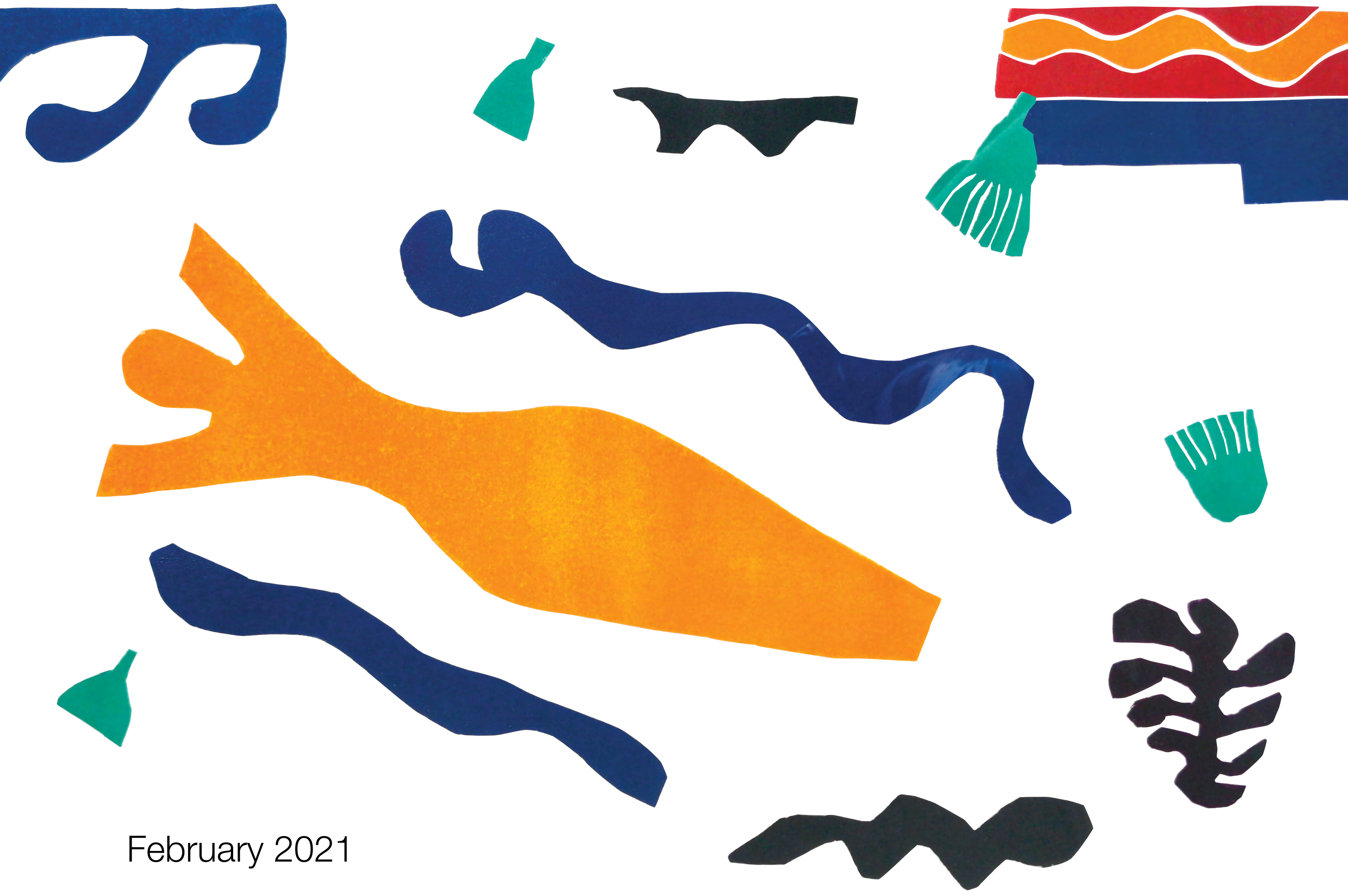
Office of the
Public Advocate

Decision Time

Activating the rights of adults with cognitive disability



February 2021

Decision Time: Activating the rights of adults with cognitive disability

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This report was prepared by John Chesterman and Lois Bedson, with comments and contributions from others at the Victorian Office of the Public Advocate, among them Colleen Pearce, Phil Grano, Claire McNamara, Sarah Hill, Sonia Gardiner, Mark Feigan, Ben Mason, Sophia Spada-Rinaldis, Michael Wells, Meagan Gaffney, Natalie Tomas, Michelle Browning and Bryan Bowditch. The report has also benefited from the capable editorial assistance of Chris Pirie. Chapter 4 draws heavily on material Phil Grano and John Chesterman presented at the International Conference on End of Life: Law, Ethics, Policy and Practice, in Brisbane on 13–15 August 2014. This report is accurate as at July 2020.

Contents

Introduction by the Public Advocate

Decision Time: Activating the rights of adults with cognitive disability **is a policy contribution relating to a number of matters that could enable Australia to better recognise and enliven the rights of people who, at times, need support with making decisions.**

The issues addressed in the report focus on matters relevant to people with cognitive disabilities, including mental health and neurological disabilities, which may affect their ability to make decisions without support.

It also builds on work the Deputy Public Advocate, Dr John Chesterman, did as a Churchill Fellow in 2013 around international adult protection systems and subsequent published research based on work done by my office.

It is hoped that the policy suggestions and recommendations contained within will assist all Australian states and territories and the Commonwealth Government to improve their laws and practices and the impact they have on people with cognitive disabilities. Such reforms will enable Australia to meet its obligations under the United Nations Convention on the Rights of Persons with Disabilities.

I commend this report to all those with an interest in the human rights of Australians who need support to make decisions.

Colleen Pearce
Public Advocate

Summary and recommendations

Summary

This report traverses the full scope of law and practice in which the Victorian Office of the Public Advocate (OPA) is involved daily. We do this work in accordance with our purpose, which is to promote and protect the rights and interests of people with disability and work to eliminate abuse, neglect and exploitation. As the result of our largest work areas—adult guardianship and the Community Visitors Program, which entails visiting people in a range of supported accommodation settings—we have developed considerable expertise in promoting and protecting the rights of adults with cognitive impairment.

OPA does not, however, confine itself to providing services and auspicing volunteer programs. We pursue our vision of a just and inclusive society that respects and promotes the dignity and human rights of all people (including those with cognitive impairment or mental illness) by advocating for better systems, laws and policies that align with this vision. We have played an effective part in recent law reform relating to guardianship, powers of attorney and medical treatment decision-making in Victoria.

This report discusses OPA's position on laws and policies that can have an impact on the decision-making of people with disability and describes guiding principles and practical reforms that would help achieve our vision for a just, inclusive society.

The UN Convention on the Rights of Persons with Disabilities provides a human rights 'road map' for the full inclusion and empowerment of people with disability and cognitive impairment. OPA's statutory role as substitute decision-maker of last resort under the Victorian *Guardianship and Administration Act 2019* and our commitment to the convention place us in the unusual position of being a substitute decision-maker while hoping to see that role played less and less, by us and others, over time. OPA endorses the National Decision-Making Principles and associated guidelines developed by the Australian Law Reform Commission (ALRC). Taken as a whole, they call for supports for people so that they can make their own decisions whenever possible and have those decisions respected, and when, as a last resort, substitute decision-makers are required the 'will, preferences and rights' of the person will direct the decisions made. The commission acknowledges that there will continue to be a small set of circumstances in which substitute decision-makers are required as a 'human rights backstop'.

As Victoria's adult guardian of last resort, and through its volunteer programs, OPA has extensive contact with and knowledge of the state's social care settings in the areas of residential aged care, disability accommodation and supports, and mental health. We also have extensive knowledge of the justice sector and the safeguarding of Victorians with disability in relation to tenancy rights and restrictive practices. It is on this basis that OPA has engaged in individual and systemic advocacy throughout the transition from state-funded disability services to the NDIS.

This advocacy work continues and has influenced OPA's position in relation to the impact on people with cognitive impairment of a 'consumer choice' framework and associated marketisation of yet another social care sector (after aged care). The concerns here are fourfold.

- First, OPA is concerned that, if insufficient decision-making support is offered to 'consumers' with cognitive impairment, neither the promised benefits of a 'consumer choice' paradigm nor the rights of people will be realised since their will and preferences will not determine service development.

- Second is the concern that marketisation of a social care sector increases the likelihood that the care providers will want to transfer risk and reduce uncertainty by seeking contractual relationships with decision-makers who have legal capacity. Throughout Australia there has been an increase in guardianship appointments in order to enable NDIS-related decision-making to occur: it is OPA's view that removing people's decision-making rights so as to fulfil administrative goals is a backward human rights step.

- Third, safeguarding the rights of people with cognitive impairment is particularly difficult in the diverse service settings that develop in marketised systems. The safeguards in these systems are largely driven by consumer complaints, which are beyond the capabilities of some people with cognitive impairment, and lack comprehensive independent onsite monitoring (such as OPA's Community Visitors) as a result of the diversification of service settings.

- Fourth, 'last-resort' and crisis service provision are not a natural fit for the marketised model of service delivery and thus are often lacking; OPA has witnessed this under the NDIS.

OPA's field of view extends from social care settings to the operation of laws in the fields of guardianship, mental health, medical treatment and advance planning. We have statutory functions in relation to guardianship and medical treatment decision-making, as well as a community education role in relation to advance planning. This report describes the current legal and practice contexts in these fields with reference to the various Australian jurisdictions, with a view to advising policy makers and law makers about potential human rights–related reforms.

Legislative reforms in each of these fields (where they have occurred since the release of the Convention on the Rights of Persons with Disabilities) have been in the direction of promotion of the rights of people with disability through enhanced focuses on self-determination and the requirement that people's will, values, rights and preferences (or some combination thereof) drive the decisions that affect them. This has been achieved through legislated opportunities for decision 'supporters' and, for example, in the recently commenced Victorian Guardianship and Administration Act, 'supportive guardians' and 'supportive administrators'. People's will, values and preferences have also been placed at the centre of newer substitute decision-making legislation: in Victoria, the Medical Treatment Planning and Decisions Act and the Guardianship and Administration Act require that substitute decision-makers make decisions that uphold the person's will and preference—subject to specific safeguard clauses, which, for example, prevent substitute decision-makers from enabling significant harm to occur. This report discusses where the balance between self-determination and protection of at-risk adults should properly lie and provides practical examples of how this could be achieved in all Australian jurisdictions.

One clear principle that is detailed in the report (in addition to the promotion of supported decision-making (and advance planning) opportunities for people with cognitive impairment) is the position that one should not take rights away from people with cognitive impairment who are suffering abuse, neglect or exploitation or are being poorly served by systems in order to protect them. To this end, OPA does not seek additional protective laws to deal with matters of national concern, such as the high rates of elder abuse. Instead, we see scope for strengthening laws in order to better enable them to focus on the perpetrators of abuse, neglect and exploitation and to enable redress to be gained thereby—for example, by enabling tribunals to order compensation for abuse or misuse of powers of attorney. We also see potential in the range of protective orders available to UK tribunals and courts that enable action protective of vulnerable adults without removing their decision-making rights. An own-motion investigation and supportive intervention role for Australia's public advocates and public guardians would also fill a crucial gap in circumstances where an at-risk adult is facing neither a health crisis nor obvious criminal negligence or mistreatment.

For OPA, the future is one in which we have a real opportunity to develop our guardianship practice and new best-practice principles under a new substituted judgment framework. We will be able to continue to uphold the principles of the UN Convention on the Rights of Persons with Disabilities and the ALRC's National Decision-Making Principles, while learning from our experiences and expanding our knowledge of how best to use supported decision-making in practice. As practice knowledge increases, so will opportunities for promoting the rights and interests of people with cognitive impairment.

Recommendations

Recommendation 1.1

OPA recommends that state and territory governments ensure that people with cognitive disability receive support in order that they can understand and participate in criminal justice processes, including procedures in police stations and in courts.

Recommendation 1.2

OPA recommends that state and territory governments ensure that all people entering correctional facilities are screened for cognitive disability.

Recommendation 1.3

OPA recommends that state and territory governments adequately fund disability support services in correctional facilities and work with the National Disability Insurance Agency (NDIA) to ensure that access to NDIS-funded services is available when such services are necessary.

Recommendation 1.4

OPA recommends that state and territory governments ensure that there are sufficient forensic disability services to meet the demand for these services.

Recommendation 1.5

OPA recommends that state and territory governments ensure that there is a sufficient number of supportive residential settings available for people who are unfit to stand trial or who are deemed not guilty by reason of mental impairment.

Recommendation 1.6

OPA recommends that the Australian Government implement a comprehensive regulatory framework for the use of restrictive practices in residential aged care. The framework should have all the characteristics and protections recommended by the ALRC in its 2017 report entitled *Elder Abuse—a national legal response*:

> ALRC Recommendation 4–10. Aged care legislation should regulate the use of restrictive practices in residential aged care. Any restrictive practice should be the least restrictive and used only:
>
> (a) as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
> (b) to the extent necessary and proportionate to the risk of harm;
> (c) with the approval of a person authorised by statute to make this decision;
> (d) as prescribed by a person's behaviour support plan; and
> (e) when subject to regular review.
>
> ALRC Recommendation 4–11. The Australian Government should consider further safeguards in relation to the use of restrictive practices in residential aged care, including:
>
> (a) establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;
> (b) requiring aged care providers to record and report [on] the use of restrictive practices in residential aged care; and
> (c) consistently regulating the use of restrictive practices in aged care and the NDIS.

Recommendation 1.7

OPA recommends that state and territory governments fund proven programs that embody a wraparound approach to housing and service provision for people with disability.

Recommendation 2.1

OPA recommends that the Australian Government fund a volunteer program that would allow isolated NDIS participants to receive support with their NDIS-related decision-making.

Recommendation 2.2

OPA recommends that all governments—federal, state and territory—acknowledge the essential role independent advocacy plays for people with cognitive impairment in promoting positive outcomes in consumer choice–driven social care settings and provide increased advocacy funding through the National Disability Advocacy Program and state and territory government programs.

Recommendation 2.3

OPA recommends that all governments—federal, state and territory—ensure that, where relevant, laws mandate a 'will and preferences' approach to substitute decision-making.

Recommendation 2.4

OPA recommends that the NDIA have a transparent and effective 'provider of last resort' system (with a framework established as soon as possible) that ensures:

- provider of last resort mechanisms are established as an ongoing component of the NDIS market
- multiple designated providers of last resort are clearly identified

- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements.

Recommendation 2.5

OPA recommends that the Australian Government ensure that the NDIS's national safeguarding regime includes an onsite monitoring component, ideally modelled on the Victorian Community Visitors Program.

Recommendation 3.1

OPA recommends that, where necessary, state and territory governments amend their guardianship legislation to include the possibility of appointing decision supporters.

Recommendation 3.2

OPA recommends that state and territory governments amend their guardianship legislation to include an automatic and rebuttable role for parents of adult children with significant cognitive disability as their legal 'supporter'.

Recommendation 3.3

OPA recommends that state and territory governments amend their guardianship legislation in order to give public advocates and public guardians the broad power 'to investigate, via complaints or on their own motion, the abuse, neglect and exploitation of adults with apparent impaired decision-making ability, where this apparent impaired ability is likely to be more than temporary'.

Recommendation 3.4

OPA recommends that, to reduce the need to appoint a guardian, state and territory governments reform their guardianship laws so as to enable tribunals to issue a wide array of protective orders.

Recommendation 3.5

OPA recommends that, where relevant, state and territory governments reform their guardianship laws by removing all references to 'disability' and by limiting tribunal appointments of guardians to situations where the person in question does not have the capacity to make the particular decision in relation to which the order has been sought.

Recommendation 3.6

OPA recommends that, with one exception, state and territory governments amend their guardianship laws to require guardians to use a substituted judgment approach wherever possible in their decision-making. The exception to this is in circumstances that would produce a risk of serious harm to the person concerned.

Recommendation 5.1

OPA recommends that the Australian Government and state and territory governments ensure that health professionals are educated about any relevant laws governing consent in their jurisdiction; this includes people working in primary care and the aged-care, disability and mental health sectors.

Recommendation 5.2

OPA recommends that state and territory governments in jurisdictions without such provisions amend their laws to enable the appointment of ‘supporters’ to help people with decision-making in relation to their medical treatment.

Recommendation 5.3

OPA recommends that state and territory governments in jurisdictions without such provisions amend their medical treatment laws to ensure that substitute decision-makers are required to adopt a ‘will and preferences’ approach to decision-making.

Recommendation 6.1

OPA recommends that state and territory governments conduct public education campaigns to promote the value of advance planning for medical, financial and lifestyle decisions—including in relation to the use of enduring powers of attorney and advance directives.

Recommendation 6.2

OPA recommends that state and territory governments in jurisdictions without such provisions legislate to enable people to make binding advance directives in medical and non-medical areas. These should be applicable in all but two circumstances: if implementing the directive would cause serious financial or personal harm to the person concerned and if the circumstances suggest that the person would have made a different decision.

Recommendation 6.3

OPA recommends that state and territory governments in jurisdictions without such provisions amend their advance planning laws to ensure that substitute decision-makers are required to act on a substituted judgment (‘will and preference’) basis unless this would cause serious financial or personal harm to the person concerned.

Recommendation 6.4

OPA recommends that state and territory governments enable tribunals to make compensation orders and apply penalties when substitute decision-makers abuse or misuse their powers.

1. Human rights developments

Human rights developments have had, and continue to have, a profound impact on protection mechanisms for adults with cognitive disability. This impact has come in the form of an ever-growing recognition that some, even many, of the measures taken in the name of protecting adults have themselves wrought harm. Such developments have also called into question the legal mechanisms whereby protective actions have been authorised and justified.

In the case of adults with significant cognitive disability, protective measures have typically involved denying the person concerned the legal ability to make their own decisions in specific realms—for example, in relation to compulsory mental health treatment, effective detention in disability or aged-care accommodation, loss of control over finances, or the ability to make decisions about medical treatment.

As people with disability began to demand recognition of their human rights—a movement that started to have political effect in the 1980s in Australia—a range of legal devices were constructed that authorised particular individuals to make decisions on behalf of these people. This included the development of modern guardianship and other substitute decision-making laws that are considered throughout this report. In the past decade these measures themselves have frequently been challenged on the basis of their inconsistency with the human rights of the people they have affected.

In short, human rights considerations have increasingly influenced the development of adult protection mechanisms, primarily by questioning exactly who is being protected and from what are they being protected.

The year 1981 is widely recognised as representing a watershed for people with disability, the United Nations having declared it the International Year of Disabled Persons. This is seen as an important moment in the evolution of thinking in relation to disability: social barriers, rather than bodily conditions, started to be seen as the main challenges to be encountered by people with disability.[1]

This switch to a 'disabling society'—as opposed to a 'disabled person'—receives its most authoritative expression in the Convention on the Rights of Persons with Disabilities, which Australia signed in 2007 and ratified the following year. The convention notes, 'Disability is an evolving concept and…results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others…' [2]

The implications of this change in focus gradually became manifest in international instruments and, to a lesser extent, in domestic legislation, including state and territory anti-discrimination laws and the national *Disability Discrimination Act 1992*, which prohibit direct and indirect discrimination on the basis of disability in employment and in the provision of specific goods and services.

Despite these developments, though, people with disability continue to face very substantial inequality in a variety of areas, among them employment and access to justice.

The Disability Discrimination Act and state and territory anti-discrimination legislation tend to be quite limited in their effect, and people with disability experience almost double the unemployment rate (about 10 per cent in 2015[3]) relative to people without disability[4] and spend longer looking for work or being underemployed. Other groups are also discriminated against in this regard, and individuals can experience intersectional discrimination. For example, older Australians have higher unemployment rates than younger Australians and spend longer periods searching for work; there has been an increase in 'mature-age long-term unemployment'[5]; and at the last census (in 2016) the unemployment rate for Aboriginal and Torres Strait Islander peoples was over 18 per cent (it is higher in remote areas and lower in major cities).[6] Members of these cohorts also have higher rates of disability than other Australians: Indigenous Australians experience disability 'at approximately double the rate of other Australians'.[7]

People with disability also face other inequalities. For example, people with cognitive disability and mental illness are significantly over-represented among offenders in the criminal justice system,[8] while in the child protection and family law arenas the existence of a cognitive impairment in one or both parents appears to be more a reason for children being removed from their parent(s) than a reason for assigning additional child-caring support to them.[9]

Among the 50 articles in the Convention on the Rights of Persons with Disabilities are undertakings by signatories in relation to education, privacy, health, employment, public participation, and freedom of choice over a 'place of residence' and 'where and with whom'[10] people with disability live. States parties to the convention must also take measures to ensure that people with disabilities are protected 'from all forms of exploitation, violence and abuse',[11] are 'not deprived of their liberty unlawfully or arbitrarily'[12] and have adequate housing.[13]

This chapter considers the human rights challenges in these three fields, focusing on the disproportionate extent to which people with cognitive disability are subject to violence and exploitation, to deprivation of liberty and to homelessness. It then examines the most important human rights topic relating to adult protection laws and practices—the future of substitute decision-making and its possible replacement by supported decision-making.

1.1 Violence and exploitation

The results of numerous small studies suggest alarming levels of violence suffered by people with disability, especially people with cognitive impairment.[14] Violence and exploitation are also experienced by victims of elder abuse, an unknown (but probably significant) proportion of whom have cognitive impairment.

People with disability

OPA coordinates the Community Visitors Program, which regularly reports evidence of high rates of violence against people with disability who reside in specialist disability accommodation, in boarding house–style accommodation and in mental health facilities.[15] Some of this violence is staff-to-client violence; some is client-to-client violence. For example, OPA's recent report *'I'm Too Scared to Come Out of My Room': preventing and responding to violence and abuse between co-residents in group homes* discusses residents' experiences of violence and the recommended policy responses.[16]

It is now widely known that violence is common for some recipients of disability services, and occasional cases receive prominent media attention.[17] Meanwhile broad inquiries have pointed, for instance, to the routine nature of staff-to-client violence and the inadequate protective and reporting mechanisms available in disability services.[18]

In a 2015 report the Victorian Ombudsman referred to a survey of disability workers revealing that '46 per cent reported witnessing violence, abuse or neglect of clients by other staff, and a further 18 per cent said they knew people who had witnessed such events'.[19] Additionally, a 2016 Victorian parliamentary committee report noted the need for broad reforms in areas such as staff recruitment and training and incident reporting.[20] In 2015 a Senate committee simply recommended that 'a Royal Commission into violence, abuse and neglect of people with disability be called'.[21] This call was heeded: the Commonwealth's Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability is under way and due to report by 29 April 2022.

All this work was given renewed energy in the context of the dramatic changes occurring in the disability services sector with the advent of the NDIS. Under the scheme we are witnessing an increasingly privatised market for the delivery of disability services. We also saw the transfer to the Commonwealth government in 2019 (earlier in some jurisdictions) of a range of regulatory roles that were previously the domain of the states and territories. This is explored in Chapter 2.

But it is not just when receiving disability services that people with disability experience violence. More general reports routinely point to the high levels of crime experienced by people with disability[22] and the inability of people with disability to gain access to the justice system. The Australian Human Rights Commission noted in 2013:

> People with disability do not receive the support, adjustments or aids they need to access protections, to begin or defend criminal matters, or to participate in criminal justice processes … Negative attitudes and assumptions about people with disability often result in people with disability being viewed as unreliable, not credible or not capable of giving evidence, making legal decisions or participating in legal proceedings.[23]

Reports also observe, 'Women with disabilities are at greater risk of experiencing family and sexual violence compared with both men with disabilities and women without disabilities … women with cognitive disabilities are particularly at risk'.[24]

Reforms to the criminal justice system are needed in order to improve policing practices, to support people bringing claims before the justice system, and to support those involved in the justice system as alleged perpetrators. Through the Community Visitors and Independent Third Person volunteer programs, OPA is well aware of the difficulties many people with disability (particularly those who have a cognitive impairment or complex communication needs) currently encounter when seeking justice.

Elder abuse

Elder abuse is a category of violence and exploitation that affects older people with and without disability. Although older people with cognitive disability are more vulnerable to such abuse, the precise extent to which cognitive disability is associated with higher rates of abuse is unknown. It is hoped that information, as discussed shortly, will be available soon.

An international convention on the rights of older persons is yet to be developed, but elder abuse is already considered a serious human rights problem that is inadequately accommodated in existing laws, policing practices and social policies. Nationally,[25] and in Queensland, New South Wales, Victoria, South Australia and Western Australia, parliamentary committees and law reform agencies have in recent years held inquiries into the topic or related topics. This has included specific inquiries into elder abuse or the wellbeing of older people and, in the case of Victoria, elder abuse being one aspect of the wider ranging Royal Commission into Family Violence, which delivered its report to government in March 2016.[26]

In 2017 the ALRC released the final report on its inquiry into 'existing Commonwealth laws and frameworks which seek to safeguard and protect older persons from misuse or abuse by formal and informal carers, supporters, representatives and others',[27] making 43 recommendations. (OPA's Deputy Public Advocate, Dr John Chesterman, served on the ALRC's advisory committee). The report draws on the World Health Organization's definition of elder abuse: 'a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person'.[28] Elder abuse—which can entail financial, physical and emotional abuse—often constitutes a crime; examples are theft and assault.

Although elder abuse has been viewed as a major social problem for some time, a number of factors contribute to making it a pressing national concern. Australians are living longer yet families are becoming smaller, meaning that more older people are more isolated than ever before. Additionally, housing costs and so-called inheritance impatience can lead otherwise law-abiding citizens to perpetrate financial abuse (often theft) through a mixture of opportunity and internal justification.

To complicate the situation, one of the problems the ALRC identified is that we do not actually know how prevalent elder abuse is as a social problem. In part, this is because the definition of 'elder abuse' encompasses harms such as psychological abuse, which can be hard to define and consistently incorporate in measuring tools. One of the reasons for this is that a substantial cohort of older people who suffer abuse are cognitively impaired, and their experiences can be difficult to capture.

A 2017 meta-analysis supported by the World Health Organization estimated that 15.7 per cent of people aged 60 or more years around the world were subjected to some form of elder abuse in the preceding year.[29] This is higher than previous estimates, which were up to 10 per cent.[30] None of the studies in the meta-analysis was drawn from Australia.

In its 2016 report on elder abuse the Australian Institute of Family Studies based its national prevalence estimates on the best international estimates available at that time—between 2 and 10 per cent[31]—and further commented:

> The available evidence suggests that prevalence varies across abuse types, with psychological and financial abuse being the most common types of abuse reported, although one [Australian] study suggests that neglect could be as high as 20% among women in the older age group.[32]

The institute noted, 'There is very limited evidence in Australia that would support an understanding of the prevalence of elder abuse, and there is emerging recognition of the need for systemic research in this area'.[33]

Following the ALRC's recommendation that there be 'a national prevalence study of elder abuse to build the evidence base to inform policy responses'[34]—and with groundwork on said study already underway—the Commonwealth Government reconfirmed its commitment to undertaking a national prevalence study in 2018.[35] The Commonwealth Government had previously made a policy commitment to this in 2016.[36]

Central to this important but difficult piece of research will be identifying the prevalence of elder abuse among people with cognitive disability. There is good evidence that elder abuse rates are higher among this group.[37] The main form of cognitive disability, dementia, affects over 354,000 Australians,[38] and the number is increasing: the condition is expected to affect 900,000 Australians by 2050.[39]

To this end, in 2017 OPA prepared an analysis of existing knowledge about how the elder abuse prevalence rate among this hard-to-reach cohort might best be determined.[40] Additionally, following a project aimed at developing a working definition of elder abuse in Australia,[41] the Australian Institute of Family Studies is conducting the National Elder Abuse Prevalence Study, which is due to be completed in 2021.[42]

Along with its recommendation for a prevalence study, the ALRC highlighted two reform areas that are particularly pertinent to the present report: they concern enduring appointments and safeguarding.

Among the ALRC recommendations relating to enduring appointments were calls for these appointments to operate on a substituted judgment, as opposed to best-interests, basis.[43] This effectively requires such appointees to make the decisions the principal would probably have made themselves had they been able to do so. The concept is discussed further in Section 1.4.

A frequently suggested reform in this regard is the establishment of a national register of appointments. The ALRC added its voice to this call, recommending such a register once agreement on national legal consistency had been reached and a 'national model enduring document' had been developed.[44]

The Commonwealth Government has taken on this challenge. The recently announced National Plan to Respond to the Abuse of Older Australians [Elder Abuse] 2019–2023 and the associated Implementation Plan express a commitment to investigating the feasibility of developing a national online register of enduring powers of attorney. In particular, the plan refers to developing a 'proof of concept' register for enduring power of attorney documents. In November 2019 Australia's Council of Attorneys-General agreed to consider a detailed proposal and implementation plan for a Commonwealth-established and maintained register in 2020.[45] The council will also focus on necessary law reform to support the establishment of the register.[46]

OPA has been involved in preparing the ground for this work. On behalf of the Australian Guardianship and Administration Council, OPA developed an options paper that identified a pathway to achieving greater national legal consistency of financial enduring appointment laws and practices throughout Australia. Completed in December 2018, this paper is being considered by state and territory officials as part of the program of work to implement the National Plan on Elder Abuse. (This is further examined in Chapter 6). The ALRC also called for state and territory administrative tribunals to have power to order compensation when substitute decision-makers breach their duties.[47]

In relation to safeguarding, the ALRC sought the enactment by states and territories of 'adult safeguarding laws' and the creation or identification of 'adult safeguarding agencies', which, among other things, would be empowered to investigate the wellbeing of and coordinate service responses for 'at-risk adults'. To date, South Australia has legislated to create an 'adult safeguarding unit' (in 2018).[48] New South Wales has created a new, independent statutory role—an Ageing and Disability Commissioner—who has an investigative function in relation to abuse, neglect and exploitation of people with disability and older people in both home and community settings. (This element of the ALRC's recommendations is further explored in Chapter 3).

Although the ALRC has proposed some national initiatives—and, indeed, some, such as the national prevalence study, are under way—much of the responsibility for reform now lies in the hands of the state and territory governments. Most of these governments do have elder abuse policies, but the policies tend to be quite weak and tend to name existing general service responses rather than promote developments in service specialisation or even require new levels of inter-agency collaboration. They also tend to highlight a victim's vulnerability, rather than outline ways of enabling people to direct the response services they wish to receive. Further, the policies look to substitute decision-making as a prime, if somewhat default, elder abuse response.[49]

As the ALRC's final report makes clear, reform in the area of elder abuse requires a mixture of federal leadership and state and territory initiatives in the amendment and development of guardianship and safeguarding laws and policies. (The suggestions OPA makes in this report largely acknowledge and support the ALRC's 43 recommendations, with minor variation.)

What is required is elder abuse legal and policy reforms that give priority to the wishes of victims and enable service improvements and responses that focus more on redressing wrongdoing than on 'protecting' victims. Indeed, the reforms ought to limit the current undue reliance on the protective use of substitute decision-making as a victim response strategy when a crime has been committed.

The National Plan to Respond to the Abuse of Older Australians 2019–2023 is now the blueprint for national reform. The first priority area of the plan concerns augmenting our understanding of the nature of elder abuse, and the first national study of the prevalence of elder abuse is scheduled for completion in 2021. Proper and rigorous conduct of this study remains a priority. The results will guide further reform at all levels of government for at least the next decade, probably longer. They will also guide the development of state and territory elder abuse plans that are more robust than is currently the case.

The ALRC also called for reporting mechanisms pertaining to new aged-care abuse and banking and superannuation reforms, as well as changes in the fields of wills, social security and family agreements.[50]

Other national recommendations—including those to do with changed banking and superannuation practices—remain important, as do the recommendations discussed elsewhere in this report in connection with restrictive interventions and the reporting of violence in residential aged-care settings.

1.2 Deprivation of liberty

People with cognitive disability are disproportionately affected by violence and exploitation. They are also over-represented in custodial settings and in other places where their freedom of movement is restricted. Such restrictions can amount to a deprivation of liberty.

The most obvious example of a deprivation of liberty is a person being jailed after having been found guilty of committing a serious offence. Another example arises when a person is involuntarily detained in a mental health facility according to processes described in mental health legislation (see Chapter 4 for further discussion of this). But deprivations of liberty can also occur in the community when, for example, a person with cognitive disability is kept in a locked house or is subject to chemical or physical restrictions that limit their ability to move freely. Other examples are seen in some residential aged-care settings—for example, locked dementia wards.[50]

Custodial settings

Many prisoners experience mental ill-health—and at rates much higher than those among the general population—and most Australian jurisdictions do not provide effective support for these individuals. The Victorian Ombudsman reported in 2015:

> Forty per cent of the Victorian prison population has been assessed as having a mental health condition, ranging from psychotic disorders to depression and anxiety. Failure to properly treat a prisoner's mental health condition during their imprisonment will have a significant effect on their rehabilitation and ability to reintegrate into the community.[52]

In April 2018 an article in *The Monthly* exploring the failure of Australia's corrective services to meet the needs of prisoners with mental illness stated, 'Nearly half of all prison entrants report being diagnosed with a mental health disorder'.[53] This equates to 40,000 people a year.[54]

Further, the rate of acquired brain injury among prisoners is extraordinarily high. One study conducted in Victoria found:

> On the basis of comprehensive neuropsychological assessment, 42 per cent of male prisoners and 33 per cent of female prisoners … were assessed as having an ABI. This compares with an estimated prevalence of ABI among the general Australian population of two per cent.[55]

Statistics such as this lead to the question, asked by some, of whether prisons are the new institutions for people with disability. Moreover, it is widely accepted that services for people with disability in criminal justice settings are inadequate.[56]

To take another Victorian example, the 2017–18 annual report by the operator of Victoria's sole mental health hospital (which can provide involuntary treatment for acute conditions) showed the average waiting time for a place in the hospital was 38 days for men and 20 days for women.[57] Additionally, following a court recommendation for placement there under a custodial supervision order, prisoners waited on average more than five months for a bed.[58]

This problem is not new. In 2016 an expert review of hospital safety found:

> It has been 13 years since the Victorian Institute of Forensic Mental Health identified that demand for forensic psychiatric beds had outstripped availability, leaving prisoners with serious mental illness untreated and at increased risk of self-harm, suicide, violence to staff, exacerbation of their illness in the prison environment and reoffending after being released. Since then, the problem has worsened and concerns have continued to be raised, but without redress.[59]

The situation has continued to cause intense frustration; one Supreme Court judge has labelled it 'disgraceful'.[60]

Provision of greater support for prisoners with mental illness is a clear reform imperative. Another more controversial reform idea, which has been floated with the support of at least one Victorian magistrate and a service provider well versed in the provision of services for released prisoners, is that mandated treatment could be a sentencing option for offenders with mental illness.[61] This idea warrants closer scrutiny.

Most prisoners are incarcerated following their conviction for having committed a crime. There are, however, other criminal and civil custodial orders that can be made in relation to people with disability—for example, custodial supervision orders and civil containment orders, enabled under discrete pieces of legislation such as Victoria's *Disability Act 2006*.[62]

In keeping with the present report's focus on decision-making, here we examine the criminal justice system's main mechanisms relating to decision-making ability—that is, the laws and practices concerning fitness to stand trial and the defence of mental impairment.

Unfitness to plead and the defence of mental impairment

Much criticism has recently centred on Australia—and in particular Western Australia and the Northern Territory—in connection with the application of 'unfitness to plead' laws and practices to people with intellectual disability and other cognitive impairments and some people's subsequent placement, for indefinite periods, in non-therapeutic environments such as jails.[63]

Piers Gooding and colleagues have noted that all Australian jurisdictions have a similar test concerning a person's fitness to stand trial, the criteria deriving from a Victorian case, *R v Presser*.[64] Among other things, the test requires an ability to understand and 'plead to the charge', mount a defence and comprehend 'the nature of the proceedings'.[65] All jurisdictions in Australia also have a version of the 'mental impairment' defence, according to which a person can be found not guilty of a criminal charge.[66]

Although it is difficult to know how many people in Australia are in custody as a consequence of their unfitness to plead or the defence of mental impairment, the Senate Community Affairs References Committee reported in 2015 that more than 1,000 individuals were detained on 'forensic detention orders' in hospitals or correctional centres; this includes people found unfit to plead or found not guilty by reason of mental impairment.[67]

A 2014 Victorian Law Reform Commission (VLRC) review of the state's *Crimes (Mental Impairment and Unfitness to be Tried) Act 1997* found that in the 12 years to 2012 there were 159 cases in Victoria's higher courts where a person was unfit to be tried or where as a result of mental impairment there was no conviction. These cases resulted in 10 unconditional release orders, 102 non-custodial supervision orders and 47 custodial supervision orders.[68] The commission recommended that there be a new ‘unfitness to stand trial’ test and a new statutory definition for the defence of ‘mental impairment’, so that it was clear that this defence could be used, where appropriate, by people with cognitive impairment as well as those with mental illness.[69]

Gooding and colleagues have noted that, despite the laws on unfitness to stand trial being ‘substantially similar’ throughout Australia, there is considerable jurisdictional variation when it comes to what happens when a person is found unfit to plead. One difference concerns the extent to which prosecution cases are tested in subsequent ‘special hearings’; another concerns the nature of the custodial orders imposed.[70]

A determination that a person is unfit to plead or that a person is not guilty of committing a crime because of their mental impairment means that the person is unable to understand or take legal responsibility for the crime with which they have been charged. Any subsequent detention occurs in the absence of a conviction and so from a human rights perspective raises some important questions. People with disability are being punished for things they are not able to take legal responsibility for. Although the detention might partly be designed to ‘protect the community’, the justification for detention without conviction is also partly based on a promise that the person concerned will be placed in a therapeutic environment. In recent years, however, it has been reported that about 30 people in Australia have been held in jail despite not being convicted of crimes, rather than in an environment that at least purports to be therapeutic.[71]

The lack of secure therapeutic options for individuals who are found unfit to plead or are found not guilty as a result of mental impairment and require specialised supports makes indefinite detention even more troubling.

Australia has been criticised for the operation of these laws and in particular for the fact that, because of the indefinite nature of the custodial supervision orders imposed, people have ended up in situations that are worse than the position they would have been in had they been convicted of the crime in question.

The circumstances of three Indigenous Australians gained considerable media attention in 2016. All resided in Western Australia or the Northern Territory and experienced insufficient support from the criminal justice system and a lack of support options in the community. Their cases highlight the intersectional disadvantage and discrimination that can impinge on Indigenous Australians with disability.

One case involved Rosie Anne Fulton,[72] a woman with foetal alcohol spectrum disorder who was jailed for 18 months without conviction in Western Australia after being charged with driving offences but found unfit to plead. There being no adequate supported accommodation available, she was kept in prison until the media drew attention to her situation, whereupon she was released unconditionally. She was later convicted of property offences and imprisoned in the Northern Territory. Where she is now is not public knowledge, but before her expected release date in 2016 her guardian and advocates were not confident she would be afforded a suitably supportive home environment. Her guardian said that without sufficient support her prospects would be extremely bleak.[73]

Another notable case concerned Malcolm Morton, who was charged with murdering his uncle in 2007 in Santa Teresa, south-east of Alice Springs, but in 2009 was found unfit to plead. Rather than receiving any therapeutic intervention, Morton, who has autism spectrum disorder and a major cognitive impairment, was the subject of considerable media interest in 2016, when he was being held in a maximum security prison in Alice Springs, subject to routine sedation and strapped to a chair when the prison could not manage his behaviour.[74] He was still in that prison in early 2018, although participating in a staged transition into secure community care.[75] His full transition to secure community care occurred in 2019, and his opportunities for supervised access to family and community have greatly increased.

In another case, Marlon Noble, a Western Australian Indigenous man with intellectual disability, was detained without trial for far longer than he would probably have served in prison had he been convicted. His case was the subject of an application to the UN Committee on the Rights of Persons with Disabilities, which in 2016 made an adverse finding against Australia. The committee noted:

> [Marlon Noble] was charged in 2001 with sexual offences that were never proven. In March 2003, he was declared unfit to plead. A custody order was made and … [Mr Noble] was detained at Greenough Regional Prison until 10 January 2012, when he was placed in an accommodation support service … The Committee notes that the State party did not provide … [Mr Noble] with the support or accommodation he required to exercise his legal capacity … [and as] a result of the application of the [Mentally Impaired Defendants] Act [WA] … [Mr Noble's] right to a fair trial was instead fully suspended, depriving him of the protection and equal benefit of the law.[76]

Common to these cases is the inadequate support provided to people who have been found unfit to plead to criminal charges and the open-ended nature of their periods of incarceration. In addition to breaching international human rights laws, their treatment also failed the justification for the existence of specific laws governing unfitness to plead, which require that people whose mental impairment renders them unable to be tried or convicted should be detained only in places where they can receive treatment and support.[77] Imprisoning such people is simply imprisonment without trial.

These cases might be extreme examples of the human rights abuses that can occur through the operation of 'unfit to plead' laws, but they do emphasise the need for reform.

Piers Gooding and colleagues have argued that existing Australian laws and practices associated with unfitness to plead fall well short of the requirements of the Convention on the Rights of Persons with Disabilities.[78] Most noteworthy here are the practices in some jurisdictions where detention is effectively indefinite. In proposing reforms, the authors wrestle with the challenge of reconciling an essentially 'protective' mechanism with the requirements of the Convention on the Rights of Persons with Disabilities.

They make a number of recommendations for reform—among them 'abolition of indefinite detention of persons with disabilities in Australian unfitness to stand trial laws'—and question the legitimacy of some jurisdictions' use of nominal terms, which can easily be extended. They call instead for a 'universal design' approach to the matter, which would probably involve a new threshold test for criminal trial participation and the provision of measures aimed at supporting people so that they can stand trial. At the same time, the authors express a keen awareness that 'the logic that a human rights approach might mean pushing *more* people with cognitive disabilities through typical criminal trials seems counter-intuitive' and advocate 'a broader range of sentencing options following findings of guilt' that would be non-discriminatory but would 'incorporate consideration of the specific needs of people with disabilities'.[79]

Gooding and colleagues were part of a research program that trialled a Disability Justice Support Program involving community legal centres and trained 'disability support persons'. The program proved beneficial and even cost-effective.[80]

One mechanism that could help people in being able to stand trial is the use of intermediaries, whose role is essentially facilitative. Intermediaries were introduced in the United Kingdom in 2004, their role being defined in these terms: 'The primary responsibility of the intermediary is to enable complete, coherent and accurate communication to take place between a witness who requires special measures and the court'.[81] In 2018 amendments to the UK legislation were sought in order to give defendants access to an intermediary to support them in giving evidence.[82] The amendment did not pass.

This concept—that of intermediaries as a witness support service—has received strong endorsement in Australia. South Australia established a volunteer support scheme in 2015 to provide support to witnesses, suspects and defendants and will eventually provide a statewide service.[83] New South Wales is piloting a three-year intermediary scheme aimed at supporting child victims and witnesses in sexual assault cases.[84] Victoria began a two-year Intermediary Pilot Program in July 2018, providing support to 'vulnerable' witnesses (children and individuals with cognitive impairment); the possibility is that this role will evolve to assist alleged perpetrators when standing trial. In different ways, laws in these states allow communication support to be provided to witnesses, and sometimes defendants, who have a need for assistance in communicating. Without established programs to support the use of such provisions, however, the evidence suggests the initiatives are underused.[85]

At this point the majority of these support services focus on vulnerable victims and witnesses. Expansion of such services to defendants, as is the case in South Australia, would allow more alleged perpetrators to be supported when standing trial.

Future reform

As noted, one uncontroversial argument for reform is that greater clinical support should be available to prisoners with cognitive disability. Further to that, a final obvious reform argument—one that has been put forward many times, including by a Senate committee[86]—is that no one who has been found unfit to stand trial or who has been found not guilty of a crime by reason of mental impairment should be held in prison. This means devoting funding to building and resourcing therapeutic facilities to house people who have not been found guilty of committing a crime.

Reform should focus on four primary areas:

- First, people with cognitive disability must be assisted to participate in the criminal justice process, ideally through the provision of paid, skilled supporters whose role is to facilitate understanding and involvement. This differs from legal representation, which obviously is also essential.

- Second, people entering the criminal justice system—and particularly people entering correctional facilities (including jails)—must be screened for the presence of cognitive disability.

- Third, the necessary therapeutic and disability support services—including NDIS-funded services where applicable (for example, during preparation for parole or release)—must be available to people in correctional facilities.

- Fourth, adequate forensic custodial services must be established and maintained in order to ensure that no person with disability is imprisoned without having been convicted of a crime. When placement in a custodial setting is deemed necessary, a person found unfit to stand trial or found not guilty by reason of mental impairment must be housed in a therapeutic or supportive setting and not simply be left to languish in prison.

Recommendation 1.1

OPA recommends that state and territory governments ensure that people with cognitive disability receive support in order that they can understand and participate in criminal justice processes, including procedures in police stations and in courts.

Recommendation 1.2

OPA recommends that state and territory governments ensure that all people entering correctional facilities are screened for cognitive disability.

Recommendation 1.3

OPA recommends that state and territory governments adequately fund disability support services in correctional facilities and work with the NDIA to ensure that access to NDIS-funded services is available when such services are necessary.

Recommendation 1.4

OPA recommends that state and territory governments ensure that there are sufficient forensic disability services to meet the demand for these services.

Recommendation 1.5

OPA recommends that state and territory governments ensure that there is a sufficient number of supportive residential settings available for people who are unfit to stand trial or who are deemed not guilty by reason of mental impairment.

Social care settings

Another area in which reforms are required concerns circumstances in which people with disability and other marginalised groups are subject to arguably unlawful incursions on their liberty that occur outside formal custodial settings. This can happen in the general community when a person is subject to a locked or controlled environment, to constant supervision, or to chemical or physical restrictions that impinge on their ability to move freely.

Some jurisdictions provide lawful authorisation for restrictions on movement in specific social care settings. In Victoria, for example, the Disability Act regulates the use of restrictive practices by disability service providers, who must lodge behaviour support plans with a state official, known as the Senior Practitioner. Restrictive practices are defined as ‘any practice or intervention that has the effect of restricting the rights or freedom of movement of a person with a disability or of an NDIS participant’.[87] The NDIS has introduced some complexity to these reporting requirements: NDIS participants who are deemed to require a regulated restrictive practice must lodge a behaviour support plan with the NDIS Quality and Safeguards Commission, and the service provider using restrictive practices must report monthly to the commission.[88] This latter requirement applies throughout Australia.

In the year to June 2017, 2,328 Victorians were subject to restrictive interventions that were authorised under the state’s Disability Act.[89] Ninety-five per cent of these interventions entailed chemical restraint, many of them involving the routine administration of anti-psychotic medication. The second most common form of restrictive intervention was mechanical restraint (about 140 people); this was followed by physical restraint and then seclusion (55 people).[90]

Other sectors are not, however, subject to similar regulation of restrictive interventions, making the lawfulness of the interventions' use to some degree legally questionable. Most notably, in aged-care facilities the use of restrictive interventions, particularly chemical restraints, is unregulated or under-regulated. When they are prescribed by doctors, their use is subject to the professional oversight that applies to all medical treatment; when, however, a medication is used to control behaviour rather than to treat a condition, professional medical oversight alone is obviously an inadequate safeguard.

A report prepared for Alzheimer's Australia found:

> About half of people in residential aged care facilities and up to 80% of those with dementia are receiving psychotropic medications … [however] the evidence supporting the effectiveness of psychotropic medications in treating [the behavioural and psychological symptoms of dementia] is modest at best.[91]

Publication of the final report of the ALRC's inquiry into the abuse of older persons was an important development in this regard. The Commission recommended regulation of restrictive practices in aged-care facilities.[92]

There are other situations in which the provision of medical treatment probably does lawfully permit a treatment-related deprivation of liberty. For example, when a patient is receiving treatment for a particular condition, such as a traumatic head injury, they might be detained in a low-stimulation environment to facilitate recovery. This presupposes, of course, that valid consent to the treatment has been given either by the person in question or by someone with authority to make medical treatment decisions on the person's behalf.

Nevertheless, questions remain about the legality of other situations in which people's free movement is constrained. They also remain about the manner in which lawful authorisation can be provided for a deprivation of liberty. Can, for instance, a guardian or someone exercising a role under an enduring power of attorney make a decision that would amount to a deprivation of liberty? This could happen, say, if such an individual made a decision that would have the person in question living in a house where staff constrain the movements of residents (for example, by deadlocking external doors).

Among the questions that need to be considered here are the extent of the power given to the substitute decision-maker by the order or appointing instrument; whether the deprivation of liberty was instituted to protect the person from harm or whether it was done to protect others from the person; and whether the constraint amounted to the least restrictive way of dealing with a risk to the person.

In 2004, in the famous *Bournewood* decision, the European Court of Human Rights ruled that an autistic man had been unlawfully detained in Bournewood Hospital in England. The man, who had apparently been compliant in relation to his situation and was regarded as an 'informal patient', was nonetheless ruled to have been deprived of his liberty.[93] In addition to casting light on modern developments in human rights, the case has direct relevance for the three Australian jurisdictions that have charters or bills of rights. Victoria's *Charter of Human Rights and Responsibilities Act 2006*, for example, protects people's 'right to liberty' and their right not to be 'subjected to arbitrary arrest or detention'.[94]

In 2012 the VLRC noted the relevance of the *Bournewood* case to Victoria, stating, ‘It is possible that Charter proceedings against a “public authority” in relation to a person without capacity who is effectively detained in a hospital or nursing home without formal authorisation could produce a similar result to the *Bournewood* case’.[95]

What, then, is a deprivation of liberty? This question is relatively easily answered in the context of imprisonment, but it is complicated in the context of ‘social care’. In the latter instance, if a deprivation of liberty is to occur there is typically a requirement for both an objective element (a restriction on movement) and a subjective element (usually at the very least an intention on someone’s behalf to constrain or unduly monitor a person’s free movement).

One UK Supreme Court decision in 2014, in what is known as the *Cheshire West* case, crafted what was termed an ‘acid test’, which is instructive when determining whether a particular social care situation amounts to a deprivation of liberty. The simple test, drawn from the *Bournewood* decision, asks whether an individual is ‘under continuous supervision’ and is ‘not free to leave’.[96] The UK Social Care Institute for Excellence put together a list of practices that might constitute further evidence that a deprivation of liberty is occurring. Among these practices were the following:

- frequent use of sedation/medication to control behaviour
- regular use of physical restraint to control behaviour
- the person concerned objects verbally or physically to the restriction and/or restraint
- objection from family and/or friends to the restriction or restraint
- the person is confined to a particular part of the establishment in which they are being cared for.[97]

In 2012 the VLRC recommended that Victoria’s Public Advocate ‘develop guidelines in consultation with appropriate professional groups that identify practices undertaken in supported residential facilities that are a restriction upon liberty and that should be authorised when imposed without consent’.[98] In 2017 OPA invited a number of experts in the guardianship, aged-care, disability and mental health sectors to attend a gathering to discuss six real-life examples of adults being in situations that arguably constituted a deprivation of liberty. There were two people in residential aged care, an inpatient at a mental health facility, a group-home resident, a person receiving treatment in hospital for a brain injury, and a young woman living with her parents. Most, if not all, of those attending agreed that the circumstances described were characterised by legal uncertainty about the measures taken and whether they amounted to deprivations of liberty.

One follow-on piece of work, led by Eleanore Fritze, involved preparation of a ‘best-practice framework’ for deprivation of liberty, which drew on principles contained in the Convention on the Rights of Persons with Disabilities and a range of state and federal laws, including the Commonwealth’s *National Disability Insurance Scheme Act 2013* and Victoria’s *Charter of Human Rights and Responsibilities Act 2006*, and disability, mental health and medical treatment legislation.[99]

The purpose of the framework was to alert service providers to the legally uncertain nature of many activities that might constitute deprivations of liberty and to promote practices that avoid deprivations of liberty. The framework emphasised the need for law reform.[100] In the absence of such reform, it was noted that best practice in this complex area would involve the following elements:

- an assessment of whether any proposed measure amounted to a deprivation of liberty (based on the simple test and practices just listed in connection with the United Kingdom)
- the need to specify the exact nature of any proposed measure, its anticipated length of use and proposed review mechanisms
- the need to assess the probable and real impact on the person
- the proportionality of the restrictive impact of the measure when weighed against the risk of harm to the person were the measure not used
- the possibility of any less restrictive protective action being taken.

Future reform

Regulation of restrictive interventions is an area in which law reform is obviously required.

The roll-out of the NDIS brought with it an expectation that there would be national regulation of disability services' use of restrictive interventions. The NDIS Quality and Safeguarding Framework that was agreed on in 2016 stated, however, that a new national Senior Practitioner 'will oversee approved behaviour support practitioners and providers' but that 'approval for the use of restrictive practices will continue to be managed through current state and territory government processes'.[101] This means the various state and territory mechanisms, where they exist, will continue for some time. The NDIS Quality and Safeguards Commission has begun operations in all jurisdictions. As noted, services using restrictive practices for NDIS participants who have a behaviour support plan are required by law to report monthly to the NDIS Commission.

Victoria's Disability Act provides arguably the best model for scrutiny of restrictive interventions: it requires that an intervention be written into a behaviour support plan, with oversight provided by a statutory official. Models in use elsewhere include authorisation by guardians.[102]

The use of guardians to authorise restrictive interventions has the potential to put the guardians in the position of having responsibility to protect not only the person for whom they are guardian but also others with whom the person under guardianship might come into contact. Guardians are appointed to protect individuals—not society at large—and such an authorising role blurs this distinction. Moreover, guardians rarely have the clinical skills to be able to effectively monitor and seek to decrease the use of a restrictive intervention, making theirs a 'consent' role in relation to the use of such interventions rather than a scrutinising one.[103]

The hope is that the clinical leadership to be exercised by the new national Senior Practitioner will lead to improved regulation of restrictive interventions in the disability setting. Meanwhile, there is an increasingly urgent need in connection with restrictive interventions used in other circumstances (particularly chemical restraints) being subject to clear regulation and oversight. OPA has long sought greater regulation of restrictive interventions in aged-care facilities, and the ALRC has suggested that such interventions be regulated under the Commonwealth's *Aged Care Act 1997*.[104]

Since July 2019 the Commonwealth's Quality of Care Principles 2014 have placed explicit obligations on residential aged-care service providers to minimise the use of chemical and physical restraints. OPA raised human rights concerns in relation to the Commonwealth's Quality of Care Amendment (Minimising the Use of Restraints) Principles 2019, which resulted in the Parliamentary Joint Committee on Human Rights conducting a short inquiry into the proposed changes and calling for amendments.[105] The amended principles came into force in November 2019.[106]

Although the amended principles require that restraints be used only as a last resort, they fall short of requiring approval or oversight of restrictive practices by an independent body. OPA questions whether principles alone are sufficient to meet Australia's responsibilities under the Optional Protocol to the Convention against Torture, which Australia ratified in 2017.

More stringent regulation is important since the use of restrictive interventions in aged-care facilities is predominantly, and inadequately, regulated by the norms and requirements of medical professional practice. Obviously, doctors can be expected to have clinical knowledge of the pharmaceuticals they prescribe, but the problem with this regulatory approach is similar to that posed by the use of guardianship as an authorising vehicle for restrictive interventions. It places doctors in a position of acting not only in the interest of a patient's wellbeing but also with a view to ensuring the wellbeing of others in contact with the patient. That can necessitate very complex judgments that will inevitably result in overly protective action.

Recommendation 1.6

OPA recommends that the Australian Government implement a comprehensive regulatory framework for the use of restrictive practices in residential aged care. The framework should have all the characteristics and protections recommended by the ALRC in its 2017 report entitled *Elder Abuse—a national legal response*:

> ALRC Recommendation 4–10. Aged care legislation should regulate the use of restrictive practices in residential aged care. Any restrictive practice should be the least restrictive and used only:
>
> (a) as a last resort, after alternative strategies have been considered, to prevent serious physical harm;
>
> (b) to the extent necessary and proportionate to the risk of harm;
>
> (c) with the approval of a person authorised by statute to make this decision;
>
> (d) as prescribed by a person's behaviour support plan; and
>
> (e) when subject to regular review.
>
> ALRC Recommendation 4–11. The Australian Government should consider further safeguards in relation to the use of restrictive practices in residential aged care, including:
>
> (a) establishing an independent Senior Practitioner for aged care, to provide expert leadership on and oversight of the use of restrictive practices;
>
> (b) requiring aged care providers to record and report [on] the use of restrictive practices in residential aged care; and
>
> (c) consistently regulating the use of restrictive practices in aged care and the NDIS.

In the case of deprivations of liberty more generally, it is worth noting that the Optional Protocol to the Convention against Torture requires that signatories establish 'national preventive mechanisms' whose role includes regular examination of 'the treatment of the persons deprived of their liberty'. The optional protocol defines 'deprivation of liberty' as involving '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'.[107]

Proper observation of the optional protocol's requirements should provide an impetus for a statutory definition of the term 'deprivation of liberty'. Eventually, it should also lead to the active monitoring of deprivations of liberty that occur in disability and aged-care settings, as well as in the more obvious settings of jails, locked mental health facilities and immigration detention facilities. The Commonwealth Government noted that the focus of Australia's National Preventive Mechanism would be 'primary' places of detention, where the 'challenges are perhaps at their most acute'.[108]

The Office of the Commonwealth Ombudsman has statutory responsibility for coordinating Australia's National Preventive Mechanism. It will work with state and territory entities appointed as NPMs to ensure the coordination of Australia's efforts.[109] In addition to a coordination role, the Office of the Commonwealth Ombudsman was the first nominated National Preventive Mechanism in Australia, having been given responsibility for inspecting places of detention that are under Commonwealth control.[110] At this stage, the only state or territory to nominate additional NPMs is Western Australia.[111] Nominations from other jurisdictions are eagerly anticipated. Australia will not be starting from scratch, though, since many existing bodies visit or inspect prisons, juvenile detention centres and locked mental health facilities; this includes, for example, OPA's Community Visitors.

1.3 Homelessness

Like violence and exploitation, as well as deprivation of liberty, homelessness disproportionately affects people with cognitive disability. People who are homeless—particularly 'rough sleepers' and people seeking cash from passers-by—probably constitute the most visible group of Australia's marginalised adults, at least for the inhabitants of the major cities.

Homelessness is, of course, a complex problem, but among other things it is a human rights problem. The Convention on the Rights of Persons with Disabilities is one of many international instruments that identify the right of people to be adequately housed. That convention, in particular, speaks of 'the right of persons with disabilities to ... adequate food, clothing and housing' and the right of access to 'public housing programmes'.[112]

It is well accepted that the term 'homelessness' encompasses several layers. Primary homelessness is said to refer to situations where people are living in non-standard accommodation, including on the street. Secondary homelessness is characterised by short-term 'making do', where people sleep on friends' couches, for example, or in emergency accommodation. Tertiary homelessness refers to a situation where someone has a bed but no security of tenure and lacks typical housing facilities such as their own bathroom or kitchen.[113]

According to the Australian Bureau of Statistics, on census night in 2016 there were 116,427 homeless people in Australia, of whom 8,200 were in situations of primary homelessness—'in improvised dwellings, tents or sleeping out'.[114] Other agencies also conduct surveys of homelessness: the City of Melbourne, for example, recorded 247 rough sleepers in 2016.[115]

Rough sleeping is often viewed as a choice. In 2017, in a debate about whether there should be by laws to make the practice illegal, Victoria's Chief Commissioner of Police was quoted as saying there was 'no reason people should be sleeping on the street'.[116] Naturally, behind any such 'choice', and the precarious and dangerous existence to which it gives rise, there lie complex service support needs.

People who are homeless often have support needs additional to those directly related to housing. The Australian Institute of Health and Welfare, which, among other things, produces information about users of 'specialist homelessness services', has reported that, in the year to June 2017, 288,273 people used such services, more than one-quarter of those people (77,569 people) being 'identified as having a current mental health issue'. In addition, 10,988 people had a disability that was defined as meaning that the person always or sometimes required assistance 'with self-care, mobility or communication'.[117]

Although it is strong, the connection between disability and homelessness is nuanced. In an important report on the subject, Beer and colleagues noted:

> It appears that disability is strongly associated with relative risk of homelessness, and further that within the disabled population, there are differences in risk depending on the severity of restriction. Those with schooling/employment restrictions appear to be most vulnerable to [the] risk of homelessness, while those with profound core activity restrictions, for example, experience a lower level of risk.[118]

This study used four disability categories, including 'psychological disability'. While it did not set out to capture the experiences of people with mental illness, the study found that half of the participants had a mental illness in addition to their primary disability and that mental illness greatly increased the risk of homelessness for this cohort.[119]

In terms of policy responses to homelessness, the first question to ask is what problem are we seeking to solve? If it is concern for the welfare of people—perhaps particularly people in primary and visible situations of homelessness—the obvious first thing to do is to ask the people themselves. When this is done, the unsurprising response is that people want adequate, safe, stable and appropriate housing.[120]

But, even if the concern were simply a desire to reduce expenditure on homelessness and other related services, the answer would be the same. A report published by the Melbourne Sustainable Society Institute, which conducted a detailed study of the societal costs associated with homelessness (including those incurred by the health and criminal justice systems), noted that over 20 years, 'for every $1 invested in last resort housing beds to address the homelessness crisis, $2.70 worth of benefits are generated for the community'.[121]

Future reform

Although homelessness affects people with and without disabilities, we do know that a relatively high proportion of homeless people have disabilities. Mental ill-health, in particular, is known to be much more common among people who are homeless compared with the general population.

When it comes to reform in connection with homelessness, the general response of systemic advocates is simply to seek provision of adequate housing. In a report on the rights of people with disability, OPA has echoed that call.[122] For people with disability, this means coupling the provision of adequate housing with the delivery of other relevant services. Importantly, it means involving the people concerned in making decisions that will affect them.

Several models of successful service provision exist. Launch Housing in Melbourne, for instance, is a service provider whose delivery model embodies a wraparound approach to housing and service provision.[123] Such models must, of course, be fully evaluated, but where they are found to be successful and cost-effective they should be resourced and rolled out more widely.

Central to models of this nature is that they incorporate the specific services the individual needs in addition to housing. Services such as Victoria's Wintringham homeless older persons program are increasingly offered on a consumer-directed care basis and fully involve the person in agreeing to, and ideally directing, the provision of services.

Recommendation 1.7

OPA recommends that state and territory governments fund proven programs that embody a wraparound approach to housing and service provision for people with disability.

The Victorian Parliament's Legal and Social Issues Committee is conducting an inquiry into homelessness in Victoria; it is due to report in February 2021.[124]

1.4 Substitute decision-making

This section and the next focus on the main theme of the remainder of this report—decision-making by, with and for adults with cognitive disability.

The continuing practice of substitute decision-making as an adult protection mechanism is the cause of much debate: human rights developments are increasingly pointing to its inconsistency with key human rights instruments. Of greatest significance for laws and practices associated with adult protection, Article 12 of the Convention on the Rights of Persons with Disabilities provides for the recognition 'that persons with disabilities enjoy legal capacity on an equal basis with others'. It also notes:

> States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse … Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body.[125]

There has been considerable argument about whether substitute decision-making laws and practices are compatible with this article. The Australian Government took steps to outline its view that such laws and practices are compatible, making its ratification of the convention subject to a 'declaration' that it understood:

> … that the Convention allows for fully supported or substituted decision-making arrangements … as a last resort and subject to safeguards … [and] that the Convention allows for compulsory assistance or treatment of persons, including measures taken for the treatment of mental disability.[126]

Although the legal status of Australia's declaration is somewhat unclear, the different interpretations were clearly on display in 2014 when the convention's treaty-monitoring committee, the Committee on the Rights of Persons with Disabilities, stated its authoritative, if technically non-binding, view: [127]

> States parties' obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.[128]

The ALRC outlined its view of this contentious matter in its *Equality, Capacity and Disability in Commonwealth Laws* report of 2014. It noted that, to the extent that Australia's declaration 'is simply stating that there are occasions when a person may be appointed to act on behalf of another—as a substitute—the ALRC considers that this is a correct understanding of the CRPD'. It also noted that the convention 'does not preclude the appointment of another to act on behalf of a person, either by the person themselves (such as by an advance directive or enduring power of attorney) or through an institutional mechanism such as a court or tribunal'.[129]

The ALRC recommended that supported decision-making become the lead option when there are concerns about a person's decision-making ability:

> Reform of Commonwealth, state and territory laws and legal frameworks concerning individual decision-making should be guided by the National Decision-Making Principles and Guidelines ... to ensure that:
>
> - supported decision-making is encouraged;
> - representative decision-makers are appointed only as a last resort; and
> - the will, preferences and rights of persons direct decisions that affect their lives.[130]

In the ALRC's view, when it came to substitute decision-making, the main reform impetus of the convention was indeed to reduce the need for substitute decision-making and, in cases where it was needed, to change the basis on which substitute decisions are made. It argued that the convention 'was principally condemning a best interests approach, not a will and preferences approach'.[131]

Future reform

The future of substitute decision-making and possible reforms to the status quo are discussed throughout this report. For the purposes of this chapter, however, there are two broad reform imperatives.

The first is that substitute decision-making—especially by tribunal-appointed decision-makers—should be restricted to situations of absolute necessity, both formal and informal alternatives being used wherever feasible. This should involve greater use of supported decision-making and higher uptake of personally appointed substitute decision-makers (through instruments such as enduring powers of attorney), as well as greater use of other support mechanisms that will limit the need for state-appointed substitute decision-makers. These possibilities are considered further in Chapters 3 and 6.

The second reform imperative is that when substitute decision-making is required a substituted judgment approach—what the person would have wanted—should be used as the basis for any decision-making, rather than what the substitute decision-maker thinks is simply in the 'best interests' of the person. This approach is discussed in Chapter 3.

1.5 Supported decision-making

Although there are ever-increasing calls for the recognition of supported decision-making, there is considerable debate about what the expression actually means. Some take it to refer to a process whereby a person is helped to exercise decision-making authority; the term 'support for decision-making' or 'support with decision-making' is sometimes used in this context. Others take the expression to refer more to a legal outcome that can be contrasted with other legal outcomes (principally substitute decision-making).[132] While this definitional uncertainty continues, a growing literature on supported decision-making is being accompanied by guides that seek to provide assistance to those wishing to support people with cognitive disability in making their own decisions.[133]

In the context of adult protection, one of the most important questions raised by developments in supported decision-making concerns whether such decision-making can be looked to as a complete alternative to substitute decision-making, as has been envisaged by the Committee on the Rights of Persons with Disabilities.

There are important ways in which supported decision-making techniques and practices can be used and developed to reduce the use of substitute decision-making, and this report discusses many of these possibilities. But no expert has yet developed a model of supported decision-making that could completely obviate the need for any substitute decision-making at all. One can imagine a situation in which no formal substitute decision-making was legally permissible, but that would tend to see informal substitute decision-making occurring, including in situations where few would view this as a positive outcome—and indeed in problematic situations the modern guardianship system was designed to resolve. In a circumstance where no formal substitute decision-making was permissible, how, and by whom, would medical treatment decisions be made in relation to unconscious patients who have no family or supporters to accompany them and where no suggestive instructions as to their views have been recorded?

In 2010 Bach and Kerzner drew on the Convention on the Rights of Persons with Disabilities to develop *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity* for the Law Commission of Ontario.[134] They drew a distinction between 'legal capacity'—the right to make decisions—and 'mental capacity' and proposed the adoption of three statuses:

> (a) Legally independent decision-making status …
>
> (b) Supported decision-making status [where a person may be unable to act independently but can] … act in a way that at least one other person … can reasonably ascribe to the individual's actions, personal will and/or intentions consistent with the person's identity; and can … give effect to the [person's] will and/or intentions …
>
> (c) Facilitated decision-making status … for those individuals with significant disabilities who do not meet either of the minimum threshold tests [for the other statuses] with respect to a particular decision … [which would enable facilitators to] be appointed by an administrative tribunal or through a planning document …[135]

The last of these statuses in effect amounts to substitute decision-making and quite closely resembles limited guardianship orders; it is just a change in terminology.

As noted, the ALRC wrestled with this topic in 2014 and stopped short of calling for an end to substitute decision-making. As it commented, ‘Some system of appointment of others to act is a necessary human rights backstop’.[136]

That point having been made, there is obviously enormous scope and potential for supported decision-making arrangements to be used and extended in ways that will see people even with significant cognitive disability playing a greater decision-making role in relation to their own life.

Pilot projects

In 2018 the National Disability Advocacy Program Decision Support Pilot was launched, funded by the Commonwealth Department of Social Services. The pilot provides advocacy and decision-making support for potential and current NDIS participants who have limited decision-making capacity and no other suitable informal or formal decision-making supports.[137]

Before this, various Australian jurisdictions had trialled small supported decision-making projects, but these, as Carney noted, were at best only suggestive of the role supported decision-making might come to play in the social services sector. The projects have been characterised by being short-term, small and quite selective in the disability profile of participants; rigorous independent research is needed to allow supported decision-making to be ‘rendered more comprehensible and meaningful in practice’.[138] South Australia hosted the first such project, which began in 2010.[139] Various evaluations have been completed.[140]

The initial pilot programs demonstrated the potential that supported decision-making has for increasing the role played by people even with significant cognitive impairment as authors of their own lives. They also point to the complexity involved in negotiating the relationships between supporters and the people being supported: important incremental developments need to occur before major ‘decisions’ can be made. This developmental stage often involves pre-decision education about possibilities and the working through of the potential consequences of particular courses of action. People with cognitive impairments often have a history of marginalisation, so it is extremely rare for a person to come to a supported decision-making program with knowledge of a particular ‘decision’ they simply want to be helped to make.

In a review of the pilot projects that operated from 2010 to 2015 Bigby and colleagues observed that evaluations to date have not been particularly rigorous and, as a result, ‘only tentative conclusions can be drawn about the effectiveness of the programs and the design features that influenced their outcomes’.[141]

OPA looks forward to the findings from the National Disability Advocacy Program national pilot.

Legal developments

Supported decision-making has been a feature of recent inquiries into guardianship and disability-related laws.

In 2012 the VLRC devoted a chapter of its final report to the subject and made 34 recommendations relating to it, among other things recommending that ‘supporters’ be able to be appointed by individuals and by the Victorian Civil and Administrative Tribunal.

Supporters would have a range of information-collecting and communication powers, while decision-making authority would rest with the person being supported. The commission also recommended that OPA host a new supported decision-making volunteer program,[142] which occurred in 2013.[143]

The language and concept of supported decision-making have now started to appear regularly in legislation.

The Commonwealth's *National Disability Insurance Scheme Act 2013* contained general principles noting that 'people with disability should be supported to participate in and contribute to social and economic life to the extent of their ability' and that 'people with disability should be supported to exercise choice, including in relation to taking reasonable risks', while stating that 'people with disability should be involved in decision-making processes that affect them, and where possible make decisions for themselves'.[144] At state level, in Victoria the *Mental Health Act 2014* recognises that 'persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions'.[145]

Subsequent developments have moved beyond the inclusion of supported decision-making terminology in general principles and started to involve the creation of new legal categories. Victoria's *Powers of Attorney Act 2014* led the way here, creating the role of 'supportive attorney', someone who can be appointed by an individual to assist in the making and implementing of decisions but who does not have decision-making authority. Supportive attorneys have power to collect information, 'communicate' information and 'give effect to' decisions (but not in relation to a 'significant financial transaction').[146]

Among other things, supportive attorneys have the power to overcome privacy restrictions that would otherwise prevent them from having access to information. OPA produced a guide to this development in 2015—*Side by Side: a guide to appointing supportive attorneys*—and updated it to align with provisions in the *Medical Treatment Planning and Decisions Act 2016* (Vic), which began operation in 2018.[147]

Some questions remain in relation to the legislation in Victoria. For example, one of the guiding ideas behind supported decision-making is that it is a mechanism whereby people with cognitive disability might be able to have others help them in situations where they might not have the legal ability to make other kinds of appointments, such as under general or enduring powers of attorney. In order that a supportive attorney can be appointed, the Victorian legislation requires that the principal have 'decision-making capacity in relation to making the … appointment',[148] although it is unclear when someone could have this ability but not the ability to make other appointments.

Similarly, although the term 'significant financial transaction' is defined in the legislation,[149] it is unclear whether repeated smaller transactions—which, when combined, could quickly exceed the statutory threshold—can be engaged in by the supportive attorney. This is just one of many instances where a balance is being sought between empowering marginalised people and protecting them from harm.

Other questions apply not only to this rendition of supported decision-making but also to supported decision-making more generally. What, for example, are the limits of a power to 'give effect to' someone's decision? Often this will technically also involve 'decisions'. For example, a person might decide that they want to go on a holiday, and the supporter might give effect to this by booking airline tickets and accommodation, which would involve expenditure of money and, indeed, the making of decisions.

Developments continue. In Victoria medical treatment legislation enacted in 2016 created the role of ‘Support Person’. Such a person does not have decision-making authority but has the power to do the following:

> support the person to make, communicate and give effect to the person’s medical treatment decisions … and … represent the interests of the person in respect of the person’s medical treatment, including when the person does not have decision-making capacity in relation to medical treatment decisions.[150]

This came into force in March 2018.

In addition, having tried to create a comparable tribunal-appointed role of ‘supportive guardian’ as far back as 2014,[151] the Victorian Government recently succeeded in passing the *Guardianship and Administration Act 2019*, which makes provision for both supportive guardians and supportive administrators. This legislation came into force in March 2020[152]; it is discussed further in Chapter 3.

Future reform

Further developments in the field of supported decision-making will have legal and non-legal elements. Elsewhere in this report we examine supported decision-making legislative reforms that have occurred and others that might occur in the fields of guardianship (Chapter 3), mental health (Chapter 4), medical treatment (Chapter 5) and powers of attorney (Chapter 6). In each case the reform involves supporters having a legal status that allows support to be provided but leaves significant decision-making authority with the person most affected by the decision.

One recommendation—promoted as a result of the supported decision-making trials—concerns the idea that a stand-alone agency should coordinate supported decision-making practices and knowledge.[153] That idea is worth pursuing.

Practice reforms are also required and should draw on rigorous research. At present there is a dearth of such research on supported decision-making, as a consequence of which we know surprisingly little about the best practical methods whereby people with cognitive disability can be supported in making their own decisions. A significant development here will, however, be the results from a project being led by Professors Bigby and Douglas at La Trobe University, entitled ‘Effective decision-making support for people with cognitive disability’. The project involves 12 partner institutions and academics from four universities and is examining practices in several jurisdictions. The results are eagerly awaited.[154] An additional part of this research program, funded by the Transport Accident Commission, began in 2019.[155]

At the heart of debates about future reform in the area of supported decision-making is the question of how developments can be promoted and supporters identified, encouraged and empowered without them—consciously or not—exercising undue influence on and control over the people they are purportedly supporting.[156]

2. Consumer choice

'Consumer choice' is central to the design of a raft of social policies worldwide as states seek the perceived efficiencies of market forces in more areas of society. In Australia it is integral to the NDIS and the provision of aged-care services.

In the case of the NDIS, it is seen to offer two important benefits. The most obvious is that consumers will be able to choose services that suit them and, ideally, feel empowered by exercising their right to choose. The second benefit accrues from the widely understood free-market economic theory that holds, very basically, that enabling consumer choice will create markets (and services) that better meet the needs of those consumers and expand their options.

As discussed in this chapter, there are serious questions about the ability of the NDIS's marketised system to adequately cater for the support needs of a group of people 'the market' has historically failed.

OPA notes that giving people a greater say in decisions that affect their lives, including in relation to service delivery, is more empowering than not. This benefit might, however, also be had in a less market driven system—for example, in a system with greater capacity to protect participants against market failure. As it stands, the NDIS's market-based version of consumer choice generates risks to the safety and rights of people for whom the market has not operated successfully in the past.

Consumer choice–based social policies are probably here to stay. Using the NDIS as a case study, this chapter looks at the impact of such policies on people with cognitive disability and proposes stronger safeguards and additional supports to redress the associated shortcomings.

Significant practical problems involving threats to the rights of people with cognitive disability have arisen in three main areas under the NDIS—the potential for individual agency, safeguarding systems, and crisis responses. The first area is clearly linked to the concept of consumer choice, while the second and third areas are flow-on effects of the promotion of 'free-market' solutions in social care settings. This chapter explores these areas by responding to three questions:

- How is consumer choice playing out for people with cognitive disability under the NDIS?
- What are the proposed NDIS safeguards and what are their weaknesses in relation to protecting people with cognitive impairment?
- What happens in a crisis and why are crisis events more likely to affect people with complex needs?

A brief overview of the NDIS and its goals is useful as a background to discussion of these operational problems.

2.1 The National Disability Insurance Scheme

The NDIS is a groundbreaking social reform that will eventually provide for about 460,000 Australians with disability the funds they need to live more active, socially engaged lives.[1] Arguably the biggest social welfare initiative since the advent in 1973 of universal health insurance, the Medicare scheme, the NDIS enables the provision of 'reasonable and necessary supports' to people eligible to enter the scheme (up to the age of 65) if they have 'substantially reduced functional capacity' and their impairment is permanent.[2]

Designed according to insurance rather than social welfare principles, the NDIS will ultimately result in a near-doubling of disability funding,[3] and its championing and continued support by both Labor and Coalition governments marks it as a relatively rare instance of bipartisan political support.

As noted, the NDIS is based on the principle of consumer choice. In outlining its blueprint for the scheme, the Productivity Commission proposed 'an "individual choice" model, in which people with a disability (or their guardians) could choose how much control they wanted to exercise'.[4]

The Productivity Commission recommended:

> Governments should give people with disabilities eligible for benefits under the NDIS, and/or people who act on their behalf, various options for exercising choice, including the power to:
>
> - choose service provider/s …
> - choose disability support organisations that would act as intermediaries on their behalf …
> - 'cash out' all or some of their individual packages …
> - choose a combination of the above.[5]

As these two quotes show, the consumer choice model here is not one that always requires decision-making by the participant themselves. It was obviously envisaged that others would act in representational roles. (It has, however, become a major practical challenge to work out when such roles should operate and what those roles should entail).

Signature Australian policy and legislative statements promote very strongly the idea that people with disability should play central roles in the decisions that affect them—something that aligns with the disability advocacy sector's long-running goal of placing a person with disability at the centre of decisions made about their life.

The National Disability Strategy, for example, expresses as one of its policy goals a 'sustainable disability support system which is *person-centred and self-directed*, maximising opportunities for independence and participation in the economic, social and cultural life of the community'.[6] [emphasis added]

When the legislation governing the NDIS was enacted, the principle of consumer choice was firmly embedded, along with the related principle of supported decision-making, in the objectives and the general principles of the *National Disability Insurance Scheme Act 2013*. For example, the Act's general principles provide that people with disability:

- should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports [7]
- have the same right as other members of Australian society to be able to determine their own best interests, including *the right to exercise choice and control*, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.[8] [emphasis added]

Of course, the outcomes that can be achieved by the NDIS and the marketisation of disability services are limited by how well mainstream services rise to the challenge of providing inclusive services for people with disability. Historically, state-based disability services (at least in Victoria) took up some responsibilities in this regard. The NDIS draws a harder line about what constitutes 'reasonable and necessary supports'.[9] We know that people with disability generally fare worse than members of the general population when it comes to the provision of mainstream services—be they in education, health, housing, transport, criminal justice or other arenas.

The NDIS is not intended to compensate for inadequate provision of mainstream services, but it can at times be extremely difficult to determine whether a person's needs exist because of the inadequacy of a mainstream service or because of the particular situation of the individual. The image that consumer choice presents—of consumers freely availing themselves of supports that best meet their needs—is limited in practice by the ability of mainstream services to meet the needs of people with disability. The NDIS seeks to augment this ability, and it is hoped that the interface will improve as the cracks between systems are identified.

One example of this arises in the provision of mental health supports. Many community-based mental health services closed down as the new NDIS funding regime was being implemented. Further, the episodic nature of mental illness and the fact that mental health treatments generally focus on a recovery framework make it difficult at times for people with psychosocial disability to gain access to the scheme because they need to prove they have a permanent functional impairment as a result of their mental illness. This situation has led to some people with mental illness not having access to support services.[10]

Another example concerns housing. Although the provision of housing support is generally considered a mainstream service, the NDIA decided, only after considerable delay, to fund the provision of 'specialist disability accommodation' support for those NDIS participants with 'extreme functional impairment' or 'very high support needs'.[11]

This 'mainstream or not' question affects service access and quality outcomes for participants but is not directly linked to the factors arising from 'consumer choice' and marketisation that are the focus of this chapter.

2.2 Consumer choice as a principle and in operation

The consumer choice principle (previously known as 'consumer directed care') is the central principle behind the very significant aged-care and disability services reforms that have been introduced in Australia in the past decade.

Although this chapter focuses on the move to a disability service sector governed by the consumer choice principle, it is important to note the principle is just as much a feature of aged care. As the Commonwealth Home Support Programme manual states, 'The high-level principles of consumer choice underpinning the CHSP include providing choice and flexibility in service delivery preferences (where possible), consumer rights and participation'.[12]

The increasing popularity of the consumer choice principle has two main bases. On one hand, it has the potential to generate considerable cost savings. Chesterman, for example, notes:

> Money is likely to be used more wisely and expeditiously when consumers decide how it is spent, and when greater flexibility is permitted (enabling spending decisions to take in a life span and not be dependent on the satisfaction of particular block-funded program eligibility criteria).[13]

On the other hand, it offers greater empowerment and agency to individuals who are able to make service provision decisions, either on their own or using supported decision-making. Where this process works as intended, people will probably play a greater role in decisions that affect them.[14]

In practice, a system motivated by consumer choice will, if it operates as intended, generate more decisions to be made about services individuals receive. For example, in the past, choosing a service provider could have locked a person into a particular model of block-funded service, while now it will ideally be more tailored to the person's preferences. Consumer choice does not necessarily require that the person with cognitive disability make service decisions by themselves. There is scope for paid or informal supporters to engage in supported decision-making with the person or, where there is no less restrictive option, for a substitute decision-maker to make service decisions. If, however, the person's preferences and needs are not central to the service decisions that will affect them, then both the assumed economic efficiencies and the hoped-for empowerment of people with disability are called into question.

Consumer choice under the NDIS and people with cognitive disability

The number of people affected

It is known that more than half of NDIS participants have a disability that affects their decision-making. At the end of September 2019, for example, among the 311,774 NDIS participants (which includes children), 54 per cent of active participants had an intellectual disability (24 per cent) or autism (30 per cent) as their primary disability. Among other disabilities that affect NDIS participants and can impair decision-making are mental ill-health (9 per cent) and acquired brain injury (3 per cent).[15] Many of these participants will probably need some form of support in order to effectively exercise their consumer choices under the NDIS.

Managing 'choices' for people with cognitive disability who need support

To date, the NDIA has provided insufficient guidance about when NDIS decisions can and should be made by adult participants, with support where necessary, and when decisions should be made on their behalf.

Although the NDIS legislation clearly supports the notion that people should be supported in making their own decisions, it also provides for the appointment of correspondence and plan nominees, with plan nominees in particular having substitute decision-making power. Among other things, plan nominees have the ability to do the following:

> Any act that may be done by a participant under, or for the purposes of, this Act that relates to:
>
> (a) the preparation, review or replacement of the participant’s plan; or
>
> (b) the management of the funding for supports under the participant’s plan.[16]

Plan nominees have extensive powers: their substitute decision-making powers in relation to NDIS-funded services are equivalent to the powers of guardians. Yet their appointment requires only an administrative action by the NDIA, not a tribunal hearing, as is the case with the appointment of a guardian. In some ways plan nominees are a kind of guardian minus the rigorous appointment process (or participant appointment).

In appointing a plan nominee—which can occur at the request of a participant or on the NDIA’s own initiative—the NDIA must have regard to the participant’s wishes and must also consider whether someone else, such as a guardian, has relevant powers under Commonwealth, state or territory law.[17]

The agency’s broad legislative power to appoint representatives who can exercise substitute decision-making power does not sit easily with the NDIS’s underlying philosophy of promoting decision-making by people with disability. Nor is it consistent with the modern trajectory of human rights.

Indeed, the ALRC recommended that the NDIS Act be amended to recast the provisions dealing with supporters and representatives in a manner consistent with the commission’s proposed decision-making model.[18] The commission also recommended that the NDIA’s power to appoint a substitute decision-maker be clarified to ensure that this power is ‘exercised as a measure of last resort’.[19] These changes have not yet been introduced, leaving current NDIA practices in relation to substitute decision-makers open to question on human rights grounds.

A potential proliferation of substitute decision-makers

One of the concerns that accompanied the roll-out of the NDIS was that dramatically expanding the kinds of decisions people with disability would be able to make about the supports they receive might generate a rush of substitute decision-making appointments for people with cognitive disability, either through the NDIS Act’s nominee provisions or through state and territory guardianship tribunals.

There is no hard evidence that this ‘rush’ has occurred in Australia, but there are indications that there has been at least some growth in guardianship appointments that are attributable to the NDIS. Queensland noted 455 guardianship applications in 2017–18 directly related to NDIS decision-making and projected an additional 500 matters for 2018–19.[20] Tasmania noted a set of new appointments specifically made for NDIS decisions. Western Australia has reported that the proportion of guardianship clients with intellectual disability overtook that of clients with dementia as the number one disability type for the first time in 11 years;[21] it attributed at least part of this growth to the NDIS. In Victoria OPA has similarly seen an increase in the proportion of guardianship clients with an intellectual disability; it strongly suspects that this growth, which has halted the usual growth in the proportion of older people under guardianship, is a consequence of the NDIS.

The NDIA, certainly in the first four years of the scheme, was reluctant to appoint plan nominees. Meanwhile, although several hundred guardianship applications were made early on in New South Wales in relation to people in residential institutions who were transitioning to the scheme, there has not to date been a similar flood of guardianship appointments as the scheme has rolled out. NDIS-related appointments instead appear to be occurring in a steady stream across the country as situations continue to arise where guardianship is proposed as a solution.

In the majority of cases where no guardian or plan nominee has been appointed, less formal practices have generally been adopted in relation to participants and prospective participants with significant cognitive disability. Family members and other supporters have become involved as the people they support have become NDIS participants. People with significant cognitive impairment who do not have supporters in their lives have on occasion been supported by paid advocates.

In practice, informal supporters might effectively empower the participant to be involved in decision-making and NDIS service choices or, at the other end of the spectrum, the supporters can operate as unofficial substitute decision-makers.

To this end, one of the questions accompanying the introduction of the NDIS concerns how people with cognitive disability will be assisted in starting to exercise choice, when many have throughout their life been disempowered in this regard. A person with significant intellectual disability cannot be expected to make a major life decision (such as where to live) without receiving support so that they know what the possibilities are and what the consequences of the various options might be.

A number of theories on decision-making—such as bounded choice theory—tell us that decision-making is always constrained by a person’s circumstances and their view as to what is actually on offer. For people with significant cognitive disability, especially those who have rarely received support in making decisions or having them acted on, these constraints on perceived options are going to be all the more pronounced. And for family members, some of whom might be used to operating as unofficial substitute decision-makers, it can be difficult to transition to supported decision-making.

It has, however, been even more challenging for people who do not have informal supporters or advocates to benefit from the promise of supported decision-making under the NDIS.

In Victoria, the advocacy agency VALID, with the assistance of OPA, implemented a small-scale supported decision-making program, matching isolated NDIS participants with volunteer supporters to help develop participants’ decision-making capabilities.

Further, as noted in Chapter 1, the National Disability Advocacy Program Decision Support Pilot was launched in 2018 to enable people with limited decision-making capability to have meaningful involvement with the NDIS.

Consent to NDIS administrative actions

Evidence that the NDIA had insufficiently planned for the circumstances of people with significant cognitive disability has also been seen in the number of times participants’ (or potential participants’) access to the scheme or services under the scheme has been jeopardised by administrative questions associated with consent and agreement—in particular, where it has been impossible to take an administrative step because of the absence of consent by a person with adequate decision-making authority.

There are three main situations in which administrative steps have stalled for this reason. One concerns the signing of access request forms, which constitute the first stage of a person's pathway to NDIS involvement. In the past a positive action of consent was all that was needed, including by a person's family or supporter, but OPA has become aware of an increase in the number of matters where more formal consent is being sought at this stage. Questions have also been asked about how consent to proceed should be sought from isolated people with significant cognitive impairment.

The second situation in which concern has arisen involves plan preparation, where questions have been asked about whether isolated people with significant cognitive impairment need to have others acting on their behalf.

The third situation relates to the signing of service agreements, under which an NDIS participant arranges and receives the services detailed in their plan. For some time there was debate about whether informal or formal decision-making authority was needed for someone to sign such an agreement on a participant's behalf. Curiously, in its guide on the topic, the NDIA advised, 'Both participant and provider—or another person (such as a participant's family member or friend) and provider—will need to sign the Service Agreement once they have agreed on its contents'.[22] The interesting thing about this advice was, of course, that family members and friends do not automatically have any lawful authority to sign anything on behalf of an adult, regardless of whether that person has a disability.

While it is important to recognise that fact, it is also important not to place too much emphasis on formal decision-making authority for uncontroversial administrative purposes. In the case of service agreements, one might ask why it is even necessary to have a signature by or on behalf of the participant. With the NDIA funding the service and having incorporated the service's provision in the participant's plan, the only question will be about the choice of service provider.

It is obviously important that the person who is to receive a service is involved as much as possible in that decision. But requiring a signature before a service can be provided then generates the question of who should sign, and with what authority, if the intended recipient of the service cannot sign. The likely outcome of the requirement for service agreements to be signed would be the routine appointment of substitute decision-makers (either guardians or plan nominees) solely for this purpose (and some service agreements contain clauses to which substitute decision-makers do not have authority to agree—such as the requirement that the service provider be treated with respect by the participant).[23]

OPA considers that the appointment of a substitute decision-maker should be reserved for significant decisions in relation to which there are multiple viable options or for decisions that are in some way contentious. Substitute decision-makers should not be used for unproblematic service delivery decisions, those where the choice in question (such as the identity of a service provider) is not controversial, where the person's views have been sought, and where there is no likely conflict of interest.

Interestingly, one point along the NDIS pathway that has not led to blockages of this nature concerns agreement about what is included in a participant's plan. One might think this would be contractual in nature, the NDIA reaching agreement with a participant about the services they would be funded to receive. The process has, however, been far more one-sided than this, the NDIA in practice informing itself as much as it chooses to about the person's particular needs and then determining what is to be included in the plan. For some participants this has been a most unsatisfactory and disempowering process.[24] To respond to this concern a ministerial commitment was made in November 2019 to provide to participants ‘draft plan summaries’; the national roll-out of this began in April 2020.[25]

In 2014 OPA developed a decision-making guide in a bid to help the NDIA and its planners identify situations where informal arrangements might be left in place and situations where more active assistance—in the form of either independent advocacy or additional support for participant decision-making—might be provided. The guide also outlined situations where substitute decision-making—in the form of plan nominee appointment or the appointment of a guardian or financial manager under state and territory law—might need to be sought. These situations were ones in which the relevant ‘decision (or lack of one) constitutes a significant risk to the personal and social wellbeing of the person’.[26]

This guide was drawn on to develop more detailed practice guidance on decision-making at important moments during a person’s involvement with the NDIS as a scheme participant. Among such moments might be initially accessing the scheme with a view to becoming a participant, the development of a support plan, and the choice of service providers. The 2014 guide made suggestions about when informal decision-making arrangements ought to be respected and when more active decision-making support might be required. A supporting poster has since been produced.[27]

Some additional problems

Alongside the practical problem of how to decide whether a substitute decision-maker is necessary and at which points along the access and service pathways of the NDIS (as described), there are at least two overarching problems with implementation of the NDIS version of ‘consumer choice’ that directly affect people with cognitive disability.

First, apart from the small supported decision-making projects involving NDIS participants and volunteers, there has been insufficient investment in building participants’ and supporters’ capacity to engage in NDIS-related supported decision-making.

Second, with the disbanding of the state and territory disability services sector, and the sector’s diversification, there is a major risk that the expertise necessary to achieve good results for individuals will be lost. If a person’s service needs are particularly complex and cut across many service systems—for example, disability, justice and health—neither that person nor their well-meaning family member or primary carer will be able to make informed decisions about the services that will best meet the person’s needs without expert advice. In practice, planners and local area coordination services, as well as support coordinators, have not been consistently up to this task and are not funded to advocate on the participant’s behalf. Chesterman has argued that a better funded advocacy sector might be able to meet this need.[28]

Without skilled decision-making supporters and (for some who need it) specialist service coordination, people with cognitive disability do not necessarily benefit from, and may suffer more under, the NDIS consumer choice system (even though the previous system was funded at a lower rate).

In late 2018 OPA released *The Illusion of ‘Choice and Control’*, which details the difficulties people with complex and challenging support needs can have in obtaining adequate support under the NDIS. The report is based on the experiences of 12 OPA clients who exemplify the kinds of difficulties and gaps that are evident under the scheme for this cohort. The recommendations arising from this research deal with failures of access to the scheme, expertise in planning, 'thin' markets, access to crisis accommodation and the need for a functional provider of last resort mechanism.[29]

This takes us to the implications for people with cognitive disability under the new and developing set of NDIS safeguards and how these safeguards differ from the protections afforded under the previous system.

Crisis situations, including market failure

Changes introduced under the NDIS

In order to understand what happens to a person in crisis under the NDIS and how that differs from what happened under the previous system, we need to understand the ways in which the NDIS has transformed funding and practice in relation to disability services.

First, although the states and territories had already moved to varying degrees towards enabling recipients of disability services to make their own service delivery decisions—through the adoption and roll-out of 'individual support packages' and similarly titled initiatives—national adoption of the principle of consumer choice in the delivery of disability services (as opposed to the block funding that characterised earlier disability funding) is the biggest change generated by the NDIS. As will become clear, however, complete rejection of block funding at the policy level might not have served the interests of all NDIS participants or promoted the service choices available to some subsets of consumers, including those with complex needs. This is borne out in the experiences of participants with complex needs described in OPA's *The Illusion of 'Choice and Control'*.[30]

The increased operation of market forces in the disability sector has already led to some improvements, especially in promoting more tailored service provision to meet individual needs, but it has also led to greater sector unpredictability as services grapple with their business models to take account of the interplay of NDIS pricing, uncertainty about future consumer demand and choices, and workforce management. It has also led to situations of 'market failure', where services are unable to be organised for some people with high or complex service needs.

Second, the NDIS is founded on an insurance model, not a welfare one, and the coordinating agency—the NDIA—is a funder rather than a provider or a regulator. In the past, state and territory governments (and their variously named disability, community or human services departments) tended to have all three roles, even in jurisdictions with a high rate of participation by non-government service providers. This has meant that governments, in effect, operated as service providers of last resort in situations of service failure. And, while the NDIA has technically assumed responsibility for ensuring that participants' needs are met in such circumstances, the details of how they will manage to create an effective safety net in the changed world of the NDIS are unclear.[31]

The NDIA and crisis response

The NDIA had a rocky start in the area of crisis response: NDIS-funded 'support coordinators' were seemingly charged with crisis resolution, despite having none of the reach and resources of divisional heads of state and territory disability departments, who were responsible under the previous system. Again, the stories related in OPA's *The Illusion of 'Choice and Control'* highlighted the poor outcomes for participants with complex needs under this regime. Since then the NDIA has developed and rolled out the Complex Support

Needs Pathway for eligible participants, with additional supports to help them navigate the system and avoid ‘falling through the cracks’.[32] This multi-pronged approach involves continued monitoring and evaluation of the plan and a much more responsive and timely approach to plan reviews to accommodate a participant’s changing circumstances.

One example of the reason there are concerns about this new model of social care service delivery occurred in late 2017, when a young man named Francis was remanded in prison. Francis has autism and an intellectual disability and had been accepted as an NDIS participant with annual funds of $1.5 million available to buy the support services he needed. But it was not possible to find a disability service provider who could meet his needs. He was released from prison only after media attention and the intervention of the state minister for disability.[33] Francis’s case is an extreme example of market failure: despite there being funds available, no service was available to be purchased.

This example and the ones discussed in *The Illusion of ‘Choice and Control’* demonstrate that the emphasis on marketisation that accompanies the NDIS’s promotion of consumer choice has created a risk of market failure for some participants. This is particularly the case for isolated people with significant cognitive impairment, complex needs and behaviours of concern who require specialised support or who have disability-specific living requirements that are currently not widely available.

In recognition of these risks, the NDIA has developed a limited suite of projects under the Maintaining Critical Supports banner (which includes the Complex Support Needs Pathway).[34] This is the name given to the NDIA’s efforts to ensure that no one is left without crucial disability supports—what we would have historically called ‘provider of last resort’ arrangements. This has included trialling of ‘after-hours crisis response mechanisms’.

These mechanisms, however, largely consist of either market intervention strategies to boost supply in thin markets or, in cases of market failure or to help participants successfully navigate the new system, the Complex Support Needs Pathway. Members of the Complex Support Needs Planning Team are skilled in responding to complex needs and can provide support to service providers to help prevent accommodation or service arrangements falling apart.[35]

OPA welcomes the positive impact the Complex Support Needs Pathway has had for some of our clients, but we do remain concerned about whether this will be sufficient to meet the needs of all participants in crisis. Historically, the state and territory disability service providers of last resort had housing stock and employed disability support workers to draw on. The NDIA does not. This has led to delays and participants being stuck in inappropriate settings for lengthy periods.[36]

Some of those people not eligible for the Complex Support Needs Pathway will, on occasion, experience crisis events. It is now widely acknowledged that the support coordinator role is often inadequate in situations of crisis. To take one example, what should happen when a service provider announces on a Friday evening that it can no longer provide services to a participant whose needs are greater than the provider expected? A support coordinator could try to organise crisis services but could not direct that they be provided. A better crisis management response is required, and the practical impacts and effectiveness of Maintaining Critical Supports are yet to be seen.[37]

The Victorian response

In Victoria, during the roll-out of the NDIS the Department of Health and Human Services established an Intensive Support Team to deal with problematic situations that were becoming apparent during transition. This approach has been successful in resolving a small number of highly complex crisis situations—at least in part because of the breadth of the departmental resources the team could draw on. The team continues to operate even though Victoria has fully implemented the scheme, but its future is uncertain.

The Intensive Support Team works closely with the Multiple and Complex Needs Initiative (MACNI) Team, which provides skilled case management and case planning and often coordinates large care teams for complex clients and works across the health, mental health and justice interfaces. The MACNI Team, similarly, has no plans to withdraw services to Victorian clients, the majority of whom would be NDIS participants. It meets a case management need that is not currently met by the NDIS.

Other proposed NDIS safeguards

Primary features of the safeguarding framework

The new safeguarding arrangements, which moved to full operation from July 2019 in Victoria, involve an NDIS Quality and Safeguards Commission headed by a commissioner whose primary roles include 'to uphold the rights of, and promote the health, safety and wellbeing of, people with disability receiving supports'.[38] The commissioner has responsibilities in the following areas:

- registration of service providers, who are obliged to comply with the NDIS Code of Conduct
- the 'notification and management of reportable incidents' (which include the 'abuse or neglect of a person with disability')
- complaints about NDIS-funded services
- 'leadership in relation to behaviour support, and the reduction and elimination of the use of restrictive practices, by NDIS providers'.[39]

Unrelated to the principle of consumer choice, the safeguarding framework, like the NDIS itself, is a national one. Development of new national safeguards was guided by the principle of achieving 'national consistency',[40] while the states and territories were keen to ensure that their existing safeguards were not diminished in the process.

Developing a nationally consistent safeguarding regime has proved complex for many reasons. Choosing the best state and territory approaches itself involves complex qualitative analysis. But even arriving at a definitive result on any one safeguarding feature does not mean that that feature can simply be nationalised or established independently and consistently in each jurisdiction.

For example, any nationally consistent approach to regulation of restrictive practices requires either the establishment of a national regulatory model or the passage of identical legislation in all states and territories. Further, the complexity of our federal system of governance means that important safeguarding roles will continue to be provided at state and territory level under the national framework—most notably worker screening checks and the authorisation process for restrictive practices, which, as noted, vary markedly between the states and territories.

Safeguarding possibilities in a marketised system

The consumer choice principle has led to the marketisation of disability services in Australia, and creating a national market was part of the way the NDIS was envisaged.[41] Safeguarding possibilities under the scheme are provided for in the NDIS legislation and principles. Many of the state and territory safeguards that existed before the NDIS was introduced are based on a much more controlled regulatory system, were tailored to their own jurisdictional needs and not necessarily aligned nationally, and would nevertheless not easily translate to a marketised service system. During transition to the full scheme the state-based safeguards continued to operate, but they were not always able to deal with anomalies that arose in the new NDIS world. Restrictive practices, for example, have very different regulatory frames across Australia, some being considered more consistent with human rights than others.[42]

One further marketisation-related impact on the effective safeguarding of the rights of people with cognitive disability is the preference for heavy reliance on what might be termed 'consumer-based' protections. This occurs where consumer choices themselves, and consumer-led complaints about the quality of services, constitute a significant element of the new safeguarding environment. This presents obvious challenges for people with significant cognitive impairment, who will often require advocacy support or other assistance to be able to meaningfully avail themselves of such protections.

Indeed, having fewer parameters around service models in order to promote flexibility and choice for participants makes it harder to set up more protective models of regulation and oversight. Community visitor schemes are an example of this. Where they exist, they are embedded in state and territory legislation and regulation of specialised disability accommodation services. The NDIS Quality and Safeguards Framework does not account for onsite visiting of participants, as is provided, for example, by Victorian Community Visitors. This is despite the Productivity Commission's identification of community visitor schemes as 'a well targeted way of monitoring groups with particular vulnerability who receive care and support in situations where poor practise or outcomes are more likely to go undetected'.[43] The commission called for community visitor schemes to 'be implemented in states where they do not currently exist … potentially with funding assistance from the NDIS. In doing so it is desirable to replicate features of the Victorian model, including publication of annual reports and the use of volunteers'.[44]

It is unclear why community visitor–type safeguards have not yet been made an integral part of the NDIS safeguarding framework, despite OPA's advocacy and the Productivity Commission's recommendations. It might be because of the probable difficulty of establishing a successful national scheme from a large range of state options that might not translate well to new jurisdictions and the fact that the effectiveness of such schemes has not been reliably evaluated. Or it could be because the marketisation of services means a diffuse service system with a much wider range of service models, which presents difficulties for designing an onsite visiting model that would protect participants who are most at risk in a complaints-based system, without undue constraints on all participant service options. Or is it simply because there is an aversion to funding such a scheme?

For example, the current Victorian Community Visitor model involves identification of particular types of accommodation settings, one of which has significantly changed under the NDIS. In Victoria those categories have been 'residential services', 'supported residential services' and 'designated mental health services', and visitors have been statutorily entitled to visit them.[45] The NDIS, however, is ensuring that participants have greater flexibility in their choice of accommodation types and arrangements. Participants have, for instance, been supported in moving to private settings, sometimes with other participants, and, although the new arrangement might closely resemble a previously visited ‘residential service’, it might no longer be able to be visited by community visitors.

Historically, ‘residential services’ were populated by people with cognitive disability. Under the NDIS, the concern has been that people with cognitive disability are less likely to be eligible for support in ‘specialist disability accommodation’—a new category of accommodation that largely aligns with the old ‘residential services’ definition—than they would have been under the old system.[46] If this cohort moves to predominantly private rental arrangements, a new regulatory pathway would have to be designed to enable onsite monitoring of disability services.

OPA supports the transition of community visitors to operating under full-scheme arrangements, but practical and difficult implementation questions have arisen. These relate to the diffuse nature of service provision under a marketised system. There is no longer one clear point of contact for a particular accommodation setting: there are accommodation providers, everyday supports providers, specialist allied health and behaviour supports providers, and so on. And different residents might also use different service providers. Who is responsible for responding to the problems community visitors might find in these settings and how should the information be communicated and to whom?

2.3 Future reform

Although the introduction of a new national scheme such as the NDIS is bound to give rise to numerous expected and unexpected implementation ‘hitches’, we want to devote attention here to the need for reform in six specific areas. The focus is on the NDIS, but OPA notes that many of these changes ought ideally also be made in relation to the provision of aged-care services.

First, in order to honour the promises associated with the consumer choice philosophy, the National Disability Advocacy Program Decision Support Pilot (following evaluation) should be rolled out and made accessible to all who fit the program criteria. Such programs should ensure they serve isolated people with significant cognitive disability. The programs, which are similar to the Oval and Choice Mentor programs in Victoria, would enable the matching of volunteer supporters with isolated NDIS participants with the aim of helping the participants with their NDIS-related decision-making.

Recommendation 2.1

OPA recommends that the Australian Government fund a volunteer program that would allow isolated NDIS participants to receive support with their NDIS-related decision-making.

Second, the availability of independent advocacy is crucial if NDIS participants and prospective NDIS participants are to be expected to negotiate the variety of information and decision-making requirements that accompany involvement in the NDIS. The National Disability Advocacy Program should be funded and considerably expanded to accommodate this reality.

Recommendation 2.2

OPA recommends that all governments—federal, state and territory—acknowledge the essential role independent advocacy plays for people with cognitive impairment in promoting positive outcomes in consumer choice–driven social care settings and provide increased advocacy funding through the National Disability Advocacy Program and state and territory government programs.

Third, there is a need for clear guidance that is consistent with human rights—including in the NDIS Act (and, indeed, in the Aged Care Act)—to the effect that substitute decision-making, either through guardianship applications or the appointment of nominees, must be used only as a last resort. Where it is used, a substituted judgment approach should be mandated.

Recommendation 2.3

OPA recommends that all governments—federal, state and territory—ensure that, where relevant, laws mandate a 'will and preferences' approach to substitute decision-making.

Fourth, last-resort service provision must be able to be mandated and provided quickly in situations where no other service provider is willing to provide services. A block-funded provider, or a panel of providers, would be required in each state and territory to fulfil this role.

Recommendation 2.4

OPA recommends that the NDIA have a transparent and effective 'provider of last resort' system (with a framework established as soon as possible) that ensures:

- **provider of last resort mechanisms are established as an ongoing component of the NDIS market**
- **multiple designated providers of last resort are clearly identified**
- **providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure**
- **as soon as possible, participants are transitioned back to support outside provider of last resort arrangements.**

Fifth, the nascent safeguarding regime at the national level must be revised to incorporate an onsite monitoring element, ideally through the adoption and extension of a community visitors scheme.

Recommendation 2.5

OPA recommends that the Australian Government ensure that the NDIS's national safeguarding regime includes an onsite monitoring component, ideally modelled on the Victorian Community Visitors Program.

Sixth, an evaluation of the effectiveness of the national safeguarding mechanisms must be conducted. It should include an analysis of the effectiveness of complaint-based protections. This is scheduled to occur in 2021, and a report is to be provided to the Disability Reform Council by mid-2022.[47]

This chapter considers the challenges posed by the application of consumer choice principles to people with cognitive impairment who are recipients or potential recipients of disability services through the NDIS. OPA notes that many of the observations expressed also apply to recipients of aged-care services, which are increasingly being provided under a consumer choice framework.

It is likely that the principle of consumer choice is here to stay. The current government has clearly indicated that the principle will continue to underpin reform in the human services sector, and the Productivity Commission was asked in 2016 to identify ‘services within the human services sector that are best suited to the introduction of greater competition, contestability and user choice’.[48]

The promises of consumer choice for people with significant cognitive impairments are that services will be better directed towards their specific needs and that service recipients will become more involved in decisions about service delivery. As discussed in this chapter, however, the dangers are that the additional decisions that need to be made about people’s needs will generate increased reliance on substitute decision-makers and, without resources, will fail to promote opportunities for self-determination through supported decision-making. At the same time, undue reliance on the profit motive—so welcomed as a natural promoter of effectiveness and efficiency—could jeopardise the wellbeing of highly vulnerable people whose needs no service provider is willing or able to try to satisfy.

3. Guardianship

Case study

In 2005 Maria Korp was brutally attacked in her garage by her husband's lover. She was choked, then placed in the boot of her car and driven to Melbourne's Shrine of Remembrance, where she was left to die. Police found her alive four days later, but her injuries were catastrophic. She was hospitalised and remained in a non-responsive state for five months.

Among the many legal and ethical questions that arose in the aftermath of this crime was the question of who should make decisions about medical treatment on Ms Korp's behalf. The Victorian Civil and Administrative Tribunal appointed Julian Gardner, Victoria's Public Advocate at the time, to be her guardian, and it was he who authorised the withdrawal of the tube feeding that had been keeping Ms Korp alive.[1]

Although the case involving Maria Korp was highly unusual, the guardianship element of it was not. Ms Korp was one of 1,088 adults in 2005 for whom OPA acted as guardian.[2] She was one of the people the Victorian Civil and Administrative Tribunal determined that year to be unable to make their own decisions and for whom the appointment of an independent decision-maker was considered necessary.

This chapter looks at the role of adult guardianship laws and practices and the most cogent critiques of these laws and practices. It proposes eight important reforms that could improve the way guardianship operates as a mechanism for protecting adults.[3]

In Australia the modern guardianship system began being developed in the mid-1980s, when a nascent human rights awareness about people with disability began to result in the closure of residential institutions for people with disability. The movement of large numbers of people with profound cognitive impairment from these institutions (such as Kew Cottages in Melbourne) into houses in the general community gave rise to the need for decisions about where people might live and what kinds of services they might receive.

Victoria's Guardianship and Administration Act was enacted in 1986 along with a suite of social welfare reforms, including new mental health legislation and legislation governing the delivery of services to people with intellectual disability. When it comes to the development of modern Australian guardianship laws, in the words of Carney and Tait, 'Victoria is where it really began'.[4]

One of the central features of the Victorian legislation was that it placed the role of determining the need for guardianship in the hands of an administrative tribunal—the Guardianship and Administration Board—rather than a court.[5] Until the developments in Victoria a mixture of common law provisions and piecemeal legislation in the financial management, health and mental health fields effectively removed decision-making authority from people with major cognitive disability. These laws and administrative practices, which varied greatly between jurisdictions, were applied especially to people who were residing in institutions, which was standard practice in Australia until the 1980s for people with major cognitive disability.[6] There continue to be a small number of residential institutions for people with disability.

Vesting the role of determining guardianship applications in an administrative tribunal had one distinct advantage: it would enable the jurisdiction to be exercised in an inquisitorial rather than adversarial manner.

The committee of inquiry whose report led to Australia's first modern guardianship Act—Victoria's Guardianship and Administration Act—was known as the Cocks Committee. It identified three weaknesses in the traditional adversarial approach used in courts. The first was the way adversarial systems tended to cast the applicant as being 'in conflict' with the subject of the hearing. The second weakness was the delays that tended to accompany adversarial systems. And the third was the difficulty an adversarial system would present for people instructing legal representatives. Instead, the Cocks report envisaged an 'active role' on the part of the tribunal in garnering information. It also recommended a jurisdiction free of application costs.[7]

Another novel aspect of the Victorian legislation was that it created the role of public advocate as the guardian of last resort, with clear legislative responsibility for advocating for people with disability about the services they receive and their general wellbeing.

In the years following 1986 all states and territories in Australia enacted their own guardianship legislation under which administrative tribunals or boards were empowered to make guardianship orders. The Northern Territory was the last jurisdiction to enact guardianship legislation, which it did in 2016.[8] All jurisdictions other than Tasmania now vest this role in one 'list' within a super-tribunal (such as the Victorian Civil and Administrative Tribunal).

Victoria and Queensland have recently acted to update their guardianship laws, with the goal of meeting their responsibilities under the UN Convention on the Rights of Persons with Disabilities. Both have moved away from a 'best interests' paradigm for decision-making towards a substituted judgment model, and both more clearly define what it means to have (or lack) decision-making capacity. While Queensland's existing legislation, from 2000, included 'decision-specific incapacity' and this has not changed, Victoria's new legislation narrows the scope for inappropriate guardianship appointments by also ensuring that future guardianship orders will be made only if the person lacks decision-making capacity in relation to the matter in question (among other criteria).

Victoria goes further than Queensland in the call for enhanced supported decision-making. It has enshrined supporter roles in legislation and given appointed supporters official status, powers and responsibilities. The purpose of this is to expand the range of supported decision-making options for people with disability. This law came into effect in the state on 1 March 2020.

3.1 Current practice

Current guardianship legislation provides authority for the making of two distinct sets of decisions—financial decisions, which are made by administrators or financial managers, and lifestyle decisions, which are made by guardians (for example, decisions about where a person lives and the medical treatment and services they receive).

Although the preference has always been for people close to the individual to be given decision-making authority, modern guardianship legislation also identifies independent last-resort guardians and financial managers. The last-resort guardians have been variously labelled public advocates (in Victoria, South Australia and Western Australia) and public guardians (in New South Wales, Tasmania and the Northern Territory); Queensland initially opted for ‘adult guardian’ (now known as the public guardian).

The role of public advocates and public guardians has developed differently in each state and territory, and Victoria has seen the office take responsibility for a wide variety of protective roles—among them last-resort advocacy and a range of discrete legislative roles such as receiving reports about inappropriate uses of restrictive interventions, the provision of rights-based information to people detained under ‘severe substance dependence’ legislation, and last-resort decision-making authority in relation to ‘significant [medical] treatment’ of adults who do not have the ability to make such decisions.[9]

Central to the work of OPA is the administration of four volunteer programs, currently involving about 800 volunteers, that seek to promote and protect the human rights of people with disability. Among these are the Community Visitors Program, where volunteers visit certain group homes and institutions (including mental health facilities) in which people with cognitive disability reside, and the Independent Third Person Program, where volunteers sit in on police interviews of people with apparent cognitive disability.[10]

In the meantime last-resort financial managers or administrators have been termed public trustees (state trustees in Victoria), with the role now able to be played in some jurisdictions by other trustee organisations. (Note that public trusteeship laws and practices—concerning the property of adults with cognitive impairment—long predate modern guardianship legislation).

The following example of a complex scenario that recently resulted in the removal of decision-making authority from an at-risk person is typical.

In 2017 the Victorian Civil and Administrative Tribunal appointed an administrator for a 92-year-old woman known as NYO. She had three sons, the older two of whom were estranged from the youngest. The youngest son moved in with his mother in 2014 and was caring for her; he also had access to her online banking account. Despite an enduring power of attorney, in which NYO appointed a solicitor to make her financial decisions, being executed in 2015, the tribunal member was concerned about the solicitor’s independence: the two older sons argued he was too closely connected to the youngest brother and was charging excessively for legal work. In the context of considerable family conflict, the tribunal member appointed an independent administrator to make NYO’s financial decisions.[11]

The criteria for the appointment of a guardian or financial manager under modern guardianship laws have tended to involve a three-prong test. Victoria’s previous guardianship legislation, for example, required the tribunal to be satisfied that the adult in question (1) has a disability, (2) ‘is unable by reason of the disability to make reasonable judgements’, and (3) ‘is in need of a guardian’.[12]

As noted, Victoria’s new guardianship legislation came into force in March 2020. To make a guardianship or administration order, the Victorian Civil and Administrative Tribunal now needs to be satisfied of the following:

> (a) because of the proposed represented person’s disability, the person does not have decision-making capacity in relation to—
>
> > (i) in the case of a guardianship order, the personal matter in relation to which the order is sought; or
> >
> > (ii) in the case of an administration order, the financial matter in relation to which the order is sought; and
>
> (b) the proposed represented person is in need of a guardian or administrator, as the case requires; and …
>
> (c) the guardianship order or administration order, as the case requires, will promote the proposed represented person’s personal and social wellbeing …[13]

This law includes the elements of the three-prong test but tightens the criteria for a guardianship order by ensuring that a causal connection between the person’s disability and their impaired decision-making capacity is articulated and that this impairment means the person lacks ‘decision-making capacity’ in relation to the matter the application is seeking to resolve. The expression ‘decision-making capacity’ replaces the reference to an ability to make ‘reasonable judgements’ and the Act further provides a definition of the new term.[14]

The 2019 legislation retains the ‘in need of a guardian’ clause. This last requirement might seem odd: one of the criteria used to assess whether you will have a guardian is whether you need a guardian. This was because the intention was always that the ‘informal system’ of decision-making by, with and for a person with significant cognitive impairment—which largely occurs only with the support of loving families—would be routine and would continue. Guardianship has always been meant to be used only in exceptional circumstances.[15]

Guardianship orders can be, and increasingly are, limited to a particular decision or realm of decision-making, such as accommodation, medical treatment or access to services. In some jurisdictions they can also be all-encompassing, or ‘plenary’, which is defined as being akin to a parent–child relationship.[16] In Western Australia a plenary guardian has ‘all of the functions in respect of … the represented person that are … vested in a person [who has] … parental responsibility for a child’.[17]

The number of people subject to guardianship

So how many adults in Australia are subject to guardianship orders (including orders relating to financial management)? Historically this has been a difficult question to answer: different jurisdictions used to report it in different ways.

The year 2017–18 was the first year of centralised reporting of new Australian adult guardianship orders by the Australian Guardianship and Administration Council. The figure tells us how many adults in Australia became newly subject to guardianship or financial management orders in that year. It does not tell us the number of adults who have orders that are continuing from a previous year (relevant especially to financial management orders, which often continue for three years or even indefinitely) or who have had a guardian or financial manager reappointed. The total number of adults in Australia subject to guardianship orders would therefore be higher than the new appointments alone.

Public advocates, public guardians and public trustees are routinely appointed under guardianship laws, and they report on their activity in annual reports. For example, in Victoria in the year to 30 June 2019 the Public Advocate was appointed guardian on 978 occasions.[18]

(This number includes reappointments and temporary appointments). Based on research it had commissioned from Monash University's Centre for Population and Urban Research, the VLRC reported in 2012 'that approximately two per cent of Victorians with severe or profound cognitive impairment have the Public Advocate as their guardian'.[19]

Table 3.1 shows the number of applications received by the Australian states and territories, as well as the total number of orders made (excluding reappointments), for 2018–19.

Table 3.1 Guardianship and financial management applications and orders, 2018–19

Jurisdiction	Applications made	Guardianship orders	Financial management orders	Total orders
ACT	380	186	184	**370**
NSW	6,832	2,184	2,280	**4,464**
NT	375	193	177	**370**
QLD	4,928	1,637	2,049	**3,686**
SA	1,389	1,108	926	**2,034**
TAS	779	211	308	**519**
VIC	6,637	1,639	2,543	**4,182**
WA	2,303	1,223	1,294	**2,517**
Total	**23,623**	**8,381**	**9,761**	**18,142**

Source: Australian Guardianship and Administration Council, Australian Adult Guardianship Orders 2018/19 (2020) https://www.agac.org.au/agac-publications

The data in Table 3.1 were published for the first time in 2019, data collection being coordinated by OPA.[20] Tribunals are the only place where all this information can be captured. Until now, publicly available tribunal statistics on the topic dealt with applications rather than orders.

Despite this substantial improvement in access to Australia-wide guardianship data, some tribunals routinely make use of self-executing orders,[21] while other orders are longer lasting (even occasionally indefinite), which makes it very difficult to know how many guardianship orders are current at any particular time.

Demographics of guardianship

The Cocks Committee's envisaging of how the guardianship system would operate was in many ways accurate. One area, though, in which it failed to anticipate what would happen in the long run relates to the typical guardianship client.

The brief for the committee had been to generate legislative proposals concerning 'the protection of intellectually handicapped persons … and the preservation of their rights', reflecting the era's dominant interest in deinstitutionalisation. Unsurprisingly, most of the scenarios the committee envisaged where guardianship would be of benefit concerned people with intellectual disability.[22]

Guardianship clients in Victoria have, however, come to be predominantly older people, particularly people with age-related dementia. Interestingly, Tasmania appears to be the only other Australian jurisdiction similarly dominated by older guardianship clients. The other jurisdictions for which data are available appear to have proportionally fewer older public guardianship clients, although people aged more than 65 years constitute a large minority. (It is of note that the introduction of the NDIS has changed the trend somewhat, there being uncharacteristic growth in the proportion of people with intellectual disability coming under guardianship, as touched on in Chapter 2).

In 2018–19 in Victoria 50 per cent of new guardianship matters concerned people aged 65 or more.[23] In 2015–16 the biggest disability category, involving more than 40 per cent of guardianship clients, was people with dementia. The next largest category (and many people have dual disabilities) was people with intellectual disability (37 per cent); this was followed by mental illness (33 per cent) and acquired brain injury (20 per cent).[24]

Other states that report the age of public guardianship clients are Western Australia (39 per cent over 65 years old[25]) and South Australia (34 per cent over 65 years[26]). These figures represent all clients for the year in question, not the proportion of older clients who became subject to new orders in that year. Since guardianship matters involving older people are more likely to be closed in a particular year compared with those for younger people, the proportion of people over 65 who are newly subject to guardianship orders would probably be a little higher than these overall figures reveal. Indeed, Western Australia noted that in 2017–18 a primary diagnosis of intellectual disability had overtaken dementia as the most commonly reported disability in successful guardianship applications for the first time in 11 years.[27]

The NSW Civil and Administrative Tribunal's Guardianship Division reported that over 56 per cent of subjects of guardianship list applications in the year to June 2018 were aged 65 years or more.[28] This includes applications for financial management. Of the people who became subject to guardianship under the NSW Public Guardian in 2017–18, however, the number of people with a primary diagnosis of intellectual disability was twice as large as the number of people with dementia, suggesting that these high rates of application for people over 65 did not necessarily translate into guardianship orders. Similarly, Queensland's Public Guardian reported dementia as the third highest primary disability type, at about 20 per cent of clients.[29]

So, although people aged over 65 years with dementia or some other newly acquired disability do not account for the majority of guardianship clients in most Australian jurisdictions, they account for somewhere between one in five and one in two such clients. At the very least, they represent a sizeable minority of Australians under guardianship.

Among other things, the disability profile of guardianship clients has major implications for advance planning, with so many of these clients being people who have had, at some stage in their adult life, the ability to make known their wishes for future care decisions (as discussed in detail in Chapter 6).

3.2 Critiques of guardianship

There are many critiques of modern guardianship laws and practices, and they have been considered in detail in the reviews of guardianship laws that have been conducted in the past decade in Queensland, Victoria, the ACT and New South Wales, in addition to the ALRC's important review of relevant Commonwealth laws in 2014.[30]

Among the continuing criticisms of guardianship laws and practices is the fact that people who are the subject of guardianship applications are typically quite marginal to—and often do not appear at—the tribunal hearings relating to them.[31] Another criticism is that guardianship orders are often more restrictive than they need to be.[32] Yet another one concerns the argument that guardianship and financial management powers should be merged into a single order. Although individuals, often family members, can and are appointed to both roles—guardian and financial manager—the tradition in Australia has been to keep the roles separate.[33]

The remainder of this section deals with the primary criticisms that have been levelled at current guardianship laws and practices in Australia.

Human rights

Chapter 1 refers to the human rights–based critiques of substitute decision-making regimes such as guardianship systems. Although those critiques draw heavily on the appalling uses to which guardianship has been put in some parts of the world, notably Eastern Europe, they remain relevant to and have implications for Australia.

There has been debate about the human rights compliance of guardianship systems since the systems' modern incarnation. Back in 1982 the Cocks Committee pointed to emerging human rights awareness in relation to people with disability as one of the reasons for the committee's formation, and it was acutely aware of the danger that guardianship legislation might 'be used to restrict as well as to protect an individual' and that 'inappropriate guardianship can lead to a denial of civil liberties'.[34]

Debate continues about whether guardianship can ever be consistent with international human rights instruments such as the Convention on the Rights of Persons with Disabilities. Chapter 1 here notes the position taken in 2014 by that convention's treaty-monitoring committee, the Committee on the Rights of Persons with Disabilities, that substitute decision-making mechanisms, including guardianship, are inconsistent with the convention.

In response to such a view, however, one might ask what should happen, for instance, in a situation such as that of Maria Korp, who was unable to make a decision about her own medical treatment and where no other appropriate decision-makers were around her. Should the decision about treatment simply be left to doctors?

Even the strongest advocates of alternatives to guardianship struggle with this. One proposal put by Bach and Kerzner is for a kind of 'facilitated decision-making' to occur, whereby the person concerned or a tribunal would enable another individual to act in a way that the person concerned would probably have acted.[35] In practice, this is akin to a limited guardianship order. (See the discussion in Chapter 1).

Leaving the most complex circumstances aside, it is important, however, to note the positive impact human rights developments have had on guardianship practice, even when legislative reform is yet to occur. In Australian jurisdictions with bills or charters of rights, the practice of public guardianship is often acutely rights-conscious.[36] In other jurisdictions, public guardianship is at least practised within a well-understood rights environment. An example arises in the case of the Australian Guardianship and Administration Council, which in 2016 revised its National Standards of Public Guardianship: human rights developments were the primary reason for this revision.[37]

Human rights–related critiques of guardianship have been a central feature of the reviews of guardianship and related topics by state and federal law reform commissions in the past decade in Australia.

In 2010 the Queensland Law Reform Commission made repeated mention of the Convention on the Rights of Persons with Disabilities and recommended major changes to that state's guardianship laws—including reformulation of the legislation's general principles 'to reflect more closely the relevant articles' of the convention.[38]

In 2012 the VLRC drew heavily on the convention in its guardianship reform recommendations, noting that it 'represents an important step beyond providing protection for people with disabilities to taking positive steps to maximise their participation in all aspects of life'.[39] Some of these recommendations have been incorporated in Victoria's new Act.

Similarly, the 2016 review of the ACT's guardianship legislation made frequent reference to the convention's impact.[40]

Human rights developments—in particular that convention—were of course an important feature of the ALRC's 2014 report entitled *Equality, Capacity and Disability in Commonwealth Laws*. As discussed in Chapter 1, in that report the ALRC proposed a new approach to decision-making by and for adults who themselves are unable to make decisions without support. It suggested the adoption of new 'national decision-making principles' that would promote supported decision-making. At the same time, though, it did acknowledge that 'some system of appointment of others to act is a necessary human rights backstop'.[41]

From all these debates there emerged three key human rights–related reform imperatives in connection with guardianship; they concern supported decision-making alternatives, more limited use of guardianship, and substituted judgment.

Supported decision-making alternatives

As discussed in Chapter 1, an increasingly common feature of reviews of guardianship and related laws is the inclusion of recommendations relating to the promotion of supported decision-making.

Chapter 1 looks at the various recommendations and initiatives that have promoted the ability of individuals to appoint their own supporters. Here we mention some supported decision-making proposals directly related to guardianship that have been made.

In 2012 the VLRC proposed a new framework for the appointment by individuals of a 'supporter' who would have powers to obtain and communicate information but would not be the ultimate decision-maker. It also recommended that the guardianship tribunal, the Victorian Civil and Administrative Tribunal, be able to appoint supporters with the same powers. This option would tend to be used in the context of a guardianship application where the tribunal might consider such an appointment preferable to a guardianship appointment. Drawing on

Canadian examples, the commission also proposed that the tribunal be able to appoint ‘a co-decision-maker’, again where this might be preferable to a guardianship appointment.[42]

In 2014 Victoria enacted the Powers of Attorney Act, under which a personally appointed ‘supportive attorney’ is able to obtain and communicate information but is not responsible for making decisions. New guardianship legislation was also introduced into the Victorian Parliament in 2014 but lapsed before a state election; the legislation contained measures whereby the tribunal could appoint a ‘supportive guardian’ for a person and the guardian would have the powers possessed by ‘supportive attorneys’.[43] In 2018 new guardianship legislation was introduced, only to lapse again before an election. The legislation, in revised form, passed on its third presentation to the Victorian Parliament, in 2019. Since 1 March 2020 the Victorian Civil and Administrative Tribunal has been able to appoint a supportive guardian and/or a supportive administrator.[44] These appointment options will most probably be used in the context of a guardianship hearing, when a tribunal member might decide the appointment of a ‘supportive guardian’ would be a suitable protective mechanism that would obviate the need for a more restrictive guardianship order. (This is because the standard ‘lack of decision-making capacity’ criteria would not be met: the tribunal-appointed supportive guardian provides practicable support to the person to assist with their decision-making capacity in the matter at hand).

As noted, in 2014 the ALRC called for the adoption of new ‘national decision-making principles’ that would promote supported decision-making. It also called for state and territory governments to review their ‘individual decision-making’ laws, including guardianship laws.[45]

Victoria has partially met the ALRC challenge, but it remains to be seen how other states and territories will respond to this proposal.[46] Queensland passed the Guardianship and Administration and Other Legislation Amendment Act in March 2019, introducing new general principles that explicitly recognise and seek to enhance the human rights and dignity of people subject to guardianship.[47] The principles do not, however, enshrine supported decision-making options. The NSW Law Reform Commission’s review of guardianship laws resulted in a number of recommendations aimed at promoting access to supported decision-making, including enshrining both personal and tribunal-appointed supporter roles in law.[48] With the exception of Victoria, however, no jurisdictions have yet engaged in legislative reform for formalising supported decision-making.

More limited use of guardianship

The second human rights imperative in the reform of guardianship laws is to limit appointments to situations of absolute necessity. In 1982 the Cocks Committee was alert to this danger, noting ‘that persons who are incapable of exercising some functions may be capable of exercising other functions’.[49]

People with disability have rightly raised objections to the fact that the mere existence of a disability, including a physical disability, satisfies the first of the three standard criteria for the appointment of a guardian. A simple reform here would be to narrow the appointment criteria.

The VLRC proposed new guardianship criteria along these lines. Its recommendations were that a substitute decision-maker be appointed only if the individual concerned ‘has decision-making incapacity caused by that person’s disability’ and ‘has decision-making incapacity in relation to the matters for which the appointment is sought’.[50] The state’s new guardianship laws incorporate these narrowed criteria.[51]

The commission also put forward the widely used four-prong test of capacity, proposing that 'a person is unable to make a decision' if they cannot:

- understand the relevant information
- 'retain that information'
- 'use or weigh that information as part of the process of making the decision'
- 'communicate the decision in some way'.[52]

This standard test, which has long existed in the UK Mental Capacity Act,[53] now appears in various formulations in Australia—for example, in Victoria's new guardianship legislation[54] and current powers of attorney and medical treatment legislation[55] and in the Northern Territory's guardianship legislation.[56] The test focuses attention on a person's ability to go through the process by which decisions are assumed to be reached,[57] rather than focusing on the actual outcomes of that process (the decisions that are made). A more outcomes-focused criterion would be more problematic in human rights terms because it would require qualitative assessments of the relative merit of a person's decisions (that is, how 'good' or 'bad' they are). This distinction, between process and outcomes, is quite important if guardianship legislation is to maintain a central philosophical element of modern liberal democracies—the freedom of adult citizens to make bad decisions (so long as they don't harm others).

A curious rider in the case of Victoria's powers of attorney legislation, which blurs the distinction between process and outcomes, is the provision that says the making of 'a decision that has a high risk of being seriously injurious to the person's health or wellbeing' could 'be evidence that the person is unable to understand, use or weigh information relevant to the decision'.[58]

Adoption of narrower capacity criteria is obviously one way to limit the use of guardianship. Another way to do this would be to enable tribunals to make an array of protective orders far broader than the appointment of a guardian. Deputy Public Advocate John Chesterman examined the adult protection systems in operation in Washington State, Nova Scotia, and Scotland and England in 2013. In his resultant report he argued that the power to make additional types of orders, as seen in some of those jurisdictions, could usefully be held by Australia's guardianship tribunals. This included:

- entry and assessment orders
- removal orders
- service provision orders
- exclusion or banning orders.[59]

This topic is discussed further at the end of this chapter and at the end of the report.

Substituted judgment

Moves towards a new paradigm

The third human rights imperative concerns the basis on which any substitute decision-making is done. Until 2020 in Australia all substitute decision-making under guardianship legislation occurred using a 'best interests' model (either explicitly using that phrase or with an intent that decisions be made consistent with the person in question's 'proper care and protection'). Use of that model means that the substitute decision-maker makes decisions they believe are best for the person. In Australia guardians are usually also directed to consider the views and preferences of the person, but in practice these views and preferences are secondary to ensuring a best-interest outcome.

An example of how this tension plays out is evident in previous Victorian legislation. Until 1 March 2020 guardians in Victoria were required to 'act in the best interests' of the person. Although the legislation required guardians to take 'into account, as far as possible, the wishes' of the person, the primary determinant of the guardian's decisions was their conceptualisation of what was good for the person.[60]

As alluded to, however, efforts to move away from the best-interests model of guardianship began with the enactment of two new pieces of guardianship legislation in 2019, in Victoria and Queensland. The aim of the reforms was to increase the alignment of guardianship legislation with Article 12(4) of the UN Convention on the Rights of Persons with Disabilities.[61] The amendments are designed to place the 'will, values and preferences' of the person above all in matters where a substitute decision on their behalf is required. Both Acts avoid the term 'best interests' completely and provide decision-making principles to guide the practice of guardians and others (including informal decision-makers).[62] For example, Victoria's new Act states:

> (1) A person making a decision for a represented person must have regard to the following principles—
>
> (a) the person should give all practicable and appropriate effect to the represented person's will and preferences, if known;
>
> (b) if the person is not able to determine the represented person's will and preferences, the person should give effect as far as practicable in the circumstances to what the person believes the represented person's will and preferences are likely to be, based on all the information available, including information obtained by consulting the represented person's relatives, close friends and carers;
>
> (c) if the person is not able to determine the represented person's likely will and preferences, the person should act in a manner which promotes the represented person's personal and social wellbeing;
>
> (d) if the represented person has a companion animal, the person should act in a manner that recognises the importance of the companion animal to the represented person and any benefits the represented person obtains from the companion animal;
>
> (e) the represented person's will and preferences should only be overridden if it is necessary to do so to prevent serious harm to the represented person.

The focus on the person's 'will and preferences' (or 'views, wishes and preferences' in Queensland), where they are known or can be determined with some confidence, should more effectively promote the autonomy of the person under guardianship.

Where the person's will and preferences cannot be determined in the matter at hand, substitute decision-makers are left to a best-interests-like framework—in Victoria to 'promote the … person's personal and social wellbeing' and in Queensland in a way that 'promotes and safeguards the adult's rights, interests and opportunities' in the least restrictive manner.[63]

Victoria's substitute decision-makers should override a person's known or likely will and preferences only 'if it is necessary to do so to prevent serious harm to the represented person'; in contrast, Queensland's guardians must make decisions that promote and safeguard the adult's rights, interests and opportunities on each occasion.[64] The role of the person's views, wishes and preferences in the guardian's understanding of the person's rights, interests and opportunities will determine how far the regime coming to Queensland will truly move away from a best-interests paradigm.

Although both states have taken steps to distance themselves from a best-interests decision-making approach, Victoria's new legislation appears to have made greater progress towards upholding the person's autonomy and ensuring that decisions are made using a 'will and preferences approach' (where their preferences can be ascertained and where serious harm to the person would not ensue). OPA notes that Victoria's new Act also requires that a guardian 'must act in such a way so to protect the represented person from neglect, abuse or exploitation'[65]: the interplay of this section with assigning priority to the represented person's will and preferences has not yet been tested.

A primary focus on the represented person's will and preferences is often referred to as a 'substituted judgment' model of substitute decision-making. Put simply, this occurs when the substitute decision-maker makes the decision they believe the represented person would have made had they been able to do so.

These two new legislative regimes came into, or come into force in 2020—in Victoria on 1 March and in Queensland on 30 November.

Ultimately, the extent to which these new regimes and future amendments to the legislation operating in the rest of Australia are able to achieve a 'will and preferences approach' and move away from best interests will lie in the interpretation of these new laws by tribunals and guardians. For example, how can 'promoting and safeguarding the adult's rights, interests and opportunities' be practically distinguished from promoting their 'best interests'? Alternatively, what constitutes 'serious harm'?

The precedents

In both Victoria and Queensland the changes just discussed were preceded by state law reform commission reports. In its 2010 report on guardianship the Queensland Law Reform Commission proposed a move away from a best-interests model, recommending that substitute decision-making be required to be done 'in a way that promotes and safeguards the adult's rights, interests and opportunities' and 'in the way least restrictive of the adult's rights, interests and opportunities'.[66] In contrast, in 2012 the VLRC recommended the adoption of new 'decision-making principles' under which substitute decision-makers would 'have paramount regard to making the judgments and decisions that the person would make themselves after due consideration if able to do so'.[67]

At the national level, in 2014 the ALRC considered the implications of the Convention on the Rights of Persons with Disabilities for substitute decision-making and outlined its argument that the convention ‘was principally condemning a best interests approach, not a will and preferences approach’.[68] Its concern was to call for, and signal, a changed basis on which decision-makers should act. Rather than making decisions according to what might be in the ‘best interests’ of the person, the commission proposed that decisions be made according to the ‘will, preferences and rights’ of the person, which is a different ordering of the phrase ‘rights, will and preferences’ that exists in Article 12(4) of the convention.[69]

How substituted judgments can differ from best-interests decisions

We return for a moment to the situation involving Maria Korp.

One of the arguments put before the tribunal in the guardianship application concerning Ms Korp was that the public advocate ought not be given power to make her medical treatment decisions because Ms Korp was a devout Roman Catholic, who, in making any medical treatment decision for herself, would probably make a decision that prolonged rather than ended her life. The tribunal rejected that argument on the basis that it was unclear how her religious faith would affect the particular decisions she faced. In the end, the decision to withdraw treatment was relatively uncontroversial. Ms Korp’s condition involved not only severe brain damage but also other catastrophic injuries that led, among other things, to her even vomiting up food that was provided through a tube to her stomach. Clinicians agreed that she was dying, so the decision to withdraw treatment from her differed from a decision to withdraw treatment from a person in a stable but persistently non-responsive state (as pertained in the high-profile case of Terri Schiavo in the United States).[70] Had that been the case—that Ms Korp was stable but non-responsive—the ‘best interest’ guardianship decision of the time might have differed from what Ms Korp might herself have wanted and could have resulted in a different decision under today’s law.

The following example is a modification of an actual guardianship case.

A 90-year-old woman, Elise, is in hospital and is unable to eat or drink. A decision must be made about whether she should have a PEG (percutaneous endoscopic gastrostomy) tube inserted, which is the only way to keep her alive. Elise has experienced considerable cognitive decline and does not appear to understand the proposed procedure; nor is she able to express a view about it. She used to be a member of a Christian community whose leaders advocate prolonging life in situations such as this, but she withdrew from active involvement in the church decades ago. Elise’s daughter, who lives with her, remains active in the church and is adamant that the PEG tube should be inserted. Many years earlier Elise had appointed her daughter to make medical decisions for her under an enduring power of attorney, but her daughter, who experiences significant mental ill-health, was removed from this role by the guardianship tribunal.

Elise’s guardian, an employee of OPA, must decide what should happen. Many people would be reluctant to agree to inserting a PEG tube in a 90-year-old, but Elise’s former religious views would suggest that this is the decision she herself would once have made. Does her withdrawal from active religious observance signify a change in her views about medical treatment and the prolonging of life? Is it relevant that she once appointed her daughter to make decisions about medical treatment and never took steps to revoke this appointment, even though she knew her daughter supported her (Elise’s) former church’s stance on medical treatment decisions?

This is one situation where a ‘values and preferences’ frame of thinking might well result in an outcome different from that achieved through a best-interests framework.

The substituted judgment framework that is already used in decisions about medical treatment

In 2016 new medical treatment legislation in Victoria was passed. It requires that a relevant decision-maker (where an adult patient does not have the capacity to make a decision) assign priority to the patient’s ‘values and preferences’ (which can be contained in a written directive) when making a treatment decision. When this cannot be done, the decision-maker must make a decision that ‘promotes the personal and social wellbeing of the person’.[71]

There are minor changes in this judgment formulation compared with that proposed by the ALRC. The term ‘will’ is not used and, in the absence of knowledge of what the person would themselves probably have decided, the Victorian rendition requires that a substitute decision-maker make a decision that ‘promotes the personal and social wellbeing’ of the individual, rather than being required to make a decision that is consistent with the person’s ‘rights’ (as the ALRC had recommended).

But the important thing to note here is the move towards giving priority to what the person in question would have done, as opposed to someone else’s conceptualisation of their ‘best interests’.

As a way of signalling this paradigm change, the ALRC proposed using the term ‘representatives’ for all substitute decision-makers. Another option would be the term ‘deputy’, which is used in the United Kingdom for court-appointed substitute decision-makers.[72]

As noted, Victoria’s new guardianship laws, operational from March 2020, require substituted judgment except where ‘serious harm’ would result from following the person’s wishes. It remains to be seen how this provision will be interpreted by guardians and administrators.

Notwithstanding this, as pointed out at the end of this chapter, the momentum for a substituted judgment approach is now irresistible.

Access to appropriate services

Guardianship is often resorted to as a result of one or more failures of the service system to respond to the needs of an at-risk adult.[73] A good example of this would be a situation of elder abuse, where a person with cognitive decline is the subject of a theft from their bank account by a family member. Current policies are inadequate in this regard, and an important response can be to remove the victim’s authority to make financial decisions.[74] An alternative to guardianship would, however, be a more effective elder abuse response. This is discussed in Chapter 6.

Chapter 2 examines the implications for guardianship (and other adult protective mechanisms) of new policy approaches to the delivery of social services. It focuses on ‘consumer choice’, the service principle embedded in the NDIS and in recent aged-care service reforms. It is noted that the ideology of consumer choice results in the need for more decisions about service delivery to be made by users of services, including those with cognitive disability. Consumers’ inability to make such decisions, partly because of a lack of supports, has resulted in increased use of substitute decision-making appointments such as guardianship in a number of jurisdictions.[75]

Some jurisdictions, such as Queensland, Victoria and Western Australia, have experienced increased demand for public guardianship services resulting from decision-making needs related to the NDIS. Any impacts stemming from aged-care reforms have not been documented. It is worth nothing, however, that it would be inconsistent with modern human rights developments if guardianship came to be used routinely and instrumentally merely so that individuals could obtain the services they need.

Exclusion of informal carers

Another major criticism of current guardianship legislation comes from carers, typically parents of adult children with significant cognitive disability who feel excluded from the guardianship system.

The Cocks Committee did not consider that parents who were carers of children with cognitive impairment would need to routinely apply for guardianship when their children reached 18 years. The report noted:

> Though parents are not the legal guardians of their adult ‘children’, it is standard practice to seek their consent in relation to personal life matters … Their consent is an informal one, but it is functionally adequate. In the great majority of cases, this authority would not be challenged and an application for guardianship would serve no real purpose.[76]

In fairness to the committee, the intention was not to downplay the role of parents: it was simply to argue that the guardianship system was being designed to cater for unusual situations. The committee’s expectation, which has been largely the practice of guardianship tribunals, was that there is no ‘need’ for a guardian if a family is uncontentiously involved in the life of their adult child.

But parents have felt undervalued, there being no official status or authority attached to the active role they play in their adult child’s life aside from ‘parent’. This concern has grown as the disability service system has, like all other social welfare policy arenas, undergone significant change.

For a start, provision of social services has become increasingly formalised and risk averse. Now, more than ever, authority is sought from a person or their representative before a service is delivered.

Provision of disability services has also become increasingly fragmented under the consumer choice philosophy (discussed in Chapter 2), with different service providers offering different services to the same person. This change, exemplified in the NDIS, leads to more service providers with whom to negotiate and more decisions about everything, including the provision of private information.

Exacerbating the situation is the contemporaneous rise of privacy laws that restrict the flow of personal and health information to people authorised to receive it. Without criticising these laws, it can be said that a poor understanding of legal requirements here has led ‘privacy’ to become a much used reason for not providing information, even when it would actually be perfectly legal to do so.

In this changing environment it is unsurprising that people advocating for their loved ones should seek the most formal legal status possible.

All of this has had implications for the people providing the great majority of support to adults with disability—their families.

OPA is well aware of the experiences of parents of adult children with profound disability; these parents often encounter difficulties negotiating with the providers of services for their adult children. In some instances this has led parents to seek guardianship orders on the basis that the status of guardian would give them greater authority.

OPA advises parents in this situation that in all likelihood they will be appointed guardian only if there is a pressing need for a guardianship-type decision to be made. We also advise them that the status of guardian does not necessarily bring with it the powers people imagine it does. Under the statutory framework in operation in most jurisdictions, parents will often be the automatic decision-maker in relation to medical treatment for adults with significant cognitive disability, so they are entitled to be offered information relevant to this role. But other expected 'powers', such as ensuring that services regularly liaise closely with them, do not come within the powers of guardians—especially not guardians with limited authority to make particular decisions.

The response of parents has tended to be that service providers do not necessarily know the limit of guardians' authority and that the status of being a 'guardian' does give the person greater advocacy power. This has led to calls for reform to make it easier to appoint parents as guardians.

Reforming bodies have listened. For example, in its 2012 report on guardianship the VLRC recommended that the guardianship criterion of 'need' be defined to include situations where decisions have for a long time been made for people whose 'decision-making ability is so significantly impaired or enduring that they are unlikely at any time in the future to be able to make their own decisions, even with significant support'.[77] In short, this would mean that parents of adults with significant cognitive impairment would be able to be appointed as their child's guardian without any guardianship decision being needed.

Similarly, in 2014 the Victorian Government sponsored guardianship legislation whereby parents would have been able to be appointed guardian for their child from the age of 18 years if specific conditions were met. Principally, these were that the adult child had a disability that prevented them from being able to appoint a supportive attorney or complete an enduring power of attorney, that this situation was unlikely to change, and that this applied only where the relevant disability had manifested itself before the age of 18 years.[78] That Bill lapsed at the end of 2014, and similar provisions were not included in the 2019 Bill, which passed into law.

There are two primary criticisms of this reform platform. First, if there is a current need for a guardian to be appointed, parents can be appointed and, indeed, in the absence of conflict between them, will usually be the first ones chosen. Second, if parents were to be appointed in the absence of current need, this would clearly be contrary to the trajectory of modern human rights developments. Moreover, taking this step simply in order to increase a parent's advocacy power, which itself results from a misunderstanding of the power of guardians, seems a poor basis for such a policy change.[79]

Nevertheless, some reform is required to elevate the status of parents of adults with long-term cognitive disability; their claims about ostracism from the disability support system have merit.

3.3 An ‘investigation gap’

While the question of investigations is not directly connected to guardianship laws and practice, it is worth considering the benefits to the Australian adult protection system of deploying the specific skills of public guardianship bodies to enhance the protections available to at-risk adults experiencing abuse, neglect or exploitation.

One of the current limitations of the adult protection system in Australia is highlighted if one asks who has responsibility for investigating situations where the wellbeing of an adult is in jeopardy but there is no immediate medical emergency and it is not obvious that a crime has been committed. The answer tends to vary according to the jurisdiction (or even the local government area) in which the person lives, their age and the nature of their vulnerability. The aged-care assessment service might have a role. Police could be asked to conduct a welfare check. If a person’s vulnerability relates to their mental health or their homelessness, or both, a particular service might be asked to attend. If the person is in receipt of a disability service or is under a guardianship order, state or territory authorities (such as the Disability Services Commissioner and the Public Advocate in Victoria) might have a role.

In 2013 Victorian Deputy Public Advocate John Chesterman examined this subject in some detail in Washington State, Nova Scotia, Scotland and England. He found that, although none of these jurisdictions had better adult protection services than Australia, there is an ‘investigation gap’ in relation to the wellbeing of at-risk adults when there is no obvious medical emergency or crime.[80] In Australian jurisdictions no agencies had broad responsibility, and the necessary powers and resources, for investigating the wellbeing of at-risk adults in anything other than emergency situations.

Guardianship legislation does give public advocates and public guardians the power to conduct investigations following referrals from the general community. In Victoria this power is limited to the investigation of ‘any complaint or allegation that a person is under inappropriate guardianship or is being exploited or abused or in need of guardianship’, which the VLRC noted is ‘limited in [its] application to circumstances where a guardianship or administration order might be appropriate’.[81] This situation remains unchanged under the new Act.

In Western Australia a similar power is used more often than in Victoria in relation to ‘community-referred’ concerns, but the public advocate cannot demand information. Queensland’s guardianship legislation does enable the public guardian to conduct investigations concerning adults ‘with impaired capacity for a matter’ if there has been a ‘complaint or allegation’ that the person ‘is being or has been neglected, exploited or abused’ or ‘has inappropriate or inadequate decision-making arrangements’.[82]

In 2012 the VLRC called for the public advocate to be given power to investigate, via complaints or on the public advocate’s own motion, ‘the abuse, neglect or exploitation of people with impaired decision-making ability due to a disability’, something that OPA had sought.[83] In 2016 the New South Wales parliamentary committee inquiry into elder abuse made a similar recommendation—namely, that a public advocate’s office be established in that state with the power to conduct investigations, via complaints or on its own motion, into the ‘abuse, neglect and exploitation of vulnerable adults’.[84]

One of the main reasons public advocates and public guardians are best placed of all existing agencies to carry out investigations into at-risk adults lies in their ability to make immediate referrals to service providers and support agencies. Other agencies that have expertise in conducting investigations, such as Ombudsman offices, are not well placed to take up this kind of ‘supportive intervention’ approach. The primary aim of investigations here is the wellbeing of the at-risk person. If evidence of a crime exists, referrals to police need to follow, and the primary challenge of implementation lies in the ability to secure seamless referrals.[85]

One of the most striking elements of the Scottish adult protection system, as Chesterman noted, was the role of adult protection committees. These 29 committees, organised at the local community level, regularly see a range of government and local support agencies discussing the wellbeing of individual community members.[86] Although it would be difficult to replicate this practice in a federation such as Australia, the idea and possibility of close interagency collaboration should be central to any adult protection system and would need to be a feature of any reform aimed at redressing the current investigation gap.

In 2016 the ALRC examined current investigation powers and practices in the context of its inquiry into ‘protecting the rights of older Australians from abuse’. That work is discussed in Chapter 1, but here we look at the central element of possible safeguarding legislation, responsibility for which will fall to state and territory legislatures. Whether broad safeguarding laws need to be enacted or guardianship laws merely need to be amended will be a matter for each state and territory. What will be important, though, is the empowering of the proposed ‘adult safeguarding agencies’[87]—which could be public advocates and public guardians—to investigate situations of concern.

The ALRC agreed that an investigation gap exists and in its 2016 discussion paper on elder abuse saw the remedy lying in expanding the investigation powers of public advocates and public guardians.[88] As noted in Chapter 1, in its final report the ALRC proposed that the states and territories enact ‘adult safeguarding laws’ and establish ‘adult safeguarding agencies’. These agencies would be empowered to conduct investigations into the situation of ‘at-risk adults’. They could be new agencies or existing ones, the Commission noting:

> Existing public advocates and public guardians have expertise in responding to abuse, and may be appropriate for this broader safeguarding function, if given additional funding and training. However, some states or territories may prefer to give this role to another existing body or to create a new statutory body.[89]

So who would be included in the proposed category of ‘at-risk adults’? Unlike other law reform commission inquiries into guardianship laws, held in Queensland, Victoria and New South Wales, the ALRC inquiry was not primarily concerned with disability. And its recommendations in that regard were aimed at expanding the investigatory functions beyond people with ‘impaired decision-making ability’ (to use the VLRC’s phrase). Instead, the ALRC called for ‘adult safeguarding agencies’ to be empowered to investigate the situation of ‘at-risk adults’, a group of people defined by the fact that they:

> (a) have care and support needs;
> (b) are being abused or neglected, or are at risk of abuse or neglect; and
> (c) are unable to protect themselves from abuse or neglect because of their care and support needs.[90]

The focus is thus on the needs of the person and their inability to act to protect themselves. This does generate some concerns about public advocates and public guardians extending their roles beyond the traditional disability sectors, which would require the approval of state and territory governments and parliaments. Avoidance of the use of terms such as ‘disability’ in the proposed definition is a positive development, although the replacement terminology uses language that is potentially very broad. Could, for instance, very minor ‘care and support needs’ bring a person within the definition? Would this include someone who has their house vacuumed once a week? Moreover, the definition’s requirement of a causal relationship between such needs and a person’s inability to ‘protect themselves’ might prove problematic. In addition to carrying an unintended message that the inability of the person to protect themselves is the problem (as opposed to the wrongdoing that might be investigated), the question of how the nexus might be demonstrated also arises.

The ALRC recommended that, before the proposed ‘adult safeguarding agencies’ could exercise coercive powers, the consent of the person would be required. This requirement could be dispensed with in several circumstances:

> (a) in serious cases of physical abuse, sexual abuse, or neglect; or
>
> (b) if the safeguarding agency cannot contact the adult, despite extensive efforts to do so; or
>
> (c) if the adult lacks the legal capacity to give consent, in the circumstances.[91]

Rather than adopting the ALRC’s proposal in this regard, at the end of this chapter a slight narrowing of the idea is proposed in order for the expanded role to fit squarely within the intended and clear role of public advocates and public guardians. This approach endorses, with minor alteration, the VLRC’s recommendation. It would see these agencies empowered ‘to investigate, via complaints or on their own motion, the abuse, neglect and exploitation of adults with apparent impaired decision-making ability, where this impaired ability is likely to be more than temporary’.

Indeed, Queensland’s public guardian has broader powers of investigation than similar bodies in other jurisdictions. These powers relate to investigating the circumstances of adults with ‘impaired capacity for a matter’ in relation to the actions of their attorneys, guardians and administrators (and others).[92] The Queensland legislation also avoids use of the word ‘disability’ in relation to adults with impaired capacity.

One of the ALRC’s concerns about such a measure—especially when it comes to responding to elder abuse—is that it would mean the situations of older people without impaired decision-making ability would not be able to be investigated by the safeguarding agency. OPA contends that this is a suitable demarcation point that goes to the core role to be played by safeguarding agencies.

Although victims of elder abuse who are not cognitively impaired are also in need of an improved police response and greater availability and accessibility of advice and support services, the central role of adult safeguarding agencies ought not to be akin to shadow police services: rather, it should be as providers of supportive interventions. The agencies would be responsible for making referrals to police where evidence of crimes exist, but their primary operating orientation should be to do with helping people to make decisions about, and to obtain, the services to which they are entitled. That is a specific set of skills that would be lost were the agencies to be available to all victims of elder abuse.

Principal among the elder abuse reforms must be the placement of victims at the centre of response strategies. Federal, state and territory service response plans must ensure that this occurs, while adult safeguarding agencies could have the particular responsibility of supporting victims with cognitive impairment in exercising their rights to obtain services and to have their wishes and preferences expressed and observed.

South Australia is the first Australian jurisdiction to engage in legislative reform to redress this gap: the Office for the Ageing (Adult Safeguarding) Amendment Bill passed into law in November 2018. The Adult Safeguarding Unit began operations in October 2019, under the amended *Ageing and Adult Safeguarding Act 1995*. After three years of operation, the mandate of the unit will broaden from responding to instances of elder abuse perpetrated against older South Australians to responding to such instances among all adults who might be vulnerable to abuse.[93]

New South Wales has also responded, creating the role of Ageing and Disability Commissioner. With astounding speed, the Ageing and Disability Commissioner Bill 2019 was introduced to parliament in May 2019 and the first Commissioner, Robert Fitzgerald, was appointed on 29 June 2019 and began in his new role on 1 July 2019.[94] The commissioner has strong powers to allow him to fully ‘investigate allegations of abuse, neglect and exploitation of adults with disability and older people in home and community settings’.[95]

As Victoria’s Deputy Public Advocate notes in his article entitled ‘The Future of Adult Safeguarding’, ‘The capacity of investigating agencies to co-ordinate multi-agency responses to situations of concern … [will be] crucial to [their] … effective operation’.[96]

South Australia also amended its laws relating to ‘criminal neglect’ to strengthen their ability to be used to prosecute child abuse and to increase the maximum penalty that could be applied to 15 years (unless the victim died, when the maximum penalty is life imprisonment).[97] The amendment also clearly defined ‘vulnerable adult’ for the first time and inserted that term (replacing ‘disabled person’) in an existing offence provision in relation to failing to provide food, clothes and accommodation.[98] This approach aligns with the ALRC’s position that new ‘elder abuse’–specific offences are unnecessary,[99] but it demonstrates that in some jurisdictions criminal laws can nevertheless be recrafted to better protect vulnerable adults.

3.4 Future reform

This section discusses the main reforms that are warranted if the laws and practices that currently affect the way guardianship is used as an adult protection device are to be more effective.

Before detailing our recommendations for reform we briefly note OPA’s position that broad new ‘adult protection’ legislation would not be worthwhile. It would bring little benefit that could not be brought by other legislative initiatives and runs the risk of being too protectively defined and implemented. It might also inadvertently stifle the broad human rights–informed move to promote more active roles on the part of people in making decisions that affect them.

Service provision

It goes without saying that good, coordinated service provision organised around the needs of the person in question offers the best way of avoiding the use of guardianship. The modern social services sector is increasingly adopting a marketised consumer choice model of delivery, which is especially prominent in aged-care and disability service provision. This can, and does, lead to service fragmentation—many different providers assisting a single person—and generates an ever greater need for service coordination. This in turn can lead to more decisions needing to be made, and the challenge (as discussed in Chapter 2) is to ensure this transformation effectively serves the most vulnerable members of society without routine recourse to more heavy handed state interventions such as the use of guardianship. What are needed are mechanisms whereby consumers are able to play a maximum role in determining what services they receive, with safeguards available if a person's ability to make decisions is significantly impaired. These safeguards should involve the tribunal appointment of substitute decision-makers, as occurs with guardianship, only in unusual circumstances.

Advance planning

Perhaps the most effective way of avoiding the use of guardianship is if a person, in advance of any loss of decision-making ability, nominates the kinds of decisions they would like to have made on their behalf should the need arise and appoints, where they think it appropriate, the individuals they would like to play central roles on their behalf. As discussed in Chapter 6, it is often the conversations, rather than the signed documents, that are important here, but advance planning is an important way in which guardianship can be avoided for those who become cognitively impaired in later life.

Supported decision-making

The most significant human rights development for people with cognitive impairment comes under the heading of supported decision-making. Most supported decision-making can occur without the need for any specific legislative reform (although it does carry resource implications). The two pilot projects in which OPA was involved occurred in the absence of law reform.

Chapter 1 argues for further general reform in this area, but there also remains a place for supported decision-making within guardianship legislation. Ideally, among their possible approaches during guardianship hearings, guardianship tribunals will have the option of appointing individuals to support people with decision-making and implementation. (Of the various terms that have been proposed here—among them 'supporter' and 'supportive guardian'—OPA prefers 'supporter'). This change has been introduced in Victoria's new guardianship law.

Recommendation 3.1

OPA recommends that, where necessary, state and territory governments amend their guardianship legislation to include the possibility of appointing decision supporters.

Status for parents

Some parents of adult children with disability feel excluded from the guardianship system, and OPA agrees that use of the term 'informal care' undervalues their role. Parents in this category do often have the status of decision-maker in relation to medical treatment, and they can be appointed guardian under guardianship legislation if there is a need for such an appointment.

Some reform is, however, required in this regard. One option is to draw on supported decision-making ideas and argue that parents of adult children with significant cognitive disability should have an automatic and rebuttable role as a supporter. Among other things, this would ensure access to information. OPA made this argument in 2012, drawing on the supported decision-making recommendations made that year by the VLRC.[100] This feature was not incorporated in Victoria's new law.

Recommendation 3.2

OPA recommends that state and territory governments amend their guardianship legislation to include an automatic and rebuttable role for parents of adult children with significant cognitive disability as their legal 'supporter'.

A broader investigation role for public advocates and public guardians

There have been various calls for reform in relation to investigatory roles. In its report entitled *Elder Abuse—a national legal response* the ALRC called for the empowerment of 'adult safeguarding agencies' (which could be public advocates and public guardians) to have complaint-generated and own-motion investigation powers in connection with 'at-risk adults', a term that would apply to people with 'care and support needs' who 'are being abused or neglected' or at risk of this and who 'are unable to protect themselves'.[101] The New South Wales parliamentary committee recommended that expanded investigation powers be applied in relation to 'vulnerable adults', while the VLRC recommended that such powers be operational if a person has 'impaired decision-making ability due to a disability'.[102]

In this regard OPA supports the more limited variation adopted by the VLRC, with a minor alteration.[103] There are two reasons for supporting this more limited power.

The first is to do with the balance that needs to be struck, as with all adult protection reforms, between an adult's right to be autonomous and the protective role of the state. Although the intent is that the broader investigation power would be exercised using a supportive intervention approach, meaningful implementation would still be accompanied by some coercive elements in relation to both the provision of personal information and the willingness to push through any immediate objections when seeking to provide social services support to people who are at serious risk of harm. Such powers are defensible, and indeed warranted, if the person concerned does not have the ability to make meaningful assessments of these courses of action; they are not justified if the person is able to make such assessments.

The second reason concerns the current role of public advocates and public guardians, which is concentrated on the wellbeing of people with impaired decision-making ability. Any provision of powers, and therefore assignment of responsibilities, to these statutory authorities that does not relate to people with impaired decision-making ability will dramatically change the authorities' important role.

Despite this, OPA agrees with the ALRC that there remains an investigation gap in relation to older people whose vulnerability does not arise from their impaired decision-making ability. In those situations, better policing practices and the wider availability of free legal assistance through seniors' rights services offer the best approach.

OPA has proposed a minor alteration to the VLRC proposal, that being to remove the VLRC's reference to disability, which is unnecessary. At the same time it is important to ensure that any impairment is considered more than temporary before the broader power of investigation can be exercised: otherwise the power might come to be applied in relation to someone who is temporarily alcohol or drug-affected, which would not be the intention. Rather than linking the impairment to disability, it could simply be required to be 'more than temporary'.

Recommendation 3.3

OPA recommends that state and territory governments amend their guardianship legislation in order to give public advocates and public guardians the broad power 'to investigate, via complaints or on their own motion, the abuse, neglect and exploitation of adults with apparent impaired decision-making ability, where this apparent impaired ability is likely to be more than temporary'.

As Chesterman notes, 'Queensland's Pubic Guardian has broader investigatory powers than other Public Advocates and Public Guardians and it constitutes one example of how this might be done'.[104]

Alternative tribunal orders

Another way of avoiding the use of guardianship is to empower guardianship tribunals to issue a wide array of protective orders that do not remove the decision-making authority of the person being protected. Such orders could include those already discussed:

- entry and assessment orders
- removal orders
- service provision orders
- exclusion or banning orders.

Tribunals could also make greater use of alternative dispute resolution mechanisms such as mediated agreements in situations where there is remediable conflict between potential supporters of the person in question (and where the rights and wellbeing of the person would not be jeopardised by such a process).

Recommendation 3.4

OPA recommends that, to reduce the need to appoint a guardian, state and territory governments reform their guardianship laws so as to enable tribunals to issue a wide array of protective orders.

Narrower guardianship criteria

Of course, the most direct way of limiting the use of guardianship is to limit the circumstances in which guardianship orders can be made. If modern guardianship laws are to be consistent with modern human rights, two things are necessary. First, the now-standard four-prong test of decision-making capacity—the ability to understand, retain, use or weigh up, and communicate information—should be preferred over older formulations that speak, for instance, of 'reasonable judgments'. Second, the criteria for the appointment of a guardian should be tied to an inability to make the decision in question.

OPA proposes that future guardianship laws in other jurisdictions follow the Victorian *Guardianship and Administration Act 2019* by including provisions that do the following:

- define decision-making capacity in relation to the standard four-prong test just mentioned
- ensure that guardianship orders can be made only in three circumstances
    - if the decision-making incapacity is specific to the matter that needs to be determined
    - if a matter cannot be resolved without the appointment of a substitute decision-maker

  - if an order limits the restrictions on a person's rights and freedoms to the least extent possible.

Although in the section dealing with orders the new Victorian law does not specify that guardianship must be the 'least restrictive' option, it does include in its general principles the statement that 'powers, functions and duties under this Act should be exercised, carried out and performed in a way which is the least restrictive of the ability of a person with a disability to decide and act as is possible in the circumstances'.[105]

A further step in the reform of Victoria's guardianship laws would be to remove all reference to disability. If this were done, the phrase 'more than temporary' could be added to the criteria to replace the need to mention disability, so that inabilities caused by short-term circumstances (such as drunkenness) are not inadvertently captured.

Recommendation 3.5

OPA recommends that, where relevant, state and territory governments reform their guardianship laws by removing all references to 'disability' and by limiting tribunal appointments of guardians to situations where the person in question does not have the capacity to make the particular decision in relation to which the order has been sought.

Substituted judgment

The final reform imperative is for guardianship decisions throughout Australia to be based on a substituted judgment approach rather than a best-interests one. This means revised guardianship legislation should ensure that substitute decision-making accords with what the person in question would have wanted, wherever this is possible, rather than simply empowering decision-makers to make the decisions they think are best.

One ethical dilemma this approach presents, however, is the possibility that a substitute decision-maker might become an agent of harm if they feel obliged to make a decision that accords with what the person in question would have wanted but that results in harm to that person. It is important that substitute decision-makers—even when operating according to a substituted judgment paradigm—still be required to exercise judgment (including professional judgment when they are being paid to exercise the role). They should not merely be conduits of wishes. It therefore seems sensible to add a rider to a substitute decision-maker's obligation to implement a person's preferences: 'so long as this will not subject the person to an indefensible risk of harm'. Victoria's new guardianship laws make this kind of provision: 'the represented person's will and preferences should only be overridden if it is necessary to do so to prevent serious harm to the represented person'.[106]

This chapter presents several formulations for a substituted judgment approach, among them the ALRC's 'will, preferences and rights' (a different ordering of the Convention on the Rights of Persons with Disabilities phrase 'rights, will and preferences') and the Victorian rendition, in both medical treatment and guardianship legislation, which requires substitute decision-making to occur in a manner consistent with the person's 'values and preferences' or 'will and preferences' and, where those cannot be known, in keeping with their 'personal and social wellbeing'.[107]

If preferences and values or will cannot guide decision-making, the use of 'personal and social wellbeing' over 'rights' is more pragmatic than philosophical. Should a substituted judgment approach be introduced, this conceptualisation would come into consideration only if a person's values and preferences cannot be known or are somehow unclear in guiding the making of a decision. In such a situation, though, would recourse to a person's 'rights' actually assist?

In 2014 the ALRC provided an indicative list of rights that could be considered in such a situation.[108] One difficulty, however, is that the list contains rights that can sometimes compete with each other. For example, a substitute decision-maker who considers 'respect for [the] home and family' of the person concerned could make a decision that detracts from or denies the person's 'liberty and security', and a decision that respects a person's 'liberty' might compromise their 'security'.

This brings us to the central drawback of using the word 'rights' here. It connotes certainty. In the context of a guardianship decision, 'rights' is actually unhelpful; indeed, it suggests that the substitute decision-maker simply needs to ensure the observance of the person's rights, as opposed to making a decision. As is the case with Victoria's Guardianship and Administration Act, OPA proposes a form of words that acknowledges the need for a decision. Queensland's new guardianship legislation does use the term 'rights', but it does not leave guardians with 'rights' alone, stating that a person 'performing a function or exercising a power' under the Act 'must do so in a way that promotes and safeguards the adult's rights, interests and opportunities'.[109]

Furthermore, it is clear that the term 'best interests' has had its day: it has come to be a euphemism for the overriding of a person's decision-making. The preference for 'personal and social wellbeing', which OPA originally recommended in 2009, is evident now in a range of statutes.[110] That expression is arguably the best modern encapsulation of a guiding principle that acknowledges a person both as an individual and as a member of society.

Recommendation 3.6

OPA recommends that, with one exception, state and territory governments amend their guardianship laws to require guardians to use a substituted judgment approach wherever possible in their decision-making. The exception to this is in circumstances that would produce a risk of serious harm to the person concerned.

4. Mental health

Case study

Robert (not his real name) resides in a secure mental health unit attached to a Melbourne hospital. Now in his late-50s, he has lived there for the past seven years, spending most of his time in his room. The interesting thing about Robert is that he is not residing there under any compulsory mental health order; he is there because he feels safe and doesn't want to leave. He has a serious mental illness that distorts his thinking at times, and he has a complex relationship with his two siblings, especially his brother, who becomes suspicious when an advocate talks to Robert about the possibility of living elsewhere. Robert just wants to be left alone.

Mental illness presents a greater challenge to the content and role of adult protection laws and practices than does any other field of medical or social welfare. The fluctuating nature of many mental illnesses—and the often lucid and intelligent discussions that can be had, even with people who are at the time quite unwell—challenge the (albeit imagined) paradigm of a passive victim who needs to be protected from others. Those who have sought to assist him might think Robert could be leading a more fulfilling and less constrained life. But is that their judgment to make? Does he need protection from his own choices? Should he be coerced into leaving his secure setting?

The balance that needs to be struck between adult protection laws and practices and the promotion of individual autonomy and decision-making freedom as well as the protection of people from harm forms a consistent theme throughout this report. And nowhere is this balancing act more contentious than in the field of compulsory mental health treatment. Indeed, as noted in Chapter 1, one argument supported by at least some UN committees is that the Convention on the Rights of Persons with Disabilities[1] prohibits involuntary treatment and involuntary confinement on the basis of disability, including mental disability.[2] Australian mental health laws do not yet reflect this position.

Before looking at compulsory treatment, this chapter considers other fields germane to mental health treatment, among them potential developments in the field of supported decision-making and the provision of non-compulsory mental health treatment. The chapter concludes with discussion of proposed reforms in the areas of supported decision-making, advance planning and compulsory treatment.

It is important to note that the field of mental health has strong links with other areas covered in this report. Chapter 1 looks at the interaction between mental health and the criminal justice system, noting, for example, the high rate of mental ill-health among prisoners. It also discusses the laws relating to unfitness to plead, the defence of mental impairment (which can apply not only to people with mental ill-health but also to people with cognitive impairment), and the over-representation of people with mental illness among the homeless population.

Chapter 2 discusses the NDIS's direct relevance to mental health: about 60,000 NDIS participants are expected to need support for psychosocial disability by the time the scheme is fully operational. Chapter 5 explores the current and potential roles of general medical decision-making laws and practices that have relevance for non-compulsory mental health treatment, and Chapter 6's consideration of advance planning mechanisms has possible implications for a person's ability to identify the mental health treatments and treatment decision-makers they would like to have involved should they lose the ability to make their own treatment decisions.

A further point of intersection lies between mental health laws and the regulation of aged-care services (particularly psychogeriatric services).

Another preliminary point worth making is that resources devoted to facilitating the functioning of the coercive elements of the mental health system are sometimes deployed as a result of shortfalls in the provision of other more supportive interventions. Research has shown that in Australia compulsory treatment can sometimes be sought in order to gain access to treatment (as a result of resource constraints) as opposed to there being a need for compulsion.[3] In practice, funding shortfalls in the mental health sector are considerable and seem to have been exacerbated by the introduction of the NDIS.[4]

A lack of affordable housing and step-down mental health supports and services also affects outcomes for service users. OPA has identified a small but significant number of patients who are residing in mental health facilities simply because there is no adequate alternative accommodation. In its original report on the subject OPA outlined specific criteria for identifying individuals who could be classed as 'long-stay' mental health patients—people who were held in an acute unit for more than three months, a secure extended-care unit for more than six months, or a community care unit for more than two years. Volunteer Community Visitors who visit mental health facilities then identified 99 people who could be classed as long-stay patients. Of those 99 people, 75 did not need to be in a mental health facility in order to receive treatment: they were there solely because there was no adequate alternative accommodation for them.[5] A review of long-stay patients in 2018–19 found 92 such patients, of whom 27 per cent were unable to be discharged because there was no suitable accommodation.[6]

At the beginning of this chapter we mention Robert, who chooses to remain in an inpatient setting. It is possible that his experience of inadequately supported and resourced alternatives is what has led him to choose to stay where he is.

4.1 Supported decision-making

The general trajectory of developments in the area of human rights is towards enabling people to make their own decisions, with support if necessary. This applies as much to the field of mental health treatment as it does to any other adult protection field.

As noted, some human rights agencies interpret the Convention on the Rights of Persons with Disabilities as proscribing any coercive mental health treatment. The convention's treaty-monitoring committee, the Committee on the Rights of Persons with Disabilities, says the 'obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives'.[7]

Domestically in Australia the Senate Community Affairs References Committee has supported this call.[8] More modestly, the ALRC has proposed that the states and territories 'review mental health legislation, with a view to reform that is consistent with the National Decision-

Making Principles and the Commonwealth decision-making model'. Those principles, as discussed in Chapter 1, promote supported decision-making over substituted decision-making alternatives.[9]

In 2018 Byrne and colleagues proposed a tool for measuring the compliance of non-forensic domestic mental health laws with the human rights outlined in Article 12 of the convention.[10] This tool could provide a clear way of assessing existing laws and help with moves towards greater compliance. Some mental health legislation has already made gestures in this direction. For example, Victoria's *Mental Health Act 2014* states clearly that 'persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions'.[11]

Supported decision-making is a field in which legislative reform will probably continue to be more symbolic than paradigm-changing until practical examples of possibilities are demonstrated. To this end, the creation of 'how to' resources and testimony about their use will be more important than well-meaning legislative pronouncements in the short term. One important development in this regard is a practical research project aimed at promoting supported decision-making for people with mental illness, led by Associate Professor Kokanovic at Monash University. It has resulted in the *Mental Health and Supported Decision-making: lived experience perspectives* website, which, among other things, provides guidance on supporting treatment and more general decision-making by people with mental illness through the use of personal testimony and the development of resources.[12]

4.2 Non-compulsory treatment

When individuals receive mental illness treatment outside a compulsory setting, the ordinary expectation is that they have given their informed consent to the treatment. This expectation can, however, sometimes be more apparent than real.

As discussed in Chapter 5, some definitions of 'medical treatment' in force in Australia do not apply to mental health treatments, either as a result of specific provisions to this effect or as a practical consequence of the wording of the relevant law. For example, in some Australian jurisdictions the laws in force specifically exclude the provision of prescription pharmaceuticals from their definition of 'medical treatment'. Most mental health treatments come within this exclusion, so the result is that the substitute consent processes required for the provision of other medical treatments (when the recipients are unable to consent to them) do not apply to mental health treatments. The patient's compliance—rather than their actual informed consent—is what has been required in order to receive non-compulsory treatment.

A second point to note is that non-compulsory patients can easily feel obliged to consent to treatment when this is asked of them. The threat of being treated compulsorily is a powerful determinant of a person's willingness to consent to treatment. And this is not an uncommon scenario. A clinician seeking compliance from a patient has two primary choices—'Look, I'm really worried about you, and I feel I have no choice but to treat you in hospital if you aren't willing to take this medication' or 'If you don't take this medication I will make you a compulsory patient'. Although there is a distinction in therapeutic tone between the two exchanges, the effect on the patient is almost identical: they do not feel free to refuse the treatment.[13]

State and territory laws determine who is the legal substitute decision-maker when a person with mental illness is being treated outside a compulsory setting and lacks the capacity to make their own treatment decisions.[14] In all Australian jurisdictions, consent from this decision-maker is legally required for non-minor medical treatment. The rates of compliance with the legal requirements are, however, unknown.

OPA notes there is a considerable practical difference between the provision of general medical treatment to people who are not able to consent to it as opposed to the provision of mental health treatment. General medical treatment is rarely refused or objected to, but the same is not the case when it comes to mental health treatment. Legal decision-making authority is one thing; the actual provision of treatment is another. OPA stresses that such decision-making authority should never be exercised in the face of sustained objection by the person concerned.

Moreover, substitute consent cannot become a de facto compulsory system for people who are offered treatment for their mental illness but are not subject to compulsory treatment orders.

Finally, in this regard OPA has concerns about the regulation of mental health treatment in some residential services—for example, some psychogeriatric services, which are largely governed by aged-care legislation. Many people can technically reside in such services on a non-compulsory basis, yet not have the ability to leave. Moreover, it is concerning that in such settings medical treatment consent processes are often not followed and the adoption of restrictive practices, particularly the use of chemical restraints, is inadequately regulated.

4.3 Compulsory mental health treatment

No area of adult protection provokes more intense debate than compulsory mental health treatment. Some consumer advocates describe such treatment as torture; clinicians and others depict it as typically a short-term therapeutic encroachment on a person's liberties in order to keep them, and sometimes others, alive and safe from harm. In human rights terms, is compulsory mental health treatment a flagrant breach of a person's human rights or a 'special measure' designed to protect them?

Compulsory mental health detention has its origins in the notion of protecting members of the general public from real or imagined dangers posed by people who are diagnosed as mentally unwell. Asylums were created to keep dangerous and difficult people locked away. More modern renditions in Australia characterise compulsory mental health treatment as a typically short-term infringement of a person's civil liberties in order that they can be treated for a mental illness (the average length of stay in Victoria for inpatient mental health services is just under 10 days).[15] In this way the person in question and other members of the public are protected from any danger posed by the person while they are unwell.

Modern challenges to the idea of compulsory mental health treatment come from a number of fronts and span theoretical and pragmatic concerns about the nature of modern compulsory psychiatric practice. For example, Gooding's *A New Era for Mental Health Law and Policy* provides a comprehensive critique of mental health laws.[16] The challenges encompass human rights concerns that essentially have two elements. One element focuses on the inappropriate and arbitrary nature of detention when this occurs as a result of someone's real or apparent mental illness. The second voices the general critique, aired throughout this report, relating to the arguable inconsistency between any substitute decision-making regime and current human rights obligations.

Added to these general challenges are more specific ones, which can be posed as questions:

- The 'bargain' being struck when a person is deprived of their liberty in a mental health setting is that they receive treatment, but could most compulsory mental health settings be described as therapeutic?
- While some compulsory treatment laws allow people with the ability to do so to consent to their own treatment, is this meaningful if the person cannot refuse treatment?
- Given that substitute decision-making is routine in compulsory treatment, why are people not generally empowered, when they are well, to write binding advance directives concerning their future treatment?
- Why are other potential decision-makers, such as personally appointed representatives, not generally empowered to make decisions about mental health treatment on behalf of people in compulsory settings who themselves are too unwell to be able to make decisions?

There are a variety of ways in which people with mental illness can be subject to detention and treatment. These range from compulsory treatment in mental health facilities (typically hospitals) under civil detention laws to treatment in forensic settings following involvement with the criminal justice system (for instance, if a person is unable to plead after being charged with committing a crime or if a person is found not guilty of a crime by reason of mental impairment). This interaction is explored in Chapter 1; the present chapter focuses on the use of civil detention orders.

First, though, there is the 'threshold' question to examine of whether compulsory treatment is ever justifiable.

Justifying compulsory treatment

It is widely accepted that compulsory mental health treatment is often instigated in order to prevent self-harm, although the data to support this are suggestive rather than definitive.[17] In 2017 in Australia 3,128 people died as a result of 'intentional self-harm' and suicide was the 'leading cause of premature death' in the nation. The Australian Bureau of Statistics found that 'on average, a person who died by suicide in 2017 lost 34.5 years from their life'.[18]

In its 2014 report *Preventing Suicide: a global imperative* the World Health Organization reported that about 800,000 deaths each year are attributable to suicide, which is the second-leading cause of death among young adults. One of the most important messages in the report concerns the preventable nature of suicide, it being noted that restricting 'access to the means for suicide works'.[19] Suicide prevention is, however, a very complex subject. As Wang and Colucci observe in relation to the WHO report:

> The central message in the document is that suicides are preventable but this requires actions such as restricting access to the means of suicide, reducing excessive use of alcohol, collecting and collating good-quality data about suicide and suicide attempts, providing training for gatekeepers, improving the quality of mental healthcare services, and promoting responsible reporting of suicide by the media.[20]

They further note, however, that the report did not consider the impact of compulsory treatment. In their own article—'Should compulsory admission to hospital be part of suicide prevention strategies?'—they discuss what we know and what we do not know about the effectiveness of compulsory treatment in stopping suicide. We do know it is very hard to predict when someone might take their own life, yet 'there is evidence that compulsory admission to hospital saves lives'. But that alone 'does not answer the question of how, when or whether [compulsory admission] should be used to prevent suicide'.[21]

Compulsory mental health detention and treatment are arguably at odds with Australia's obligations under the Convention on the Rights of Persons with Disabilities, particularly its guarantee of equal legal capacity for all (Article 12) and its prohibition on people with disabilities being 'deprived of their liberty unlawfully or arbitrarily' (Article 14).[22] The Committee on the Rights of Person with Disabilities has provided advice about this in connection with people with mental illness:

> Recognition of legal capacity is inextricably linked to the enjoyment of many other human rights provided for in the Convention on the Rights of Persons with Disabilities, including … the right to be free from involuntary detention in a mental health facility and not to be forced to undergo mental health treatment (art 14).[23]

A competing human rights argument is that compulsory mental health treatment does constitute discrimination on the basis of a person's disability but that the discrimination in question is positive discrimination aimed at providing a special benefit or 'special measure' to the members of the group concerned.[24]

Without wishing to overly rehearse this debate, the response then is to question whether the aim of compulsory mental health treatment is the wellbeing of the individual concerned or the safety of members of the public. If it is the latter, compulsory mental health treatment cannot reasonably be called a special measure. Further, one would expect that, if indeed this were a case of positive discrimination, mental health facilities would be far more therapeutic environments than they often are.

A further human rights consideration that is occasionally raised concerns relevant professionals exercising their duty of care. In short, the failure of a mental health professional to ensure adequate treatment of a person with acute mental illness, where this results in a person's death, could constitute a breach of the person's other human rights.[25]

The fusion argument

If specific mental health laws were jettisoned what, if anything, might take their place? One reform idea is that a generic substitute decision-making law should exist, one that would essentially 'fuse' together guardianship laws and mental health laws. The idea is that such a law would govern and authorise the use of substitute decision-making without discriminating as to why it is needed.

In its review of Victoria's guardianship laws, the VLRC considered the argument that mental health laws and guardianship laws should be amalgamated and summarised the possibilities and arguments associated with the topic.[26] The commission stated that the fusion idea rests on the argument that there should be one law governing substitute decision-making and that people ought not be discriminated against on the basis of their particular disability. The difficulty with this is that the guardianship and compulsory mental health treatment systems have developed differently and these differences would need to be resolved or removed.

Among the differences are two important factors. First, guardianship laws provide for individuals to be appointed to make decisions, whereas mental health laws install a clinician as the substitute decision-maker. Second, mental health laws have greater focus and more detailed requirements in relation to emergency scenarios than do guardianship laws.[27]

Added to these points is the fact that substitute decision-making can occur in compulsory mental health settings in some jurisdictions, such as Victoria, even when the person has the capacity to make their own decisions, which is not the case when it comes to guardianship.

Although during the course of its inquiry the VLRC commented that the fusion of mental health laws and guardianship laws was ‘a step too far because of the need for comprehensive emergency procedures when dealing with mental health crises’,[28] it ultimately made recommendations that amounted to small steps towards fusion.

The commission recommended that individuals be able to appoint representatives who could make decisions about mental health treatment in some circumstances for compulsory patients who were unable to make decisions. These powers would be limited to situations where the risk was to the individual’s ‘health or safety’ and where there was ‘no significant risk posed by the person to the public’. The commission also recommended that the guardianship tribunal and the Mental Health Review Board (as it was then) be able to appoint guardians with the same powers if the person had previously expressed a desire for such an appointment to be made but was no longer able to make the appointment themselves.[29]

OPA agrees with the commission that complete fusion between mental health laws and guardianship laws would not adequately deal with emergency situations, but it contends that there is scope for greater change than the commission called for in its recommendations.

Contemporary Australian practice

When looking at contemporary mental health laws and practice in Australia it is important to recognise that it is very rare—in any other field of life—for a person other than a judge to be legally authorised to detain another person for a period of weeks (up to 28 days in Victoria) through the exercise of their professional judgment and without having to negotiate extensive safeguards that have been established to prevent arbitrary use of such power. An exception does, however, exist when it comes to compulsory detention and treatment of people with mental illness: typical safeguards then require confirmation of a compulsory treatment order by a tribunal within a set period, but even then the clinical expertise of a treating psychiatrist is strongly persuasive.

Compulsory mental health treatment in Australia typically takes one of two forms. Either a person is treated in a secure setting such as a hospital or the person is free to reside in the community on the condition that they take their medication. Nationally, there were more than 12,000 compulsory inpatient treatment orders and nearly 15,000 compulsory community-based orders in the year to June 2015.[30]

The laws and practices differ in each state and territory in Australia.

In Queensland, for example, a person can be detained for mental health assessment for up to three days. Further, the ‘authorised doctor’ can complete a ‘treatment authority’ under which a person can be detained as an inpatient or can receive community-based compulsory treatment, which must be reviewed by the state’s Mental Health Review Tribunal within 28 days. Further reviews by the tribunal must be conducted at six-monthly intervals on two occasions, following which reviews must occur annually.[31] The Queensland Mental Health Review Tribunal reviewed a total of 10,466 orders concerning involuntary treatment in the year to June 2016.[32]

Similarly, in Victoria a doctor or 'mental health practitioner' can make an assessment order, which lasts for up to three days and allows for the person to be located and taken to a hospital for assessment. They then must be seen by an 'authorised psychiatrist', who can make a temporary treatment order in accord with legislative criteria; the order can last up to 28 days. The Mental Health Tribunal can then make an inpatient treatment order, which can last up to six months for an adult, or a community treatment order, which for adults can last up to 12 months.[33]

Among the states and territories, Victoria is one of the highest users of compulsory community treatment.[34] Although community-based compulsory treatment is not explored further in this report, it is important to note that community treatment orders are often criticised for their inconsistency with human rights principles and requirements.[35]

In the year to June 2019 the Victorian Mental Health Tribunal issued 6,297 compulsory treatment orders, consisting of 2,462 'inpatient treatment orders' and 3,835 'community treatment orders'.[36] More than half of Victoria's adult inpatient admissions (54 per cent) are on a compulsory basis, while this is the case for about 14 per cent of adults receiving community-based treatments.[37] The numbers of people on compulsory orders under the previous mental health legislation in Victoria were even higher.[38]

Current detention and treatment criteria

This section looks separately at the criteria for mental health *detention* and for mental health *treatment*. Many jurisdictions run these two elements together, but not all do. The distinction becomes important when considering possible reforms.

The criteria for compulsory mental health detention are largely similar throughout Australia, the differences being only minor. The criteria routinely speak of a person having a mental illness who presents a danger of 'serious harm' to themselves or others. South Australia just uses the term 'harm', and Tasmania permits detention when a 'person's safety or the safety of other persons is likely to be at risk'.

Some minor differences exist when it comes to the question of whether the detention criteria include the inability of the person in question to consent to treatment. Most jurisdictions do not include this as a criterion, but two states do. South Australia requires that the person have 'impaired decision-making capacity' before they can be detained, while Queensland also requires that the person 'not have capacity to consent to be treated for the illness'.[39]

When it comes to compulsory treatment, there are some subtle but important differences between the laws in force in the various Australian jurisdictions.

Mental health legislation in Victoria and the ACT explicitly states that compulsory treatment can be provided even if the person themselves has capacity to consent to treatment. Victoria's *Mental Health Act 2014* states, 'The authorised psychiatrist may make a treatment decision for the patient' when a patient 'does not have the capacity to give informed consent' or 'has the capacity to give informed consent, but does not give informed consent to treatment proposed by the authorised psychiatrist'.[40] Similarly, in the ACT compulsory treatment can be provided if 'the person has decision-making capacity to consent to the treatment … but refuses to consent'.[41]

One study of the situation in Victoria found that 'the Tribunal only explicitly considered a person's capacity in a very limited number of cases'.[42]

Although the rationale for these odd provisions lies in a wish for patients wherever possible to be able to consent to their own treatment, Victoria and the ACT effectively permit the existence of a bizarre situation in which a person can say 'yes' to treatment but not 'no', which of course severely impinges on any meaningful ability to consent.

Three states, however, permit compulsory mental health treatment only when the person has an impaired ability to consent to it. Tasmania enables compulsory treatment only when the person 'does not have decision-making capacity'. Similarly, Queensland requires the person not to 'have capacity to consent to be treated for the illness', while South Australia requires the person to have 'impaired decision-making capacity'.[43]

Of those three states, both South Australia and Queensland require decision-making incapacity for both detention and treatment. But Tasmania does not: it requires incapacity for compulsory treatment only, not for detention. The difficulty with the Tasmanian model is that a person might meet the detention criteria—jeopardising their own safety or that of others—and yet have decision-making capacity. This could mean a person is detained but refuses, and is therefore not given, treatment, which itself challenges the therapeutic model under which mental health detention is justified (whereby detention occurs in order to allow treatment).

When considering reform possibilities for compulsory treatment and detention criteria, two options should be pursued. One is to consider whether a lack of ability to consent to treatment should be a required minimum criterion for compulsory treatment and detention; the other is ensuring that people who are primarily a risk to themselves retain greater access to advance planning and support from self-appointed substitute decision-makers compared with people who pose a risk to others in the community.

Clarifying criteria for detention under a compulsory treatment order

OPA considers one major reform principle should be that if a person has the ability to consent to treatment that ability should be respected. The only way to properly do this is to also recognise that person's ability to refuse treatment.

The direct implication of this is that one of the compulsory treatment criteria must be the inability of the person to consent to treatment. It makes no sense for treatment criteria to permit—as is the case in Victoria and the ACT—some people to consent to treatment while not allowing them to refuse treatment.

That then raises the question of how the treatment criteria relate to detention criteria. One option is to have separate criteria. Detention criteria could deal only with risk, while treatment criteria could focus on capacity. The problem with this, though, is that a person could meet the criteria for detention but not meet the criteria for compulsory treatment. This is possible in a regime such as that applying in Tasmania. The result can be that a person is detained in a mental health facility because of the risk they pose, but that same person may not be treated (on the basis that they have capacity to make this decision and are choosing to refuse treatment). This challenges the fundamental therapeutic basis justifying mental health detention in the first place—that people are detained in order to be treated.

The only sensible and consistent approach is to make incapacity to consent to treatment a criterion for both detention and compulsory treatment. The important implication of this is that people with capacity to consent will not then be able to be detained in mental health facilities, even if the risk they pose is high. Some people would be alarmed at this. But if a person is not going to be treated (because they are refusing treatment and have the capacity to do so) surely there is no reason for them to be in a mental health facility. This would mean that there are people who, although they are behaving destructively and causing harm to friends and family, will not be able to be compulsorily treated.

To put it another way, if the person is not so unwell as to be incapable of making their own treatment decisions, to what extent is the risk they pose to themselves or others attributable to their mental illness? And to what extent could that risk be mitigated by compulsory treatment of the person's mental illness?

So what then happens if someone with mental illness does not meet the detention and treatment criteria but does pose a risk to themselves or others? The response is the same as it is for anyone else in society who poses such a risk. In short, it will be a matter for the criminal justice system to respond to such a circumstance, which might even involve preventive detention (as can be used in criminal justice areas concerning, for instance, potential terrorist offences or even in a public health crisis). In effect, this is what mental health detention for people in this category probably already amounts to, although with inadequate safeguards. The existing safeguards concentrate on the therapeutic model of compulsory treatment and are not designed to be safeguards simply in relation to the use of preventive detention.

Thus the criteria for all compulsory mental health treatment should require two things:

1. The person lacks decision-making capacity in relation to the treatment of their own mental illness.

2. Without immediate treatment for their mental illness, the person poses a risk of serious harm to themselves or others.

Subsequently, the question of whether the person needs to be detained in order to facilitate treatment and/or prevent the imminent risk of serious harm should be confronted.

Recommendation 4.1

OPA recommends that, where necessary, state and territory governments amend their mental health laws to ensure that only people who lack decision-making capacity in relation to the treatment of their mental illness can be subject to compulsory treatment and detention.

Separating the risk criteria

The second proposed reform to compulsory treatment criteria involves separating the standard risk criterion of 'risk to self or others' into two distinct criteria, with different treatment authorisation processes then ensuing according to the nature of the risk involved.

If the risk presented by the person is to their own health and wellbeing and not to the safety of others, the individual themselves (where they had written an advance directive) or others appointed by them could have a greater role in making treatment decisions in compulsory settings. This is discussed in the following section, in the context of advance planning.

The distinction between risk to self and risk to others can sometimes seem artificial: a person who dies by suicide, for example, will almost inevitably have family members and friends who are terribly and permanently affected. It is worth noting, however, that in situations where the risk is primarily to the health of the person in question and does not affect community safety the right to self-determination is promoted in other substitute decision-making regimes. For example, medical decision-making laws give priority to the decision-making authority of the person in question above concerns about the impact of the person's illness and treatment on their family or community. There is no clear reason why substitute decision-making regimes for people undergoing compulsory treatment for mental illness should assign priority to protection in preference to self-determination.

Advance planning

Advance planning in relation to mental health treatment—particularly compulsory mental health treatment—is far less broadly accepted and practised than it is in relation to general medical treatment. The possibilities that do exist tend not to include the possibility of people making directives that would be binding were they to lose decision-making ability and find themselves in a compulsory treatment situation. Nor are people generally able to appoint others to make substitute treatment decisions in compulsory settings.

Some steps have, however, been taken to enable people at least to nominate treatment preferences that must be considered in a compulsory treatment situation and to enable people to appoint others to roles that require that those other people are consulted in a compulsory situation.

In Victoria, for example, people can make 'advance statements' outlining, among other things, treatment preferences and can also appoint 'nominated persons'. In making a compulsory treatment decision, the authorised psychiatrist must have regard to any advance statement and to views expressed by any nominated person. But the authorised psychiatrist may still make a decision that goes against the contents of the advance statement or the views of a nominated person if 'there is no less restrictive way for the patient to be treated'. In particular, advance statements can be overridden if a patient's preferences are 'not clinically appropriate' or if they specify treatments that are not 'ordinarily provided by the designated mental health service'.[44]

To take another example, in Queensland people can make advance directives that are suggestive in compulsory mental health settings, although again there is no requirement that these directives be followed.[45]

These tentative developments could be made stronger. An advance statement, for example, could constitute advance consent to or refusal of particular treatments if the person concerned is being detained on the basis that the risk they pose is to themselves only and not to others.

Another option that has been put forward as a way for compulsory mental health patients to retain some control over the decisions that affect them concerns an enhanced role for personally appointed decision-makers. Such individuals could make treatment decisions for compulsory patients who are unable to make these decisions if the risk presented by the patient is to them alone. This would provide some limitation on the otherwise wide scope of decision-making power possessed by the authorised psychiatrist.

This proposal is more limited than allowing automatically appointed substitute decision-makers to have this role (such decision-makers have a role in relation to general medical treatment, as discussed in Chapter 5). The reason for limiting the proposal to personal appointments relates to the often contested nature of compulsory mental health treatment. As noted, although general medical treatment is not typically opposed by people who are unable to consent to it, the same is not the case with mental health treatment, where objections to treatments are common. This can be a result of disturbance to thinking processes, the stigma associated with mental illness or a wish to avoid the side-effects of medications.[46] Such a reform would empower patients to appoint people to make treatment decisions for them when they were unwell, including if they became compulsory patients.

The VLRC proposed that adults should be able to appoint others to make mental health treatment decisions on their behalf, including when those adults are compulsory patients. Moreover, the commission argued that such decisions should prevail over those of an authorised psychiatrist in specific circumstances. In identifying those circumstances, the commission recommended a separation of the risk elements that typically enable compulsory treatment (as discussed). If the risk was to the person concerned, the commission argued that the decision of a personal representative should prevail over that of the authorised psychiatrist; if the risk was to others, however, the authorised psychiatrist should prevail.[47]

The rationale for this distinction was that substitute decision-making should not be used to protect the public.[48] The commission also proposed that a tribunal should be able to appoint a substitute decision-maker with the powers just mentioned, but this would only be in situations where the person clearly wanted the substitute decision-maker in that role and did not have the ability to appoint them.[49]

Although this proposal would serve to promote a person's opportunity for self-determination in a compulsory treatment setting, the commission also proposed that the authorised psychiatrist should be able to challenge the appointment of the substitute decision-maker at a tribunal in particular circumstances.[50] The same challenge could be made in relation to binding advance care statements or directives on the basis that following the directive would be harmful to the health and wellbeing of the principal.

Restraints and seclusion

Mental health legislation typically contains provisions dealing with the use of restrictive interventions such as seclusion and physical restraint in compulsory settings. It often specifies maximum periods for which a restrictive intervention can be used and usually specifies monitoring requirements.[51]

The availability of data on restraints and seclusion varies between jurisdictions and depends in some cases on the nature of the facility: it is particularly difficult to obtain reliable data on the subject from private facilities. We do know, though, that in Victoria, for example, the Chief Psychiatrist reports on the use of restrictive interventions in 'Victorian public mental health inpatient units and secure extended care units'. Of the 16,268 people admitted to such facilities in the year to June 2016, 1,293 people were at some stage placed in seclusion and 1,259 were restrained.[52]

This is an important subject in relation to which major reform ideas are being considered and promoted. One leading project is being conducted by the University of Melbourne's Institute for Social Equity; it involves 12 staff members and more than 60 mental health service consumers and supporters and receives funding from the National Mental Health Commission. Staff from the project have released survey findings—drawn from more than 1,000 service providers, carers and consumers—that point to some benefits arising from the use of seclusion and restraint but also identify '… strong agreement across all participants that the use of seclusion and restraint is harmful, breaches human rights and compromises the therapeutic relationship and trust'.

The project is looking at alternative mechanisms, drawn from consumer perspectives, that might be introduced where restraints are currently used. These alternatives would be more focused on 'calming' rather than 'dominating' and 'controlling'.[53] Reform recommendations from the project are keenly awaited.

Electroconvulsive treatment and psychosurgery

Electroconvulsive treatment has a long and controversial history, despite the benefits that can be derived from it. No other area of medical treatment bears anything approaching the stigma of compulsory ECT, perhaps most infamously depicted in the Oscar-winning film *One Flew Over the Cuckoo's Nest*.[54] Forced ECT continues to generate headlines such as '"They're Terrified": mental health patients fight electro-shock therapy in court'.[55]

ECT is widely used in Australia, although different state and territory authorisation requirements and reporting practices make it difficult to determine exactly how often it is used or how usage in one jurisdiction compares with usage elsewhere. We do know, however, that in Victoria in 2017–18 ECT was used in public mental health facilities on 13,281 occasions, treating 1,029 individuals.[56] We also know that during this period the state's Mental Health Tribunal issued 682 orders for compulsory ECT to be performed on adult patients who were unable to consent to the procedure. During the same period, on 411 occasions the Queensland Mental Health Review Tribunal approved the use of ECT on patients who were unable to consent to it.[57]

State and territory mental health legislation typically requires tribunal consent before ECT can be given to patients who are unable to consent to it.[58] The jurisdictions do, however, vary in the extent to which they empower substitute decision-makers to consent on a person's behalf to ECT and in the extent to which tribunal oversight extends from inpatient to community settings. For example, South Australia enables substitute medical decision-makers to consent on behalf of patients, while Victoria now requires tribunal authorisation before ECT can be performed on compulsory patients who themselves do not have the ability to consent (whether or not the patient is in a compulsory setting).[59]

State and territory mental health legislation also typically requires authorisation from a tribunal or administrative panel before neurosurgery can be performed on compulsory patients.[60]

Access to advocacy

One often discussed, but often poorly resourced, service that is routinely called for by consumer groups in relation to mental health treatment is individual advocacy. The need for it has become more pronounced as the service sector is increasingly privatised and atomised around the concept of consumer choice,[61] something discussed more fully in Chapter 2.

The point here is a simple one: in compulsory mental health settings access to individual advocacy can be a crucial way of ensuring both rights protection and maximisation of people's ability to know about, question and even be involved in decision-making in relation to their own treatment.

And good models for this kind of advocacy do exist. In Victoria, for example, Independent Mental Health Advocacy, which is run by Victoria Legal Aid, provides advocacy support to compulsory mental health patients. In the year to June 2018 it provided 8,399 instances of advocacy and self-advocacy support and 17,349 instances of information and referral.[62]

Research into the outcomes of Australian mental health tribunal processes, including the conditions that influence the success of therapeutic jurisprudence goals, was conducted between 2005 and 2010.[63] Among the main findings from the research were that 'strategies to improve the attendance and participation rate of clients' legal representatives, carers and allied family members at hearings … may lead to improved therapeutic outcomes for clients'[64] and that constructive dialogue would be facilitated by having a body that could help a person navigate the mental health system and by ensuring that the tribunals themselves have sufficient time and resources to fully deal with the matters before them.[65] The researchers recommended that 'independent advocacy be provided for involuntary clients'.[66]

4.4 Future reform

OPA has identified three important areas for reform. They involve supported decision-making, advance planning and compulsory treatment. Implementation of the recommendations would enable people to play a greater role in the decisions that affect them.

Supported decision-making

One obvious reform imperative, repeated in every chapter of this report, concerns the need for people to be offered greater support when seeking to make and implement their own decisions. In the context of consumers of mental health services, this involves identifying the practices that actually do allow people to have the time, space and resources to make and implement decisions. The research led by Professor Kokanovic at Monash University is an important development in this regard.

Advance planning

OPA proposes the 'stepped' introduction of laws that promote self-determination for people who have experience of mental illness—such that a person may make an advance statement (as they currently can under the Victorian *Mental Health Act 2014*) even if they would not meet the higher bar of being able to make a binding advance directive (as required, for example, under the Victorian *Medical Treatment Planning and Decisions Act 2016*). This is crucial if we are to offer opportunities for self-determination to people who might not meet stricter mental capacity criteria that would enable them to, say, appoint their own substitute decision-maker.

Recommendation 4.2

OPA recommends that the states and territories legislate to create opportunities for self-determination for people with a range of capabilities—not just those who are able to appoint their own substitute decision-maker.

Consideration should be given to two important advance planning reform proposals that are particularly germane to people whose mental illnesses might at some stage prevent them from making decisions.

First, we should make it easier for people with mental illness to create binding advance directives that would constitute advance consent to or refusal of treatment. This should apply to voluntary patients as well as compulsory patients so long as the risk the treatment was intended to redress was to the person, not to others.[67] For compulsory patients, the approval of the relevant mental health tribunal (or similar body) would be required to override such advance directives.

Similarly, we should clarify the ability of personally appointed and automatic statutory decision-makers to make decisions about mental health treatment for people who are not on compulsory orders, in a way similar to the situation that pertains in most jurisdictions in relation to general medical treatment. For example, Victoria's Medical Treatment Planning and Decisions Act allows personally appointed 'medical treatment decision-makers' to make decisions about mental health treatment for people in non-compulsory settings. It needs to be made clear, however, that such decisions cannot be enforced in the face of sustained objection by the person concerned, a requirement that in practice would align with current consent processes for general medical treatment.

When it comes to substitute decision-making in a compulsory setting, OPA supports the position advocated by the VLRC—that personally appointed decision-makers should be able to make treatment decisions even in compulsory settings if there is no significant risk to other people (in other words, where the primary risk is to the person themselves).[68] This power should extend, as the commission also proposed, to a tribunal-appointed person whom the individual would probably have appointed were they able to do so.[69]

Recommendation 4.3

OPA recommends that state and territory governments introduce legislation to empower personally appointed substitute decision-makers to make treatment decisions for individuals on compulsory mental health treatment orders if the individual does not pose a serious risk of harm to others. This power should extend to tribunal-appointed substitute decision-makers whom the person would probably have wanted to make those treatment decisions.

Compulsory treatment

Reform of compulsory mental health treatment laws and practices is a very complex challenge for adult protection. The justification for such treatment is often about saving lives, and the high stakes mean that risk aversion almost becomes a default position. Framed in this way, the idea of allowing a person to make their own decisions can easily appear a gamble that is not worth the taking.

It is important, though, to be mindful that most people—including most of those who design laws and policies in this field—have not experienced compulsory mental health treatment. And some of those who have experienced it describe it in harrowing terms.[70]

Reform in this complex area must stem from basic principles:

- Clinicians and others must be required to ensure that all reasonable steps are taken—including delaying treatment where it is safe to do so—to enable the person to make their own treatment decisions and support them in doing so.
- If a person has the ability to consent to treatment that ability should be respected, even in a compulsory setting.
- The role of any substitute decision-maker must be to make the decision the person concerned would probably make themselves were they able to do so.
- Substitute decision-makers must not be put in the position of being asked to make decisions that have as their primary aim the protection of other members of society.
- The nature of many mental illnesses is such that objections to substitute consent are far more common than is the case with general medical treatment. For that reason, OPA supports the position of the VLRC: only individuals who have been personally appointed (or appointed by a tribunal on the basis that the individual would probably have appointed them had they been able to) should be able to make substitute mental health decisions in a compulsory context.[71]
- Although some decisions associated with medical treatment carry with them implications for the individual's freedom of movement—and enable treatment authorisations effectively to permit detention—detention in a mental health context should not be treated in the same way.[72] This is because the nexus between detention and mental health treatment is not as close as is the nexus between other forms of medical treatment and the constraints on movement that accompany them. For example, a decision to have surgery will mean a sedative and anaesthetic will probably be given and will make the person bed-bound, but here the immobility is required so that the surgery can be performed. A closer analogy might be a person with a traumatic head injury who is kept in a locked low-stimulus environment in order to facilitate brain recovery. But even then the purpose of the detention is a direct physiological outcome—brain repair. Detention in a mental health setting is often as much about risk avoidance (risk to the person or to others) and is designed to ensure that the person is physically present and able to be treated. The fact that many people can be, and are, treated in the community (albeit on compulsory orders) attests to this.
- It is necessary to acknowledge the need for and facilitate emergency treatment in order to save lives at times of acute crisis.

These principles underlie OPA's recommendations for reform.

Reduced length of detention without independent review

Detention decisions, which are often made in emergency situations, are primarily about risk management. Current laws almost universally empower an authorised psychiatrist to make these decisions. Because of the emergency nature of many such orders, caution must be exercised in order to avoid advocating for too great a change. At the same time, however, the power to order a person's detention is a very serious power that ordinarily warrants greater procedural safeguards than exist in the mental health field.

OPA considers that the possible length of time for which a person may be compulsorily detained without independent tribunal approval should be limited to 14 days (as opposed to the current 28 days in Victoria). Such a change would necessitate significant reform in the mental health sector due to the new time pressures imposed.

Recommendation 4.4

OPA recommends that state and territory governments legislate to ensure that people are not subject to compulsory detention under mental health legislation for more than 14 days without tribunal approval.

Increased self-determination in relation to treatment decisions

When it comes to treatment decisions, two reform ideas discussed in this chapter hinge on separating current risk criteria into two elements—a risk to the person's health and wellbeing and risks to the health and wellbeing of others.

If the risk is to the person themselves and not to others, OPA considers that advance statements should be permitted, in order to provide advance consent to or refusal of mental health treatment. Application to a tribunal would be necessary if something other than the person's wishes were to be proposed.

Similarly, it is OPA's view that a person specifically appointed by an individual to make decisions on their behalf should also be able to make decisions about mental health treatment in a compulsory setting if the risk is to the person and not to others. The same should apply to a person appointed by a tribunal to make such decisions (who would be appointed on the basis that the individual probably wanted that person to play this role).[73]

If, however, the risk extends to other people, such appointees should not be asked to make treatment decisions. Instead, such decisions should be the preserve of the authorised psychiatrist, accompanied by a requirement for tribunal authorisation for any continuation of compulsory treatment beyond 14 days.

Recommendation 4.5

OPA recommends that state and territory governments legislate to ensure that a person's advance statements are binding even when the person is subject to a compulsory treatment order. An exception should be made if the person's behaviour poses a risk to others.

Access to advocacy

Finally, all compulsory patients in detention should be entitled to individual advocacy. In view of the deprivations involved in detention, it seems not too much to require that state and territory governments allocate resources to ensure that any detained person has the chance to speak to an advocate and to have that advocate express the individual's concerns on their behalf.

5. Medical treatment

Case study

In 2003 ‘Barbara’ (not her real name) lay uncommunicative in a foetal position in hospital. She had been in that position for three years, moving nothing but her eyes. Five years earlier, in 1998, she had had a percutaneous endoscopic gastrostomy, or PEG, tube inserted, through which she received food and water. Barbara had a form of dementia known as Pick’s disease and expert medical opinion suggested there was no chance of her condition improving. But Barbara was still alive. The Victorian Public Advocate was appointed to be her guardian.

It was well accepted at the time that existing Victorian law allowed guardians and agents (appointed under medical treatment enduring powers of attorney) to refuse medical treatment on a person’s behalf if the person was unable to make decisions about medical treatment on their own behalf, if the treatment would cause ‘unreasonable distress’ or if the person concerned would have considered the treatment ‘unwarranted’. It was also accepted that ‘palliative care’, which included the ‘reasonable provision of food and water’, could not be refused.

The question here was whether food and water delivered through a PEG tube constituted medical treatment, which could be refused, or palliative care, which could not. The Victorian Supreme Court was asked to arbitrate. It did so by examining the debates leading up to the enactment of the law as it was at the time and concluded that the definition of ‘palliative care’ did not extend to food and water delivered through a PEG tube. Rather, this was found to be a form of medical treatment, which the Public Advocate was free to refuse on Barbara’s behalf. He refused the treatment shortly after the ruling. Soon after that Barbara died.[1]

Here was a case in which a court was effectively being asked to decide whether an adult protection law—in this instance the law concerned the inability of a substitute decision-maker to refuse palliative care—applied to the situation of a person who was receiving food and water artificially.

This chapter explores the way adult protection laws in Australia apply in the field of medical treatment. It examines the mechanisms whereby we enable decisions about medical treatment to be made by and on behalf of adults with impaired decision-making ability. This is a widely developed, if poorly understood, area in which considerable change has occurred, and continues to occur, in the way modern Australian society seeks to balance adult protection principles with the aim of maximising the role people play in decisions about their medical treatment.

It is important to note at the outset the poor general health status of some of the people who find themselves the subject of these protective laws and practices.

5.1 The health status of people with disability

It is well known that people with disability have worse health outcomes than people without disability, even when taking out of the equation health factors that relate specifically to the disability. In other words, their poorer health outcomes and health status are not linked organically to disability.

The most prominent example of this concerns people with intellectual disability, who account for just under 2 per cent of the population and are known to have comparatively poor health. One 2017 study, by Trollor and colleagues, noted, ‘Compared with the general population, people with ID [intellectual disability] experience very poor mental and physical health status and substantial barriers to accessing quality health services’.[2] This large study examined the deaths—in particular, avoidable deaths—in New South Wales of people with intellectual disability who were in receipt of state disability services support. The researchers examined 732 deaths and found that the rate of ‘potentially avoidable deaths’ for people with intellectual disability (38 per cent) was more than double that of the general population (17 per cent). They also observed:

> Potentially avoidable deaths in people with ID were dominated by deaths due to infections, diseases of the circulatory system, cancer and other external causes … Particularly stark is the large proportion of potentially avoidable deaths due to infections. Such deaths suggest that people with ID experience delays, difficulties or differences in accessing specific and effective interventions for infections.[3]

The study confirmed other research pointing to the poorer health status of people with intellectual disability. Webber and colleagues examined the experiences of people with intellectual disability in hospital settings and identified poor support practices as a contributing factor.[4] They were also involved in the development of manuals to help support staff manage the health needs of older people with intellectual disability in a community setting.[5]

One suspects that a large part of the reason for the poorer health status of people with disability is to do with the attitudes of health professionals and the public at large in relation to reasonable health expectations for people with disability. This then influences an array of actions and decisions, on the part of other people, that have health implications for people with disability—from the routine monitoring of health and wellbeing and the provision of information about healthy eating and exercise habits to the decision to offer particular treatments and health services and the advocacy in connection with the provision of such services.

The law does offer protections associated with consent processes if adults are not able to make their own health decisions, and most of this chapter is devoted to this subject. It is worth noting here, though, that the law is quite weak when it comes to ensuring that people with disability, including people with impaired decision-making ability, have equal access to adequate health care. To be sure, the decision to offer or not to offer a particular treatment to a person because of the presence of a disability could constitute unlawful discrimination on the basis of disability, contravening federal, state and territory anti-discrimination laws.[6] Successful actions on this basis are rare, however, and treatment options are typically crafted on the basis of what is ‘clinically indicated’, meaning that even clinical determinations involving prejudicial and irrelevant views about a patient’s disability cannot easily be shown to be unlawfully discriminatory.

This is a complex topic on which there is considerable literature. In 2014 Williams and colleagues wrote about one case, involving a neonate, in which treatment decisions were being made in the context of a future life that would be characterised by the existence of very significant disabilities. When particular treatments are being considered, it is often hard to disentangle prejudicial views about disability from relevant considerations about the effect of the person's current and likely future disabilities on their future prognosis.[7] This complexity and the same prejudices also affect adults with disability.

End-of-life matters are particularly difficult in this regard. Although clinicians are under no obligation to offer futile or unduly burdensome treatment, the presence of a disability can affect a clinical assessment about these factors. OPA's Principal Lawyer, Phil Grano, neatly summarised this complexity by asking, in the context of the neonate's case, whether the treatment itself was futile or unduly burdensome or whether in fact the clinician in question believed the life to be lived was futile or unduly burdensome.[8]

The remainder of this chapter focuses on how our medical treatment laws and practices seek to balance the protection of vulnerable people and the promotion of individuals' ability to make decisions about their own medical treatment. In order to do this, though, we first explore an apparently obvious question: what exactly is medical treatment?

5.2 The nature of medical treatment

Defining 'medical treatment'

Australia's states and territories define 'medical treatment' or 'health care' in largely similar ways. When a particular treatment is captured by the relevant definition, the relevant protective laws and any substitute decision-making processes provided for by those laws will apply.

Victoria, for example, defines 'medical treatment' thus:

> … treatments of a person by a health practitioner for the purposes of diagnosing a physical or mental condition, preventing disease, restoring or replacing bodily function in the face of disease or injury or improving comfort and quality of life.

Those treatments encompass 'treatment with physical or surgical therapy', 'prescription pharmaceuticals', 'dental treatment' and 'palliative care'.[9]

Queensland defines 'health care' for an adult thus:

> … care or treatment of, or a service or a procedure for, the adult—
>
> (a) to diagnose, maintain, or treat the adult's physical or mental condition; and
>
> (b) carried out by, or under the direction or supervision of, a health provider.

Queensland specifically excludes some treatments from its definition; examples are 'first aid treatment', 'a non-intrusive examination made for diagnostic purposes' and non-prescription pharmaceuticals.[10]

Other jurisdictions have their own variations on the definitions.[11] Although they are largely similar, some minor variations actually have quite important practice implications. Later in this chapter some of these apparently minor differences are examined along with the practice implications they entail; for example, whether or not the provision of pharmaceuticals is considered medical treatment has important implications for the role of substitute decision-making for non-compulsory mental health patients.

The definition of what constitutes medical treatment brings with it important consequences. Medical treatment can generally be refused by a person or their authorised representative, which means that the determination of whether an activity or procedure amounts to medical treatment can have life or death implications.

‘Barbara’, discussed at the beginning of this chapter, was the subject of the *BWV* case, where the provision of food and water through a PEG tube was ruled by the Victorian Supreme Court to constitute medical treatment. In that case the ruling permitted the treatment to be refused on the patient’s behalf.[12] In 2009 a comparable ruling was made in the Western Australian Supreme Court, one major point of difference being that the person in question, Christian Rossiter, was able to make his own medical treatment decisions and was neither terminally ill nor dying. He was, however, quadriplegic, having suffered three serious injuries, including a fall of 30 metres from an apartment building. His movement was extremely limited: he could move one finger and had limited ability to move his feet. The state’s Supreme Court was asked whether a direction by Mr Rossiter to cease provision of food and hydration through a PEG tube should be upheld or whether the care provider would be obliged to keep him alive. The court ruled that an informed request by Mr Rossiter to cease PEG feeding would have to be acted on.[13]

A similar case went to the New South Wales Supreme Court in 2014. It concerned a 27-year-old man with quadriplegia who was receiving medical treatment, including artificial ventilation, to keep him alive. The court ruled that a request by the man to cease his artificial ventilation should be respected.[14]

The decision-makers

It is now widely expected that before a person undergoes medical treatment they must consent to it. Moreover, all states and territories in Australia have laws that provide protections for people who are unable to consent to their own medical treatment. Consideration of those laws must be placed in the context of the role of the law in the field of medical treatment, something that has long been an uneasy fit for reasons explored briefly here.

The law is poorly understood by medical practitioners—particularly when it comes to laws governing the provision of treatment to people with impaired decision-making capacity. For example, when Deputy Public Advocate John Chesterman was a member of a panel making a presentation to a group of clinicians about new medical treatment laws that were soon to come into force, he briefly went through the existing and the new requirements for substitute consent. A very senior practitioner from interstate then commented that he had understood about 10 per cent of what had just been described, despite practising medicine for decades. He had been, on his own admission, utterly unfamiliar with legal requirements in relation to substitute consent (which were quite similar in his jurisdiction to the ones in Victoria).

He was not alone. White and colleagues have done considerable work evaluating doctors’ legal knowledge in relation to end-of-life care and the powers of substitute decision-makers. In one study they analysed the responses from 867 doctors in Queensland, New South Wales and Victoria who had been asked seven questions about the legal status of advance directives and the powers of substitute decision-makers. Out of a possible score of 7, the mean score for correct responses was 3.26. The researchers concluded, ‘Our results demonstrate critical gaps in the legal knowledge of many doctors who practise end-of-life medicine’.[15]

There are many reasons for this lack of knowledge. For a start, the laws differ in each state and territory and are generally quite complex. As an obscure example, in Victoria until 2018 a legal distinction separated the withholding of consent to treatment from the refusal of treatment. Any substitute decision-maker could do the former, but only two kinds of substitute decision-maker were able to do the latter.[16]

Another reason for the lack of knowledge is probably connected to the high standing generally of the medical profession and the existence of, in some cases, centuries-old ethical guidelines and principles. Far from being an area devoid of regulation, medical practice has long been subject to its own rules and norms and this perhaps has led to clinicians and their educators being unconvinced of the need to know the law. (One would also have to note that lack of enforcement of the law is surely relevant).

This is perhaps borne out by White and colleagues, who noted:

> Law appears to play a limited role in medical decision-making at the end of life with doctors prioritising patient related clinical and ethical considerations … Different legal frameworks … did not lead to different decisions about providing treatment.[17]

This observation leads to the third consideration offered here, which is that the adult protection elements of medical treatment laws are often seen to be a poor fit for the practice of medicine.

The contractual and consensual models of medical decision-making

The adult protection elements of medical treatment laws are predicated on a contractual view of such treatment, whereby the treatment is offered by a clinician and that offer is accepted or refused by the patient or their representative. That is certainly the way the law is crafted.

Medical practice tends, however, to involve a more consensual approach to decision-making: a clinician discusses possible treatments with a patient and a path forward is developed.

An example of the different framing of medical decision-making is evident in the case of decisions about whether to provide treatment that might be considered futile. It is widely accepted that doctors are under no obligation to provide futile or unduly burdensome treatment (although in Queensland the decision to withdraw such treatment from someone who cannot make their own decision requires the consent of the health decision-maker).[18] Under the contractual paradigm, the decision about whether or not such treatment should be offered is a clinical determination. The patient or their representative has a role only in accepting or refusing an offer of treatment if one is made.

Medical practice in relation to futility assessments and treatment is, however, far more consensual than that. Stewart noted:

> Futility assessment is difficult and requires consideration of medical and social factors in the assessment of the patient’s best interests. A procedural approach to futility assessment, involving the treatment team and substitute decision-makers, is the best way forward for an assessment, and this necessitates a good-faith attempt at reaching consensus.[19]

As this quote suggests, in practice the determination of what treatments, if any, to offer patients is intrinsically bound up with the expectations of the patients and their representatives. It also demonstrates that the assessment of whether a particular treatment is 'futile' or 'unduly burdensome' will often involve factors additional to the relevant person's medical presentation and the likelihood of successful medical intervention. Such factors can include some quality-of-life considerations (such as pain and psychological elements), as well as the personality and preferences of the individual in question.

Given the breadth of these considerations, another question arises: what role should doctors have in making these determinations?

Some legal academics have been keen to ensure that medical experts don't stray from their field of expertise into assessing non-medical matters. For example, Willmott and colleagues have argued:

> Treatment might be regarded as not worth doing because the chance of it working is too small or because the treatment might work but the resulting quality of life would be poor. These are not medical assessments, although medical evidence would, of course, assist a decision-maker … We suggest that medical evidence be examined critically to separate opinion that is based on medical evidence and that which is values-based.[20]

The admixture of medical and other factors creates a complex environment for decision-making—especially when it comes to substitute decision-making, when assumptions and guesses must often be made about personal preferences.

The consensual model tends not to generate problems when the patient is able to make their own decisions. Thorough discussion between doctor and patient will usually lead to a shared understanding of possibilities and risks. This model's operation, and its ability to meet legal requirements, can be far more problematic when a substitute decision-maker is involved, especially when that decision-maker has not previously been involved in discussions about the patient's care.

5.3 Medical advance directives

Chapter 6 describes how advance directives allow people to direct their medical treatment into the future, even after the person loses the ability to make their own treatment decisions. It discusses the legal and ethical complexities involved, among them the philosophical question of the extent to which we can and should in the future be bound by choices we make now. It also argues that any concerted promotion of advance care planning should be accompanied by clarity about whose purposes are being served by that promotion—individual patients or institutions such as hospitals and residential aged-care facilities.

For the purposes of the present chapter, however, it is important to note that the existence of a valid advance directive can guide a substitute decision-maker, where one exists and is needed, in the making of a decision about medical treatment. Further, a valid advance directive can indeed obviate the need for a substitute decision-maker when the law in that jurisdiction allows for the advance directive to constitute advance consent to or refusal of treatment. This is the case in Victoria, for instance, when a valid instructional directive is made.[21]

Medical advance directives, which express a patient's treatment preferences or directions, are not to be confused with other health-related documents or plans, which typically are clinician-led. 'Not for resuscitation' orders are a case in point: confusingly, they can be viewed as either advance refusal by a patient in relation to a particular treatment (resuscitation) or a clinical decision not to offer that particular treatment. Technically, these 'orders' are in the latter category unless they comply with the jurisdiction's legal requirements whereby treatment may be refused in advance. Confusion here is widespread.

One study that examined 'not for resuscitation' forms and other relevant documents from five Melbourne hospitals looked at the documents' consistency with Victorian legal requirements and found, 'These [not for resuscitation] forms send mixed messages about whether an NFR decision is a medical or a patient decision'.[22]

The reason for this returns us to the differing ways in which decision-making relating to medical treatment is framed. The decision not to offer resuscitation will often stem from discussions between a clinician and the person concerned or that person's family members or supporters. To that extent the line is blurred. Is it a clinical determination about the treatment that is medically indicated? Or is it documentation of what the person or their representative actually wants?

5.4 Supported decision-making

A central theme of this report concerns developments in the area of supported decision-making, a term that has been 'loaded up' to refer to practices that encourage and help people to make their own decisions as well as being an exhortation to use substitute decision-making only as a last resort, if at all. As in other decision-making areas, a great deal of practice reform can be achieved in the medical decision-making area without the need for legislative reform.

In Victoria, Monash Health's Centre for Developmental Disability Health provides education, resources and advocacy designed to promote improved outcomes for people with cognitive impairment.[23] In New South Wales, the Council for Intellectual Disability provides advocacy and information about the health status of people with intellectual disability.[24]

Although practice reform can be achieved in the absence of legislative reform, one novel Victorian legislative development has led to the creation of the role of 'support person' in medical treatment legislation. The state's *Medical Treatment Planning and Decisions Act 2016* enables anyone with the ability to do so, even children, to appoint a support person to assist with the making of decisions relating to medical treatment. Although medical treatment decisions remain those of the person concerned, support people are able to gain access to and communicate information in a way that privacy and health records legislation would ordinarily inhibit.[25]

In addition to having the role of supporting the person concerned 'to make, communicate and give effect to the person's medical treatment decisions', support people have the role of 'represent[ing] the interests of the person … including when the person does not have decision-making capacity in relation to medical treatment decisions'.[26] This is an interesting extension of the role of a supporter. Most formally recognised supported decision-making appointments end when the person being supported no longer has the ability to make their own decisions. Here, however, the role continues. A typical situation in which a supporter might exercise their representational or advocacy role, beyond a loss of decision-making ability by a principal, would be if the principal is unconscious during or following surgery, when decisions made by the principal might need to be acted on. This broadly defined advocacy role of support people might, however, extend to applications more traditionally associated with the realm of substitute decision-making.

5.5 Substitute decision-making

Most jurisdictions in Australia have legislative mechanisms enabling medical treatment to be given to an adult who is unable to consent to it. Usually this involves an automatic statutory hierarchy of possible substitute decision-makers and further processes if consent or authorisation cannot be obtained in this manner.

The first question that must be answered before substitute decision-making requirements are invoked concerns whether the person in question has the capacity to consent.

Capacity

Increasingly, ‘capacity’ is being defined according to the four-prong definition that exists in the UK Mental Capacity Act. In Victoria, for instance, the relevant legislation expresses the constituent elements as involving the ability to:

- ‘understand’ relevant information
- ‘retain that information’
- ‘use or weigh that information as part of the process of making the decision’
- ‘communicate the decision’.[27]

Some jurisdictions continue to define the word using older terminology. New South Wales, for example, provides that a person is deemed unable to consent to medical treatment if they are ‘incapable of understanding the general nature and effect of the proposed treatment’ or are unable to indicate whether or not they consent.[28]

The question of whether someone has the capacity to make a decision about medical treatment is sometimes quite complex, especially if the condition at issue (the one for which treatment might be provided) itself affects decision-making.

In one notable English case, a judge ruled that a 32-year-old woman with anorexia nervosa did not have the capacity to refuse life-sustaining interventions. The judge referred to the difference in her case compared with one involving someone in an advanced non-responsive state. Here the anorexic woman was ‘fully aware of her situation’ and had been described as ‘intelligent’. The judge noted:

> She does not seek death, but above all she does not want to eat or be fed. She sees her life as pointless and wants to be allowed to make her own choices, realising that refusal to eat must lead to her death. Her situation requires a balance to be struck between the weight objectively to be given to life on one hand and to personal independence on the other.

The judge determined that the woman’s illness meant she was ‘incapable of weighing the advantages and disadvantages of eating in any meaningful way’. He ruled that she did not have ‘capacity to make decisions about life-sustaining treatment, and that it is lawful and in her best interests for her to be fed, forcibly if necessary’.[29]

Emergencies

All jurisdictions in Australia allow for emergency or urgent treatment to be provided without consent.[30]

Jurisdictions with advance planning legislation typically require that any binding directive be observed, even in an emergency setting. The practical question that arises, however, is how, in the absence of electronic registration of such directives, will a practitioner know about the existence of an advance care directive? Legislators have been loath to place too great an onus on practitioners to search for directives. For example, Victoria’s legislation obliges health practitioners to observe an ‘instructional directive’, but they are not obliged ‘to search for an advance care directive that is not readily available’.[31]

Appointing a substitute decision-maker

When a person is deemed unable to consent, most jurisdictions have a statutory list that enables a substitute decision-maker to be identified. The list will include at the top individuals either appointed to the role by the person in question (often through an enduring instrument such as an enduring power of attorney) or by a tribunal (such as a guardian). Chapter 3 discusses the role of guardians; Chapter 6 considers the personal appointment of representatives.

The focus here is the identification of a substitute decision-maker when such an appointment has not been made. Again, most jurisdictions have a list that includes people who can play a substitute decision-making role. In Victoria, for example, an adult’s ‘medical treatment decision-maker’ is the first-ranking person in a statutory hierarchy that, after listing decision-makers appointed to the role by the person in question and tribunal-appointed guardians, includes in descending order:

- ‘spouse or domestic partner’
- ‘primary carer’
- ‘adult child’
- ‘parent’
- ‘adult sibling’.[32]

Victoria’s hierarchy list is shorter than hierarchy lists used in other jurisdictions. In South Australia, for example, the automatic hierarchy extends from a spouse to a ‘domestic partner’ to ‘an adult related to the patient by blood or marriage’ or through adoption; it also recognises relationships through Indigenous ‘kinship rules’.[33]

Some jurisdictions place a rider on the operation of this automatic hierarchy. In Western Australia the statutory appointee must have ‘a close personal relationship with the patient’,[34] while in Victoria an automatic decision-maker must have had ‘a close and continuing relationship’ with the adult. These qualifications ensure that a distant relative who has had no meaningful relationship with the person concerned cannot find themselves suddenly in a decision-making role.[35]

In situations where there is no decision-maker available, all jurisdictions in Australia provide for guardians to be appointed to make decisions about medical treatment. Some jurisdictions also have alternative processes short of guardianship that allow some decisions to be made.

In New South Wales potential treatments are divided into two categories—'major' and 'minor'. Minor treatments may be provided without consent; major treatments require the consent of a guardian or approval by the state's Civil and Administrative Tribunal. Major treatments are defined by regulation to include a variety of matters, including treatments requiring the provision of a general anaesthetic.[36] In Queensland treatments can be provided without consent if they amount to 'minor and uncontroversial health care'; other treatments require authorisation from a medical decision-maker, who can be a 'statutory health attorney', a guardian or the Queensland Civil and Administrative Tribunal.[37]

Until 2018 Victoria had a procedural authorisation process that did not involve substitute consent but required, among other things, registration of a notice under the guardianship legislation. These notices—so-called section 42K notices—were required to be lodged with OPA. Although OPA received hundreds of these notices each year (553 in 2016–17) there was poor compliance with this requirement.[38] Some hospitals in the state, for example, rarely if ever submitted such notices (and it is highly unlikely they never needed to do so).

Since 12 March 2018 Victoria has had a changed mechanism whereby consent to medical treatment can be provided in non-emergency situations if the adult is unable to consent and does not have an appointed substitute decision-maker. In these circumstances the medical treatment legislation divides possible treatments into two categories—'routine' and 'significant'. Routine treatments can be provided without consent; significant treatments can be provided only when the Public Advocate consents to that treatment on the person's behalf. The definition of 'significant treatment' allows for objective and subjective elements to be taken into account and involves any of the following:

> (a) a significant degree of bodily intrusion;
>
> (b) a significant risk to the person;
>
> (c) significant side effects;
>
> (d) significant duress to the person.[39]

The Public Advocate's role in making such decisions arises outside any formal appointment process by a guardianship tribunal. In the first full financial year of operation (2018–19) 455 applications were made under section 63 of the *Medical Treatment Planning and Decisions Act 2016*. The legislation has struck an effective balance in not unduly constraining non-contentious medical treatment while empowering an independent decision-maker to ensure whenever possible that treatment decisions accord with the values and preferences of people who themselves cannot consent and do not have others to act on their behalf.

Sterilisation and other restricted treatments

Most jurisdictions in Australia legislatively identify specific 'special treatments', 'special procedures' or 'prohibited treatments' that cannot be the subject of ordinary substitute consent processes and instead require tribunal or board authorisation.

In New South Wales 'special treatment' takes in treatments that will probably render the person 'permanently infertile' and new treatments not practised by 'a substantial number' of clinicians.[40]

In South Australia ‘prescribed treatment’ includes sterilisation and abortions.[41] Victoria uses the term ‘special procedure’ to refer to sterilisations, abortions and tissue transplantation, all of which require tribunal authorisation.[42] Western Australia specifically prohibits sterilisations and abortions being performed if the person in question is unable to consent to the procedure and it has not been authorised by the State Administrative Tribunal.[43] In Queensland ‘special health care’, which generally requires Queensland Civil and Administrative Tribunal authorisation, includes abortions, sterilisations and live tissue donation.[44] The Northern Territory proscribes substitute decision-makers from consenting to ‘restricted health care actions’, which includes sterilisations (unless this is a secondary result of another treatment).[45]

The sterilisation of people with disability has been a particularly contentious topic and was the subject of a Senate committee inquiry in 2013. The inquiry was told of the uneven laws, practices and data entry concerning sterilisation procedures throughout Australia, which, among other things, made it virtually impossible to compare the rates of sterilisation of people with disability throughout the various jurisdictions. Among the committee’s 28 recommendations was a call for data about sterilisation cases to ‘be recorded, and reported, in the same way in each jurisdiction’. The committee also concluded that ‘substituted decision-making must only occur where appropriate supported decision-making has not resulted in persons having the capacity to decide for themselves’.[46]

One direct outcome of the Senate committee’s report was the engagement of the Australian Guardianship and Administration Council to develop consistent cross-jurisdictional criteria to enable the recording of meaningful national statistics on the sterilisation of people with disability. OPA led this work, and the council’s first national data report on the sterilisation of adults with cognitive impairment showed that two sterilisation procedures had been approved by tribunals in the first six months of 2016. The second report showed there had been 10 sterilisation approvals by tribunals and boards in 2016–17;[47] the third report showed three such approvals in 2017–18.[48]

These sterilisation reports provide figures on the number of times tribunals and boards approved the sterilisation of adults with cognitive impairment in the relevant period. The extent to which they accurately capture the number of procedures in fact occurring depends, however, on health practitioners and others adhering to the legal requirements when the person concerned is unable to consent to a proposed sterilisation procedure. The Senate committee noted, ‘Nowhere was a lack of uniformity in data and practice more starkly illustrated for the committee than in a discussion about vasectomies in young men’.[49] There is good reason to be concerned that such procedures continue to happen without appropriate consent or tribunal authorisation.

Mental health treatment

As discussed in Chapter 4, the compulsory mental health provisions currently in force in Australia outrank general medical treatment laws. Sometimes, however, the general medical treatment laws that are in force in a jurisdiction also apply to non-compulsory mental health treatment: in large part this depends on how ‘medical treatment’ is defined in the general medical treatment legislation.

Some jurisdictions are silent on this. The Northern Territory guardianship legislation does not specifically provide an automatic statutory health decision-making regime, but it defines ‘health care’ in such a way that the term extends to the provision of ‘mental health services’, meaning that guardians can have this responsibility.[50]

New South Wales, Tasmania and Queensland define ‘medical treatment’ in their guardianship legislation in such a way as to exclude many mental health treatments from the legislation’s purview. These jurisdictions all exclude the provision of pharmaceuticals at standard dose levels from their definition.[51] Most mental health treatments come in the form of pharmaceuticals, so this suggests that most mental health treatment, apart from that delivered in compulsory circumstances, is not required to comply with the processes set out for substitute consent.

This was also the case in Victoria until changes to the legislation in 2016 made it clear that pharmaceutical treatments were included.[52] This means that non-compulsory mental health treatment in Victoria—including treatment taken in the form of a pharmaceutical—requires substitute consent if the person in question is unable to consent to it. Victoria also has a specific requirement that electroconvulsive treatment requires the authorisation of the Mental Health Tribunal if the person does not have the capacity to consent to it, regardless of whether the person is subject to a compulsory order.[53]

In its *Consent to Medical Treatment and Palliative Care Act 1995* South Australia also defines ‘medical treatment’ broadly to include ‘health care’, which itself includes ‘diagnosing … or treating a … mental condition’. The legislation also includes ‘the prescription or supply of drugs’ in its definition of ‘medical treatment’.[54]

Particular complexity emerges when substitute consent in relation to mental health treatment is considered. This topic is examined in Chapter 4, but some observations are worthy of note here. Recipients of general (non-psychiatric) medical treatment rarely object to the provision of treatment, including when that treatment has been consented to by someone on their behalf. The same does not apply to the provision of mental health treatments. Leaving to one side the question of compulsory mental health treatment, the provision of non-compulsory mental health treatment is often problematic if a substitute decision-maker consents to the treatment. Indeed, recipients of mental health treatment might see no significant difference between compulsory treatment (according to mental health legislation) and treatment that is provided on the consent of a substitute decision-maker (under general medical treatment legislation).

This has implications both for psychiatric practice and for substitute decision-makers. There is debate about whether substitute decision-makers should have a role in authorising mental health treatment—at least those substitute decision-makers who have not been appointed by the person themselves but who have been assigned the role as a result of their appearance at the top of an automatic statutory hierarchy. One response to this concern is to point out that removing the decision-making authority of substitute decision-makers—at least those who are automatically appointed according to a statutory hierarchy—could simply mean that more mental health patients are placed on compulsory orders. This is discussed in Chapter 4, where it is proposed that, as a matter of practice, substitute decision-makers should refrain from authorising treatment if the person concerned expresses anything more than fleeting objections to it.

Restrictive interventions

Chapter 1 discusses the under-regulation of restrictive interventions in many settings in Australia—particularly in residential aged-care facilities, where up to half of residents are subject to behaviour-modifying medications. The most common restrictive intervention is chemical restraint, which typically takes the form of a pharmaceutical given to control a person’s behaviour. Some service settings, such as disability settings in Victoria, have a restrictive intervention authorisation process that extends to the provision of chemical restraints, but many service sectors do not. This means that the only regulation of such interventions occurs through medical treatment laws and the regulation of health practitioners.

Undoubtedly it can be difficult to determine whether a pharmaceutical is being prescribed to treat a condition or more simply to control a person's behaviour. Sometimes it will be both. The point is that sometimes this will fall outside the reasonable definition of 'treatment' and, as argued in Chapter 1, ought to be subject to a specific authorisation process. For present purposes, though, it should also be noted that clinicians might be acting outside the bounds of their legal and professional authority when drugs are being prescribed simply to control untoward behaviour.

Medical research

Some jurisdictions provide for substitute consent processes whereby medical research can be consented to on a person's behalf. In Victoria, for example, the medical treatment decision-maker can make this decision on a person's behalf, and there is a further authorisation process, involving lodgment with OPA of a form, if no medical treatment decision-maker is available.[55] In New South Wales the state's Civil and Administrative Tribunal can authorise a person's involvement in 'clinical trials'.[56] The ACT allows guardians to provide substitute consent for an adult's involvement in medical research.[57]

Best interests or substituted judgment

An important change is occurring in Australia in connection with the basis on which substitute medical decision-makers are required to act. Some jurisdictions continue to require these decision-makers only to make decisions according to their concept of what is in the patient's 'best interests'; others require decision-makers to adopt a substituted judgment approach and make decisions according to what the person would probably have wanted.

Western Australia's guardianship legislation, for example, provides, 'When making a treatment decision for the patient, the person responsible for the patient must act according to the person's opinion of the best interests of the patient'.[58] Tasmanian legislation is similar, requiring a best-interests approach and defining such an approach to include ascertaining any preferences on the part of the person concerned.[59] New South Wales, meanwhile, requires a 'person responsible' to take into account a person's views but to make the decisions that promote and maintain 'their health and well-being'.[60]

Queensland legislation currently occupies a curious mid-ground, requiring a substituted judgment approach but with an overriding protective element. The guardianship legislation's principles, which apply also to substitute medical treatment decisions, provide as follows:

> The principle of substituted judgment must be used so that … a person or other entity in performing a function or exercising a power under this Act must take into account what the person or other entity considers would be the adult's views and wishes … However, a person or other entity in performing a function or exercising a power under this Act must do so in a way consistent with the adult's proper care and protection.[61]

Some changes to the Queensland Act passed in 2019 but have not yet been proclaimed; they would amend these principles and remove the phrase 'proper care'. The new principles would instruct those engaged in decision-making to promote supported decision-making opportunities if possible and, where this is not possible, to use a substituted judgment approach. The only reference to the protective element of guardianship legislation that will be left following amendment is that ‘A person…performing a function or exercising a power under this Act … must do so … in a way that promotes and safeguards the adult’s rights, interests and opportunities … and … is least restrictive …’ [62]

Legislation in the ACT is also a combination of substituted judgment and best interests, requiring that the relevant person’s wishes ‘must be given effect to, unless making the decision in accordance with the wishes is likely to significantly adversely affect [their] interests’.[63]

South Australia and Victoria more clearly require a substituted judgment approach to substitute medical decision-making. Victoria, for instance, requires that its medical treatment decision-makers ‘make the medical treatment decision’ they reasonably believe ‘is the decision that the person would have made’.[64]

This gradual shift—which is seeing substituted judgment replace best interests as the basis on which substitute medical decisions are made—is clearly in keeping with modern human rights developments. It is worth noting, however, that there is potential for introducing new ethical challenges for substitute decision-makers. Where once substitute decision-makers simply made the decision they thought was ‘best’, now those decision-makers are increasingly required to make decisions that the person in question would have wanted (which is akin to being the person’s delegate). Sometimes there will be a conflict between the two, and substitute decision-makers will need to consider whether they are comfortable with making such decisions.

As discussed, this will probably pose less difficulty in the field of medical treatment than in other decision-making arenas because professional regulations for health practitioners and well-developed ethical norms constrain the kinds of decisions substitute decision-makers might be asked to make. Substitute decision-makers cannot, for instance, require that particular treatments be given if health practitioners are not willing to offer those treatments.

The changing basis on which substitute decisions are made will probably prove more challenging in other decision-making realms, such as guardianship. For example, if a guardianship client expressed a wish to be homeless, would the guardian, operating on a substituted judgment basis, be obliged to enable that to happen?

Earlier in this chapter it is noted that substitute decision-makers can themselves hold discriminatory or otherwise inappropriate views about disability when it comes to making substitute decisions. A safeguard in Victoria’s new medical treatment legislation provides some protection in this regard. The legislation expands the ability of all substitute medical treatment decision-makers to refuse treatment on behalf of adult patients, regardless of whether the substitute decision-making role came about through appointment by the person concerned, appointment by a tribunal or simply as a result of the statutory decision-making hierarchy. This means, for example, that a woman with a profound cognitive impairment might be subject to the decision-making of her brother, despite never having appointed him to the role. Imagine that the woman required simple life-sustaining surgery for a particular condition but the brother refused to consent to it, meaning the woman would die. The new Victorian safeguard requires that the Public Advocate be notified by health practitioners in such situations, where treatment is being refused in relation to someone whose ‘preferences and values … are not known or are unable to be known or inferred’.[65]

5.6 Euthanasia

A central theme of this report is the balance adult protection laws and practices strive to achieve between respecting individual autonomy—people's right to make their own decisions—and protecting those most at risk of harm. Nowhere are the tensions between these two elements clearer than in the debate about legalisation of euthanasia, where long-settled determinations of where the balance lies are being renegotiated.

It is important to note here that euthanasia is not a medical treatment decision that can be consented to by a substitute decision-maker anywhere in the Western world. In the Netherlands, however, an advance directive in relation to euthanasia can be made and can 'be regarded as a request for euthanasia by the patient if s/he becomes unable to express his/her will'.[66]

'Euthanasia' is typically defined as the hastening or causing of death, usually in the context of a person who is in unrelenting pain. Although the practice remains illegal in most of Australia, the so-called doctrine of double effect has long permitted the provision of medical treatments that hasten death, so long as the principal aim in providing them is not the hastening of death but instead has another goal, usually the relief of pain.

To some people, this has been a historical legal nicety, a form of wilful blindness that ought not be distinguished from the simple provision of a drug with the aim of ending life. To others, the doctrine of double effect allows the maintenance of a clear line between relieving distress and the intentional causing of death and enables clinicians to honour their basic therapeutic obligations.

Various terms are used in the context of euthanasia. 'Assisted suicide' generally refers to the provision to a person of a drug that will enable that person to end their life, while 'voluntary euthanasia' generally refers to the involvement of a doctor in ending a person's life. Perhaps the least contentious terms to use in this discussion are 'assisted dying' or 'voluntary assisted dying', which have come to refer to the provision of assistance that enables a person to end their life, usually through use of a drug prescribed by a doctor.[67] Indeed, in June 2019, with the commencement of the *Voluntary Assisted Dying Act 2017*, Victoria became the only jurisdiction in Australia in which euthanasia was legal under specific strict conditions.

Prohibitions on euthanasia have historically existed on the basis that the state has a duty—some would say its foremost duty—to protect the life of its members and not to assist in their death (an argument that in Australia led to the abolition of the death penalty). At the same time, a growing movement of public opinion has sought to enable some individuals—at the very least people at the end stages of a terminal illness who are suffering unrelievable pain—to be assisted in ending their life.

Advocates of euthanasia see the practice as a humane way of enabling people who are suffering to exercise their autonomy and allow them a 'death with dignity', a term that has become a catchphrase of proponents.

Those opposed to the legalisation of euthanasia fear the practice will see highly vulnerable people presented with an invidious choice that will, over time, turn into an expectation. They fear that legalisation will usher in a change whereby society comes to privilege the quality of life over the fact of life itself, meaning that the state will in effect be stating that some lives are worth saving but others are not. Following this line of argument, members of marginalised groups—such as people with terminal illnesses, people with significant disability and particular groups of older people—will come to be viewed by society, and sometimes by themselves, as a burden, which will lead to external and internalised pressure on people to end their life. Opponents of euthanasia also fear that the involvement of doctors in legalised killing would see their role become intolerably compromised and would inevitably lead to poorer provision of other health care, especially palliative care.

These arguments have been rehearsed many times around the world and are well captured in the writings of two literary physicians, Atul Gawande from the United States and Australia's Karen Hitchcock.

Gawande has observed, 'We are running up against the difficulty of maintaining a coherent philosophical distinction between giving people the right to stop external or artificial processes that prolong their lives and giving them the right to stop the natural, internal processes that do so'.[68] While cautiously supporting the legalisation of euthanasia, he has urged caution, fearing the implications for the provision and development of good palliative care options.[69]

Hitchcock, meanwhile, opposes the legalisation of euthanasia, expressing strong concern about its implications for already vulnerable people and for society's obligation to care for them:

> If death becomes an option in the face of debility, then debility is turned into a lifestyle choice. Lifestyle choices are the responsibility of the individual. Our social responsibility is dissolved …
>
> Any attempt to make death easy will inevitably expose those in the community who are vulnerable to untimely deaths, to feeling worthless and burdensome. No panel of doctors or booklet of rules, no ream of checks and balances, can prevent this invisible coercion based on new social norms.[70]

Some forms of assisted dying have been lawful in overseas jurisdictions for some time, among them Canada, Switzerland, Belgium, Luxembourg, the Netherlands, and an increasing number of states in the United States.[71] In Australia, the Northern Territory enacted the *Rights of the Terminally Ill Act 1995*, but it was repealed by Commonwealth legislation in 1997. In every other Australian parliament apart from Queensland attempts have been made to enact assisted dying laws[72], but Victoria and Western Australia are the only jurisdictions to have succeeded.

In Victoria's case, voluntary assisted dying legislation was introduced into the parliament in 2017. The legislation was developed following an exhaustive review by a parliamentary committee and the release of the final report of a ministerial advisory panel that had been charged with developing a preferred model.[73] The legislation narrowly passed both houses with amendments after marathon sitting sessions in November 2017; it came into effect on 19 June 2019.

The Victorian legislation has multiple safeguards and limits assisted dying to adults who are in the last six months of life (or 12 months for people with neurodegenerative diseases) and who are able to make the decision to end their life. The person must also be experiencing suffering 'that cannot be relieved in a manner that the person considers tolerable'.[74] This has meant that large numbers of terminally ill people—for example, people with progressed dementia—are not candidates.[75]

Western Australia passed voluntary assisted dying legislation in December 2019; there will be an 18-month implementation period led by the state's Department of Health.

5.7 Future reform

A number of reform imperatives are apparent when it comes to the medical treatment of adults who do not have the ability to consent to that treatment. They range from reforms requiring broad societal change (such as improved knowledge of current protections) to more narrowly constrained ones (such as changes to the basis on which substitute decisions should be made).

Improved provision of health services

The first imperative is easily stated but difficult to put into practice. It concerns the need for health and support services to improve their delivery of services to people with significant cognitive impairment. Important initiatives are occurring in some jurisdictions, but this is an area where improvements are clearly required. They cover a vast array of practices, from ensuring that routine health checks occur to ensuring that treatments are not withheld on the basis of irrelevant and prejudicial views about a person's life trajectory and health expectations. On this latter point, anti-discrimination laws—particularly those prohibiting discrimination on the basis of age and disability—certainly apply: OPA wonders why they are not more frequently used.

Education of health practitioners

The field of medical treatment and adult protection is one in which sometimes quite advanced laws already exist, yet we know that health practitioners often are not conversant with the law relating to adults with cognitive disability. There are many reasons for this, among them current legal complexities as well as sociological considerations relating to the role of health professionals in society.

There is an obvious need for specific education and readily available information. Federal, state and territory health departments, statutory agencies, universities, and professional organisations and colleges all have responsibilities here. Ignorance of the law is never an excuse for breaking it.

Recommendation 5.1

OPA recommends that the Australian Government and state and territory governments ensure that health professionals are educated about any relevant laws governing consent in their jurisdiction; this includes people working in primary care and the aged-care, disability and mental health sectors.

Education of the general public

Members of the general public also need to be able to learn how they can play a role in their own medical treatment decision-making, how they can be supported, if necessary, in making decisions, and what they should do if they are called on or appointed to make decisions on behalf of someone else.

Chapter 6 looks at the general public's knowledge of advance planning processes (including the ability to create advance care plans and the appointment of decision-makers). It is worth noting here, though, that a need exists for simple information to be readily available to 'automatic' substitute decision-makers—those who find themselves in the role by virtue of their appearance at the top of a statutory list. (Developing information technologies could play a role here: the creation of an app, for instance, for such people is long overdue.) In addition, the needs of Australia's culturally and linguistically diverse communities must be met through the availability of both translated information and accessible interpreting services.

Promotion of supported decision-making

Decision-making relating to medical care is an area in which all people would, at least at some stage in their adult life, agree they would like to have better support in making their own decisions. People with significant cognitive impairment could plainly be better supported in this regard.

Much reform here can occur informally: one doesn't need to have special legal status to help a person make their own medical treatment decisions. Nevertheless, benefits do accrue from the kind of legislative reform that has occurred in Victoria, where 'support persons' can be appointed to assist with medical treatment decision-making by the person concerned. The benefits are twofold. First, they enable supporters to gain access to information that health records and privacy laws would perhaps inhibit. Second, such reform sends a signal about society's expectation that a person should play the central role in their own decision-making about medical treatment, even if that person has a cognitive impairment.

Recommendation 5.2

OPA recommends that state and territory governments in jurisdictions without such provisions amend their laws to enable the appointment of 'supporters' to help people with decision-making in relation to their medical treatment.

Substituted judgment

As noted, Australian state and territory medical treatment laws take differing approaches to substitute decision-making in relation to medical treatment: some opt for a best-interests approach; other laws take a substituted judgment approach; yet others adopt elements of both. Obviously, for the reasons set out in Chapter 1 and elsewhere in this report, the imperative is for a substituted judgment approach to become the norm.

Recommendation 5.3

OPA recommends that state and territory governments in jurisdictions without such provisions amend their medical treatment laws to ensure that substitute decision-makers are required to adopt a 'will and preferences' approach to decision-making.

Difficult cases

One truism of jurisprudence is that hard cases make bad law. In the medical treatment field it is important to remember that there will always be some cases that blur the line—if such a line really exists—separating clinical judgments from judgments about a person's quality of life. For example, a clinical determination about whether a potential treatment is 'unduly burdensome' or 'futile' can easily stray from being a professional opinion about the merits of a particular treatment and end up being a value judgment about the quality of a person's life. All we can hope is that clinicians, supporters and decision-makers are alert to these complexities and that, when making clinical determinations, clinicians are wary of taking into account irrelevant and prejudicial considerations.[76]

Euthanasia

Finally, as noted, legislative attempts have been made in almost all Australian jurisdictions to legalise euthanasia in one form or another, and it is likely that such efforts will continue until more assisted dying laws are enacted.

It is worth stressing, though, that such developments need to be accompanied by strong and visible protections to ensure that members of marginalised groups are not pressured, or do not feel pressured, to end their life earlier than they might otherwise have chosen. Such protections would include a range of elements, from narrow eligibility criteria—excluding, for example, the possibility of substitute decision-making—to the existence of strong prohibitions against undue influence and inducements for people to end their life.

6. Advance planning

Many people who are subject to adult protection interventions have or have previously had the ability to outline their preferences for the kinds of decisions that might one day be made about them and to nominate the people they would like to be involved in making those decisions. As discussed in Chapter 3, the most common disability among people for whom a guardian has been appointed is dementia, although mental illness and acquired brain injury feature strongly. Most people with a disability of this nature would have lived for considerable periods, perhaps even decades, during which choices about the future could have been canvassed and made.

‘Advance planning’ is the term given to the broad field of social and legal policy whereby choices for the future might be identified by an individual and later implemented if the individual has limited ability to make their own decisions. The term—and the similar ‘advance care planning’—is often associated solely with future medical treatment planning and decisions, but there is no reason for it to be confined to medical treatment.

Relatively clear instructions on how to engage in advance planning are becoming increasingly available at state and territory level in Australia,[1] and there are many reasons for this trend to continue. The reasons range from increasing consciousness of personal rights, the rise of consumer-directed care as a core delivery principle for social policy, medical developments that enable people to live longer, the ageing of the population generally, and rising health costs and healthcare expectations. Advance planning is one response to all these trends.

Although the notion of planning for the future might seem very straightforward, considerable legal, policy and philosophical questions abound. These questions concern the binding nature of future wishes, as well as the role of personally appointed future decision-makers, and they include the following:

- To what extent can and should an individual be able to make binding decisions about their future care and treatment? In other words, when should an individual be able to obligate their future self?
- When should such choices be activated?
- On whom should these decisions be binding?
- What circumstances should enable these decisions to be overridden?
- How much power should personally appointed decision-makers have?
- When should their powers be activated?
- On what basis should personally appointed decision-makers be able to act?
- How should they be monitored?

This chapter examines these questions. First, though, it is worth noting that there is a slow, seemingly inexorable trend towards allowing adults to make binding choices about their future care and treatment.

6.1 Human rights and advance planning

Human rights concerns about substitute decision-making and the developments that are occurring in relation to supported decision-making have clear relevance for advance planning, just as they do for the other subjects covered in this report.

The appointment of a future decision-maker can be an exercise in self-determination, yet the activities of such a person when their powers are activated can be every bit as disempowering as the activity of any other substitute decision-maker. The fact that the person in question appointed them will make little difference if obvious harm is being done.

Similarly, it is an exercise in self-determination for an adult to nominate decisions they would like honoured in future should specified circumstances arise. This can include the types of medical treatment the person would like, or not like, should a serious medical condition become apparent.

But even the strongest advocate of self-determination can envisage situations in which recognition of human rights would temper simple implementation of those choices. The most obvious example in this regard is the development of new medical treatments, unknown to the person at the time their instruction was issued, that the person would probably have wanted to make use of had they known about them. It would also, however, include situations where implementation of a directive would cause unforeseen harm to a person. Or there could be situations in which implementation of the person's directive ethically or legally compromises the individuals tasked with honouring the directive.

The ALRC's proposed 'national decision-making principles' have implications for advance planning, as they do for most other areas covered in this report. The commission's preference was for supported decision-making to be promoted, for substitute or 'representative' decision-making to be used 'only as a last resort', and for a substituted judgment ('will, preferences and rights') approach to be used whenever substitute decision-making was required. The commission also sought state and territory legislative reform that was consistent with these principles.[2]

Finally, this consideration of human rights must take account of the need for advance planning to serve the interests of the individual planner. Advance planning can be, and indeed should be, an exercise in self-determination. But it runs the risk of doing the opposite, of inhibiting autonomy, when, for example, it becomes a tool for dealing with the costs and complexities of ageing. Advance planning policies—particularly those that are medically oriented—can be viewed as a way of reducing health costs and administrative burdens on health and care agencies by encouraging people to say they do not want particular (and often costly) medical interventions towards the end of their life.

To be sure, advance health planning will often achieve both outcomes. It can be a mechanism whereby individuals express their desire not to have heroic medical interventions used in order to save them when they are near death, thus sparing them from the treatment and sparing their family members from feeling obliged to advocate for all available steps to be taken to keep them alive. This can be an exercise in self-determination and can result in cost savings.

The goal needs to be self-determination rather than cost constraints, and the balance can easily shift. It is thus good policy to enable a resident of an aged-care facility to nominate who should be making medical treatment decisions on their behalf if they are not able to make those decisions and to outline any advance wishes they have for particular treatment interventions. This is consistent with the goal of self-determination. A policy that would require advance plans to be prepared for all people entering aged-care facilities, as is sometimes recommended,[3] changes that characterisation and risks giving priority to administrative efficiency and cost containment as opposed to the goal of self-determination.

In short, it is important to ask whose interests are being served by advance planning.

Writer and physician Karen Hitchcock has urged caution in requiring the broad societal uptake of advance planning instruments:

> There is often in the advocacy for [advance] plans a whiff of resource-saving, of a belief that 'probably billions' are being wasted on the elderly. As such, there is a danger that we are not offering a real choice—even if we believe we are—but merely securing acquiescence'.[4]

6.2 Appointing supporters and substitute decision-makers in advance

All jurisdictions in Australia make provision for the appointment of substitute decision-makers through use of enduring powers of attorney or other appointing instruments.

The field of supported decision-making is emerging and, as discussed in Chapter 1, new supported decision-making legal entities are being legislatively created; examples are 'supportive attorneys' and 'support persons' in Victoria.

The theory behind supported decision-making is that people are supported in making their own decisions, which means the role of any legislatively created supported decision-making entity should last only as long as the person is able to make the decision with support. Technically, 'supportive attorneys' have the power to put decisions 'into effect' and, while this in theory could take place after a principal lost the ability to make the actual decision, the legislation makes clear that the appointment 'does not have effect for any period … during which the principal does not have decision-making capacity' for the relevant matters.[5] Interestingly, however, 'support persons' under Victoria's medical treatment legislation do have a role even after a patient's loss of decision-making ability. Although they do not have formal decision-making authority, their role is to help 'give effect to the person's medical treatment decisions' and 'to represent the interests of the person … including when the person does not have decision-making capacity'.[6]

As the ALRC has noted, there is broad consistency among Australia's states and territories concerning the ability of adults to appoint substitute decision-makers through enduring powers of attorney or similar instruments.[7] Important differences remain, however, and the goal of national consistency is unfulfilled. Some change is promised, though: the Australian Council of Attorneys-General has agreed to look at law reforms supporting the mandatory national register for enduring power of attorney instruments.[8]

In Queensland, the ACT and Victoria an individual can execute an enduring power of attorney that enables financial and 'personal' decisions to be made. 'Personal decisions' tends to be defined to include health and residential decisions, although in Victoria such decisions no longer include medical treatment. Separate legislation enables the appointment in Victoria of a 'medical treatment decision-maker'.[9]

South Australia provides for decision-makers to be appointed under advance care directives legislation; they can have the ability to make 'health care', 'residential' and 'personal affairs' decisions, while financial decision-makers can be appointed under the state's powers of attorney legislation.[10]

Tasmania, New South Wales and Western Australia all provide for financial decision-makers to be appointed under enduring powers of attorney while also retaining the 'enduring power of guardianship', under which accommodation and medical treatment decisions can be made.[11]

In the Northern Territory the *Advance Personal Planning Act 2013* enables individuals to make decisions about their 'care and welfare (including health care) and property and financial affairs'.[12]

In most jurisdictions representatives are able to be removed, usually by the tribunal that appoints guardians, if they are not complying with the requirements of the legislation under which they were appointed.[13]

Activation of enduring instruments

In Australia there is much variation in the time at which substitute decision-making appointments are activated. Tribunal appointments tend only to take place from a time when the tribunal considers an adult unable to make their own decisions (so long as other criteria are also satisfied), whereas individual appointments of substitute decision-makers can, in the case of some decisions, begin immediately, while the donor of the power (the 'principal') still has the ability to make their own decisions.

Most jurisdictions allow for personally appointed substitute decision-makers to make financial decisions from the time of their appointment. It is important to note, however, that people can, and often do, specify that such appointments should begin operation only when the principal loses the ability to make their own decisions. Health decisions, in contrast, tend to be able to be made only after the principal loses decision-making ability. The situation for other 'lifestyle' decisions (such as accommodation decisions) varies between jurisdictions.

In New South Wales an enduring power of attorney, under which someone can be appointed to make financial decisions, can operate immediately and continues to operate beyond a person's loss of decision-making ability.[14] In contrast, an enduring guardian in that state, who can, depending on the terms of the appointment, have health and other personal decision-making powers, has power to act only when the person is 'incapable of managing his or her person'.[15]

Similarly, in Western Australia an enduring power of attorney can enable substitute financial decisions to be made from the time of execution, and this power survives 'the subsequent legal incapacity' of the maker.[16] An enduring guardian can act only when the person 'is unable to make reasonable judgments in respect of matters relating to his or her person'.[17]

Victoria's *Powers of Attorney Act 2014* provides that the power to make financial and/or personal decisions is 'exercisable' from the date it is conferred, unless the principal specifies otherwise.[18] The power to make substitute medical decisions applies only 'to a person who does not have decision-making capacity' in relation to the particular medical treatment decision that is to be made (and who does not have a relevant instructional directive).[19]

Financial powers exercisable under an enduring power of attorney in South Australia can operate immediately; they can be expressed to operate ‘notwithstanding the donor’s subsequent legal incapacity’ or ‘in the event of the donor’s subsequent legal incapacity’. In contrast, under that state’s advance planning legislation, which can cover a broad array of medical and personal decisions, a substitute decision-maker can make a decision only if the person ‘has impaired decision-making capacity in respect of the decision’.[20]

In Queensland a principal can activate a financial enduring power of attorney immediately, the default time of activation being the execution of the document. Decisions by an attorney on a ‘personal matter’ are able to be made only ‘during any or every period the principal has impaired capacity for the matter and not otherwise’.[21]

In the Northern Territory personally appointed substitute decision-makers can exercise their authority only ‘when the represented adult has impaired decision-making capacity for the matter’.[22]

In Tasmania financial powers under an enduring power of attorney can operate upon execution, but an enduring power of guardianship can operate only if the person ‘subsequently becomes unable by reason of a disability to make reasonable judgements in respect of matters relating to his or her personal circumstances’ (although the legislation suggests alternative conditions might be able to be placed on this power).[23]

In the ACT an enduring power of attorney can operate while the principal is able to make their own decisions, but it operates as a general power of attorney in relation to property matters. This suggests that decisions on ‘personal matters’ are exercisable only when the principal has ‘impaired decision-making capacity’.[24]

At the heart of these varying legal requirements and possibilities—and perhaps in explanation of just why there are so many possibilities—lies a complex policy and human rights debate.

It is widely recognised that a person’s capacity to make a particular decision is specific to that decision. A man with quite progressed dementia, for example, might have the ability to make a decision about where he would like to live but no longer have the ability to make a complex financial decision, such as how his superannuation funds might best be invested. A person with mental ill-health might have fluctuating ability to make decisions.

The widely used New South Wales *Capacity Toolkit* notes:

> It is very rare for a person not to have capacity for any decisions. However, this can happen when a person is unconscious or has a severe cognitive disability, for instance.
>
> More often, people lack capacity only in making one sort of decision …
>
> Capacity varies from person to person and from situation to situation. Capacity is not something solid that you can hold and measure. Neither is it something that is the same all the time. It is affected by a person’s abilities and by what’s happening around them …
>
> Also, each person’s capacity can fluctuate, depending on things such as their mental and physical health, personal strengths, the quality of services they are receiving, and the type and amount of any other support …

> It is essential to remember that capacity is decision specific. This means that, where there is doubt, a person's capacity must be reassessed every time a decision needs to be made.[25]

In these circumstances the human rights–compliant practice should be to enable and support the person in making the decisions themselves where that is at all feasible. This would mean waiting, if possible, until the person is well enough to make the decision for themselves. For the person with dementia it would mean allowing them to make the decision about where to live while helping them make, or indeed making on their behalf, the decision about how to invest their money.

In addition to capacity being decision-specific, it is also important to recognise the law's, and third parties', preference for certainty. The operational preference of banks and hospitals, for example, will clearly be for some degree of certainty in relation to the legal authority of substitute decision-makers. This would be provided were there to exist a kind of capacity or ability 'bright line'—a point in time after which a person no longer has the ability to make their own decisions.

In defence of this preference, it is also important to take account of the difficulties presented to third parties if there were to be a legal requirement that barred them from relying on any substitute decision that was made when the person concerned was able to make that particular decision. It would simply not be practical, for example, for a bank teller to seek evidence of a person's inability to make their own decision for every transaction they conducted with an otherwise appropriately empowered attorney.

So what would characterise a policy outcome that recognises both the human rights principle that capacity or decision-making ability is decision-specific and that provides sufficient certainty for third parties and for others who seek to implement and recognise substitute decision-making appointments?

This question has been wrestled with in many forums and inevitably results in compromise. In 2009, during a parliamentary committee inquiry into powers of attorney, OPA argued that the best compromise would be to give people making substitute appointments the freedom to activate them immediately, thereby avoiding the need for capacity assessments to be done.

OPA proposed that all enduring powers of attorney should be able to be activated immediately. In evidence to support this stance, Chesterman pointed out:

> If you say enduring powers of attorney can only be activated when someone lacks capacity and a person has fluctuating capacity, there is a question about whether the enduring power of attorney is being appropriately used. It is even more complex if you think about capacity as being decision-specific … A person might have capacity to make some decisions but not others, so the appropriate use of an enduring power of attorney here, requiring the person to be lacking capacity in regard to the particular decision, is very difficult to be certain about.

The parliamentary committee agreed and recommended that enduring powers of attorney become active immediately, unless principals specified otherwise.[26]

This compromise result would mean that principals and representatives would each have power to make decisions. The danger with this, of course, is that it can result in substitute decisions being made long before principals have any decline in their decision-making abilities.

This is a complex problem and, as with other complex problems discussed in this chapter, the best way to deal with it is to alert people to it in advance and let them decide how they would like to respond. Giving people the opportunity to make appointments active from the date of their execution allows them to avoid the need for capacity assessments in relation to their instruments' activation. Similarly, allowing people to decide that the instrument will come into effect only when they are unable to make decisions ensures that their decision-making authority will remain with them for as long as possible, although this option carries with it the uncertainty related to the need for the person's decision-making ability to be assessed, perhaps many times.

The basis on which substitutes act

A central theme of this report is the clear trend whereby reforms are requiring substitute decision-makers to adopt a substituted judgment approach rather than making decisions that accord with their personal view as to the 'best interests' of the person in question. It is worth reiterating here the point, made in Chapter 3, that this trend increasingly sees substitute decision-makers as conduits or channels through which the decisions of the person concerned can be implemented.[27]

This will generally be unproblematic, although it is likely to give rise to ethical headaches for some substitute decision-makers. In the field of medical treatment it is very likely to be relatively straightforward: advance planning is widely discussed and practised and medical decision-making is tightly constrained by well-developed and, in some cases, centuries-old ethical norms and practices. These norms and practices serve to limit the types of medical treatments doctors and other health professionals would be willing to provide and thus limit the kinds of decisions able to be made by substitute decision-makers.

A patient might, for example, express in an advance directive a wish to receive an obscure and untested medication but, unless a medical practitioner was willing, and indeed able, to prescribe it, the person's substitute decision-maker would not be in a position of having to decide whether or not to give consent.

Advance planning is, however, possible in other areas that are less subject to strong ethical principles and practice constraints. Take, for instance, a possible future accommodation decision. In an advance plan a woman might express a desire to live in a particular boarding house if she loses the ability to continue living independently in her own home. If in time a substitute decision is needed, should the decision automatically be that the woman moves into the specified boarding house, regardless of the condition it is in? Or what if, as in the case of one OPA guardianship client, the person has expressed a desire to be homeless? What if the person asserted that they wanted to live under a bridge? When might a person's advance wishes be considered so potentially detrimental to their health that a substituted judgment approach would be considered unethical?

In reality, any case that generated such concerns would not be answered through recourse to an abstract principal: it would be considered and resolved through engagement with the detail of the person's life. The man who wanted to be homeless might in fact be expressing a desire to associate with former friends who were homeless or might be wanting to avoid living with family members. This could perhaps be worked through, and a legitimate honouring of the person's wish might be possible. The point to be made here is that such situations will become increasingly common as substituted judgment becomes the basis for substitute decision-making.

When it comes to the requirements in Australian powers of attorney and advance planning legislation, several variations exist.

Powers of attorney legislation typically requires appointed attorneys to have regard to the wishes of the principal but to follow a best-interests model when making any decisions in situations where the principal is unable to make decisions. A best-interests model takes into account the wishes of the principal, but these wishes do not necessarily dictate what decision is made.

Victoria's *Powers of Attorney Act 2014*, for example, obliges attorneys to 'give all practicable and appropriate effect to the principal's wishes' and to 'act in a way that promotes the personal and social wellbeing of the principal'.[28] Queensland's *Powers of Attorney Act 1998* contains 'general principles' governing the actions of attorneys. Although these state that 'the principle of substituted judgment must be used', the attorney is only required to 'take into account … the adult's views and wishes' and must exercise their power 'in a way consistent with the adult's proper care and protection'. That Act's 'health care principle', meanwhile, requires an attorney exercising health powers to take account of the person's views but to act in their 'best interests'.[29]

Jurisdictions with advance planning legislation tend to require that substitute decision-makers use a substituted judgment approach to their decision-making. This is consistent with Australia's National Framework for Advance Care Directives, which contains a Code for Ethical Practice for Advance Care Directives. The code notes that substitute decision-makers have 'an obligation to make the decision the person would have made in the current circumstances had decision-making capacity not been impaired'.[30]

The Northern Territory requires an appointed substitute decision-maker to adopt a substituted judgment approach but provides exceptions if doing so would be 'impracticable' or would place an 'unreasonably onerous' burden on someone or, indeed, if doing so 'would be so unreasonable that it is justifiable to override the adult's wishes'.[31]

Victoria's legislation allows fewer exceptions to the requirement for substitute medical decision-makers to use a substituted judgment approach. It provides only that in situations where 'it is not possible to ascertain or apply the person's preferences or values' the decision-maker must 'make a decision … that promotes the personal and social wellbeing of the person'.[32]

South Australia's legislation outlines the expectation that a substitute decision-maker 'must, as far as is reasonably practicable, reflect the decision that the person would have made in the circumstances' and, if no specific views have been expressed, make decisions that are 'consistent with the proper care of the person and the protection of his or her interests'.[33]

6.3 Advance directives

The term 'advance directive' tends now to be used to refer to legislatively authorised directions concerning a person's future (typically medical) treatment, for which there are usually prescribed requirements. The common law has, however, long recognised some forms of advance directives—particularly advance refusals of treatment,[34] which can take the form simply of notes made by the person. Increasingly, though, Australia's states and territories have legislated to encourage and regulate the making of advance directives.

Ethical considerations

Section 6.2 discusses the ethical concerns that can arise when substitute decision-makers are required to adopt a substituted judgment approach and are in the position of implementing wishes they disagree with or feel compromised in implementing because of the harm they perceive might be caused to the principal. The same considerations apply when an advance directive is required to be acted on without the mediation of a substitute decision-maker. Here the question will be the extent to which a doctor, for example, acts on a binding advance directive in a situation where clinical practice would normally require treatment and where an adverse outcome, even death, results.

Almost always this will occur in the health field since there are few other areas where a written instruction can be expected to be relied on without the advocacy, or indeed decision-making authority, of a representative. Nevertheless, this situation will probably change at some stage, given the current path of human rights developments.

So the ethical question—routine in the realm of adult protection—is when should such an exercise in self-determination be overridden through the operation of protective safeguards?

In some circumstances the answer to this question is reasonably clear-cut. For example, few would argue against overriding a person's written advance decision if an unforeseen medical breakthrough could probably have changed a person's advance refusal of all future medical treatment.

The answer is less clear-cut, though, when there is merely a concern or a suspicion that a person's expression of their wishes for their future care, made when they were considering their hypothetical future, no longer reflects their current view (were they able to express it). That might be because of medical or other developments, or it might also be because the person outlined their views in the context of an unpalatable and abstract future without great insight into the person they would become and the choices they would confront. Humans' views can readily change in response to experience and developments. The challenge for advance planning is that advance plans come to be put into effect when the person is no longer the person they were, because of illness or accident. In these circumstances, implementation of the person's pre-illness or pre-accident wishes might not accord with the wishes they might have expressed had they known more about the situation in which they would later find themselves.

An obvious example might be a young, athletic woman who has expressed her desire to refuse all medical interventions should she ever have an accident or illness that leaves her without use of her legs. It is unlikely this woman would hold such a view if a car accident left her in that situation: in time, she would very probably find different ways to make her life fulfilling. The philosophical difficulty arises when we imagine that the woman completed a binding advance directive and her car accident leaves her in a coma, without the ability to clarify a change in her view. What are the ethical implications if her directive is honoured in the name of self-determination and she dies without the opportunity to receive potentially life-sustaining treatment?

Medical directives

In 2011 the Australian Health Ministers' Advisory Council produced a National Framework for Advance Care Directives, which sought to outline consistent terminology and expectations in relation to the production and regulation of advance health care directives. It contained a ‘code for ethical practice’ made up of 15 elements, as well as ‘best practice standards’. Among other things, the framework identified ‘substituted judgement as the primary decision-making standard’ for substitute decision-makers.[35]

The discussion that follows focuses on people’s documenting of their wishes for future medical treatment. A preliminary and important point needs first to be made, however: it concerns the crucial role of conversations between health professionals, patients and their supporters in the advance planning process and in the ultimate provision of care.

As noted in Chapter 5, laws and legal frameworks dealing with the provision of medical treatment tend to suppose, and model, a contractual paradigm: the health clinician diagnoses a condition and concludes by offering one or more treatments to a patient, and the patient, or their authorised representative, accepts or refuses that offer. Yet medical practice tends to operate more on a ‘consensus’, or even ‘shared decision-making’, model, whereby clinical determinations are arrived at more iteratively, with treatment options discussed and patients’ and supporters’ views sought, before consensus is reached about the treatment that will be provided.

The relevance of this for advance planning is clear: there is a risk that the legal or contractual paradigm might achieve undue prominence if a patient is unable to express their thoughts about future treatment options but earlier written instructions by them ‘set their views in stone’.

Research shows us that conversations are a more crucial aspect of the advance planning process than are any documents that result from it. As Detering and colleagues argued:

> The focus of advance care planning needs to be on improving communication between patients, their families, and doctors. Although documentation is often completed during the process of advance care planning, documentation alone is unlikely to improve outcomes.[36]

The more that conversations can be held between patients and health professionals as part of the advance planning process, the better any resultant documents, and indeed the ultimate outcomes, will be.

As discussed in Chapter 5, recent research shows that, despite the existence of different laws, the notion of good clinical practice tends to outweigh legal requirements in the minds of doctors.[37] This points to the law sometimes being viewed by doctors as suggestive rather than obligatory, which certainly should encourage a somewhat sanguine reading of the following paragraphs.

A number of Australian jurisdictions now provide for the use of either binding or suggestive advance plans.

South Australia’s advance care legislation enables ‘binding’ refusals of health treatment and provides exemptions for not following them if to do so would be illegal or would cause a breach of a ‘professional standard or code’.[38]

Advance medical treatment directives operate in Western Australia unless an unanticipated situation arises that would probably have caused the person to change their mind.[39]

In Queensland advance health directives can operate as binding advance consent to or refusal of future medical treatment, although the ‘direction to withhold or withdraw a life-sustaining measure' is valid only if the person is expected to die within 12 months or is 'in a persistent vegetative state' or 'is permanently unconscious'.[40]

Northern Territory legislation provides for 'advance consent' to be given to health treatment. Exceptions apply if circumstances suggest the person would not have wanted their consent to have been given, if the provision of treatment would cause 'unacceptable pain and suffering' or if it 'would otherwise be so wholly unreasonable that it is justifiable to override the adult's wishes'.[41]

Victorian legislation permits two kinds of advance directives to be completed. 'Values directives' can contain the general thoughts and wishes of a person in relation to medical treatment and life in general; these directives are then required to guide the person's 'medical treatment decision-maker' in making decisions when the person is no longer able to make such decisions on their own part. 'Instructional directives' can operate as advance consent to or refusal of particular medical treatments if the person does not have the ability to make such decisions. They thus obviate the need for a substitute medical decision-maker, and they are binding in the absence of a change in circumstances that suggests 'the practical effect of the instructional directive would no longer be consistent with the person's preferences and values'.[42]

It is important to note here that even technically 'binding' directives cannot oblige clinicians to provide treatment. The decision whether to offer treatment is ultimately a clinical one, and clinicians are generally under no obligation to provide futile or unduly burdensome treatment. (Note that in Queensland consent must be provided when a decision is made to withdraw a 'life-sustaining measure' owing to the broad definition of 'health care' in that state's guardianship legislation).[43]

Euthanasia

Euthanasia is a topic perennially, if tangentially, associated with advance planning. Chapter 5 describes some of the attempts to legalise various forms of euthanasia, including the voluntary assisted dying legislation which came into operation in Victoria in 2019.[44] Some people want to be able to empower, or even require, others to help them end their life should they lose the ability to make their own decisions and should other criteria be met.

Legislation such as that in operation in Victoria allows people access to voluntary assisted dying only if they have the ability to make the decision to end their life when they are sufficiently close to death. The legislative scheme is thus unavailable to people with advanced dementia or other major cognitive impairments, so for them voluntary assisted dying is not an advance planning option.

People in some jurisdictions can, as noted, create binding directives whereby they can refuse future medical interventions (which may result in their death), but this is in no way the same as requiring, at some future time, the provision of a drug that will cause death. The doctrine of 'double effect' does exist for some in a legal grey area—or some might call it a legal fantasy—in allowing the provision of pain relief such as morphine in sufficient quantity as to hasten death. According to the doctrine, this can be done only if the primary reason for the drug's provision is pain relief. The primary aim cannot be the bringing about of death, even though this can be an effect.

Advance planning in Australia does not at present incorporate euthanasia as an option.

6.4 Future reform

There are six broad areas in which future reform is probable and warranted—public education, promoting conversations, binding advance directives, empowering supporters, substituted judgment, and improved safeguards.

Public education

Public knowledge about advance planning is not well-developed. Although there is little survey information available to back up this claim in relation to non-medical advance planning, it is certainly the case in relation to medical treatment, the field in which advance planning has the longest history. Even the expert service providers, in this case doctors, struggle to know the legal limits of and possibilities for advance planning.

Chapter 5 highlights doctors' limited knowledge of the law in relation to substitute consent to medical treatment. When it comes to advance planning laws, a 2016 study of 389 Victorian doctors found that doctors' knowledge is patchy at best. In the study, jointly auspiced by the Australian Medical Association (Victoria) and the state's Department of Health and Human Services, the 389 doctors were asked 10 treatment-related questions that covered, among other things, refusal of treatment, the role of representatives, interpretation of advance plans, and the use of palliative care. The average number of correct answers to the 10 questions was six: no one correctly answered all questions. The authors identified 'a significant lack of certainty amongst respondents'.[45]

The implications of this for the operation of advance planning are of course important. Even if members of the general public somehow happened to know more than doctors about advance medical planning—and there is no reason to think this is the case—doctors are important 'gatekeepers': they are usually required to acknowledge the existence of and implement advance plans if the plans are to be operational.

There is clearly a case for substantial public education in relation to advance planning, both within and outside the field of medical decision-making.[46]

One particular challenge in this regard concerns the provision of information to culturally and linguistically diverse communities, and to Indigenous Australians. The challenge involves the promotion of conversations, rather than simple translation of material into culturally appropriate and sensitive resources. This in turn requires, among other things, familiarity with basic concepts and engagement with culturally specific decision-making processes where they exist; it will often also require tailor-made modes of providing information.[47]

Inclusive public education dealing with the potential benefits of advance planning for people with disability is also important, especially for groups of people made invisible by virtue of assumptions about their disability—for example, people with mental illness or intellectual disability.

Recommendation 6.1

OPA recommends that state and territory governments conduct public education campaigns to promote the value of advance planning for medical, financial and lifestyle decisions—including in relation to the use of enduring powers of attorney and advance directives.

Promoting conversations

Research consistently reveals that the most important element in advance planning is not the documentation of the thoughts and expectations of the person concerned: it is the conversations that are held between that person, the relevant professionals, and the person's family or supporters.[48] This will typically involve discussion of the kinds of thoughts that should influence future decision-making and that will enable future decision-makers to know the parameters and considerations they should entertain if the time comes for them to make decisions.

Any future reform should therefore focus on promoting such conversations. State and territory health departments have already made inroads here; Victoria's advance care planning strategy, for example, is subtitled 'Have the Conversation'.[49] Any other initiatives that seek to promote discussion by people about their future life and possible future decisions will be welcome. For example, OPA developed the free booklet *Your Voice—trust your choice: tips for seniors making enduring powers of attorney*, which encourages older people to talk to potential supporters and helps them make decisions about enduring power of attorney appointments.[50]

All the time, of course, as Hitchcock has written, one needs to be mindful of just whose interests are being served by the promotion of advance planning.[51] It is necessary to ensure that advance planning is ultimately, and meaningfully, a matter of individual choice.

Binding advance directives

Another reform imperative involves enabling people who wish to do so to document suggested and binding directions about their future treatment in the event that they are unable to make their own decisions. The challenge here is to set the right parameters. OPA proposes that we allow people to decide their own future, even when they can no longer make their own decisions. We also need not to unduly bind people to decisions they probably would not later have made and not to place substitute decision-makers in untenably compromised situations from an ethical perspective.

What would this mean in practice?

Binding directions should be possible in relation to medical treatment, with clear exceptions existing when circumstances suggest the person would have made a different decision.

Such directions should also be possible in relation to other, non-medical decisions, although there would need to be a wider basis for non-compliance, for reasons to do with the absence of similar practice norms that contain possible medical interventions. That qualification could, for example, provide that advance plans should be implemented 'unless to do so would cause significant financial or personal harm' to the person concerned.

Recommendation 6.2

OPA recommends that state and territory governments in jurisdictions without such provisions legislate to enable people to make binding advance directives in medical and non-medical areas. These should be applicable in all but two circumstances: if implementing the directive would cause serious financial or personal harm to the person concerned and if the circumstances suggest that the person would have made a different decision.

Empowering supporters

Legal developments empowering supporters to help adults with their decision-making are becoming increasingly common. Further reforms might lead to supporters being empowered to assist principals with advance planning decision-making and carrying out advance plans, even when the principal no longer has the ability to make their own decisions.

As discussed, recent Victorian developments have seen the supporter role extend into assisting with putting decisions 'into effect'. This is complex terrain since it can be unclear whether the power to put a decision into effect carries with it some degree of decision-making power itself.

Despite this complexity, further reform along these lines is likely. One possibility is that future legislative description of the role of supporters will clarify that a supporter's role can continue even after the principal loses the ability to make their own decisions. Victoria's medical treatment legislation now does this, although the envisaged scenario justifying this extension of the 'support person' role is a procedure or series of procedures the patient anticipated and made decisions about but that result in the patient being unable to make decisions at the relevant time—for example, if complications arise when the principal is unconscious but the principal had foreshadowed such complications and made decisions in that regard.

Extending the role of supporters more broadly—to enable them to help carry out the decisions of principals who no longer have the ability to make decisions—does present some philosophical challenges for the role of supporters: normally their role ceases when the person they are supporting loses the ability to make (with support where necessary) their own decisions. And yet this development would allow supporters to play a greater role in advance planning. They could be both decision-making supporters and later advocates, and this certainly would result in principals having a greater say over future decisions that affect them.

Substituted judgment

The fifth advance planning area for potential reform concerns clarification of the basis on which a substitute decision-maker should act. Increasingly, as noted, reforms that see substituted judgment as unequivocally the preferred option, in preference to a best-interests approach, have been called for and implemented.

This reform process is consistent with giving priority to the wishes of the individual concerned over what others think is best for them, but it will also probably give rise to considerable ethical and legal complexity in a small but significant proportion of cases, when representatives find themselves in the position of making decisions on things about which an individual expressed clear wishes but that the representatives consider will place the individual at undue risk. This is more likely to be a problem in relation to non-medical decisions, since medical ethics and norms constrain the scope for possible future medical decisions.

This situation will best be dealt with through the development of detailed legal and ethical guidelines on the way substitute decision-makers should act. Such guidelines will be needed to help decision-makers assess possible risks and determine what thresholds should be reached before they either seek to act in a manner contrary to the principal's wishes or seek to excuse themselves from the role of substitute decision-maker. This will undoubtedly give rise to applications from substitute decision-makers to guardianship tribunals for authority to act in a manner that is consistent with the spirit rather than the letter of the principal's expressed wishes.

The reform suggestion advanced here is for legislative expression of the same qualification OPA suggested in relation to implementation of non-medical advance directives—namely, that a substituted judgment approach should be required of representatives in relation to non-medical decisions 'unless this would cause significant financial or personal harm' to the person concerned.

Recommendation 6.3

OPA recommends that state and territory governments in jurisdictions without such provisions amend their advance planning laws to ensure that substitute decision-makers are required to act on a substituted judgment ('will and preference') basis unless this would cause serious financial or personal harm to the person concerned.

Improved safeguards

Finally, numerous inquiries have heard and found that advance planning processes can provide avenues for the committing of crimes and that advance planning documents can be used as instruments of abuse.[52] Although existing crimes, such as theft, apply, there is very little prosecution in relation to the abuse of advance planning processes such as substitute decision-making powers.

Important reforms here deal with policing improvements and better responses to the abuse of at-risk people. In recent times that has included people with disability and victims of elder abuse.

In addition to calls for improvements to service responses, a number of specific safeguards associated with advance planning have been sought. The challenge here is to provide protections that do not unduly inhibit the legitimate use of advance planning mechanisms.

Offences for misuse of powers of attorney

Among the possible safeguarding improvements is the creation of specific offences in relation to advance planning. Victoria, for example, has created offences in relation to the dishonest use or acquisition of powers of attorney, which other jurisdictions have been encouraged to emulate.[53]

Some jurisdictions do provide recourse for compensation to be paid by representatives who breach their legislative duties,[54] but Victoria's powers of attorney legislation enables the state tribunal to order attorneys to pay compensation to aggrieved principals for losses occasioned by the attorney's breach of the law.[55] In its final report on elder abuse the ALRC called for state and territory tribunals to have jurisdiction and powers comparable to those of supreme courts when it comes to possible actions against substitute decision-makers who 'abuse, or misuse,' their powers.[56]

Recommendation 6.4

OPA recommends that state and territory governments enable tribunals to make compensation orders and apply penalties when substitute decision-makers abuse or misuse their powers.

In view of the prohibitive cost of court action, a nationally consistent reform of this nature would constitute a big improvement to the ability of victims of this kind of abuse to gain access to justice.

Registration of directives and appointments

One popular and very important, albeit costly, reform recommendation concerns compulsory registration of advance directives and instruments whereby representatives and supporters are appointed, either by the person in question or by a tribunal.

Advance planning documents—including enduring powers of attorney—have long been seen as private documents. At the time they are needed, though, how does someone know they exist or that they are the most recent expression of a person's wishes? Mandatory registration of such documents would solve this problem and at the same time establish a threshold or hurdle that might serve to discourage fraudulent execution or use of such documents.

Law reform commissions and other inquiry bodies have often called for mandatory registration of advance planning documents and appointments. For example, the VLRC has sought the compulsory registration of personal and tribunal appointments of substitute and supported decision-makers and the voluntary registration of advance directives.[57] The Queensland parliamentary committee inquiry into 'financial protections for Queensland's seniors' called for mandatory registration of powers of attorney.[58] The ALRC has proposed 'a national online register of enduring documents, and court and tribunal appointments of guardians and financial administrators' once national agreement can be reached on consistent enduring appointment laws.[59] And Western Australia's Select Committee into Elder Abuse has recommended that the state investigate developing its own central register of enduring powers of attorney.[60]

The ALRC's recommendation for a national online register has been taken up. The feasibility of developing such a register for enduring powers of attorney is being investigated, with support from the Commonwealth Attorney-General's Department, as one of the actions under the Implementation Plan to Support the National Plan to Respond to the Abuse of Older Australians 2019–2023.[61] The features and design of the register are being negotiated, and differences in state and territory legislation and local priorities are playing a role in the discussions. Some jurisdictions do not at present support making registration mandatory.

Particular questions arise in relation to when registration should be required and what registration should entail. Should registration be required at the time of execution or at the time of activation? Should registered documents be checked for completeness? Who should have access to the registry? How should privacy concerns be dealt with?[62] These questions are being examined in the discussions about the development of a national online register.

Registration of medical advance directives and other advance planning documentation is now possible with the My Health Record facility. However, unless such registration were to become mandatory, or at least highly utilised, it is unlikely that health professionals would routinely check the facility for evidence of advance plans made by their patients.

Difficult as it might seem, registration of advance planning documents is the most obvious of all advance planning reform imperatives and work is under way at the national level to achieve this.

Endnotes

1. Human rights developments

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22 *Advance Personal Planning Act 2013* (NT) s 20.

23 *Powers of Attorney Act 2000* (Tas) s 31; *Guardianship and Administration Act 1995* (Tas) s 32.

24 *Powers of Attorney Act 2006* (ACT) ss 9, 31.

25 Attorney-General's Department of NSW, *Capacity Toolkit* (NSW Government, 2009) 19–23.

26 Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney* (2010) 91–93. Note that while the committee's terms of reference enabled it to inquire into enduring powers of guardianship (under which medical treatment decisions could then be made) they did not extend to the enduring powers of attorney (medical treatment) that could then be made under the *Medical Treatment Act 1988* (Vic).

27 See, eg, Australian Law Reform Commission, *Elder Abuse – A National Legal Response*, Report No 131 (2017) 164.

28 *Powers of Attorney Act 2014* (Vic) s 21.

29 *Powers of Attorney Act 1998* (Qld) sch 1 cl 12.

30 Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, *A National Framework for Advance Care Directives* (2011) 15.

31 *Advance Personal Planning Act* (NT) s 23.

32 *Medical Treatment Planning and Decisions Act 2016* (Vic) s 61.

33 *Advance Care Directives Act 2013* (SA) s 10.

34 See, eg, Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) 211–213

35 Clinical, Technical and Ethical Principal Committee of the Australian Health Ministers' Advisory Council, above n 30, 18.

36 Karen Detering et al, 'The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial' (2010) 340 *British Medical Journal*, 7. See also Hitchcock, above n 4, 49–50.

37 Ben White et al, 'Comparing Doctors' Legal Compliance Across Three Australian States for Decisions Whether to Withhold or Withdraw Life-Sustaining Medical Treatment: Does Different Law Lead to Different Decisions?' (2017) 16 *BMC Palliative Care* 63.

38 *Advance Care Directives Act 2013* (SA) ss 12, 19.

39 *Guardianship and Administration Act 1990* (WA) s 110S.

40 *Powers of Attorney Act 1998* (Qld) ss 35, 36.

41 *Advance Personal Planning Act* (NT) s 41.

42 *Medical Treatment Planning and Decisions Act 2016* (Vic) pt 2, s 51.

43 *Guardianship and Administration Act 2000* (Qld) s 79, sch 2.

44 *Voluntary Assisted Dying Act 2017* (Vic).

45 Australian Medical Association Victoria and Department of Health and Human Services Victoria, *Advance Care Planning: Have the Conversation. Result of a Survey of Doctors' Knowledge* (AMA Vic and DHHS, 2016). The laws in Victoria have changed since the survey was conducted, with the enactment of the *Medical Treatment Planning and Decisions Act 2016* (Vic).

46 See, for instance, Hal Swerissen and Stephen Duckett, *Dying Well* (Melbourne: Grattan Institute, 2014), pp. 22, 29.

47 For a discussion of some of the complexities here, which in this case concern education about protections against, and responses to, elder abuse, see Legislative Council General Purpose Standing Committee No. 2, Parliament of New South Wales, *Inquiry into Elder Abuse in New South Wales* (2016) 36–40.

48 See Detering et al, above n 36; Cognitive Decline Partnership Centre and HammondCare, *Future Planning and Advance Care Planning: Why it Needs to be Different for People with Dementia and Other Forms of Cognitive Decline* (CDPC and HammondCare, 2016) 5.

49 Victorian Department of Health, *Advance Care Planning: Have the Conversation* (a strategy for Victorian Health Services 2014–2018). See also Atul Gawande, *Being Mortal: Illness, Medicine and What Matters in the End* (Profile Books, 2014) 180.

50 Office of the Public Advocate, *You Decide Who Decides: Enduring Powers of Attorney Explained* <http://www.publicadvocate.vic.gov.au/you-decide-who-decides/>.

51 Hitchcock, above n 4, 49.

52 See Australian Law Reform Commission, *Elder Abuse*, above n 7, 85; Legislative Council General Purpose Standing Committee No. 2, above n 47, 83–88; Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into the Adequacy of Existing Financial Protections for Queensland's Seniors* (2015) 147–9; Victorian Law Reform Commission, above n 34, 183, chpt 18; Law Reform Committee, Parliament of Victoria, *Inquiry into Powers of Attorney* (2010) 27–30.

53 *Powers of Attorney Act 2014* (Vic) pt 9. See Legislative Council General Purpose Standing Committee No. 2, above n 47, 101.

54 See, eg, *Powers of Attorney Act 1998* (Qld) ss 66, 106.

55 *Powers of Attorney Act 2014* (Vic) s77.

56 Australian Law Reform Commission, *Elder Abuse – A National Legal Response*, above n 27, 177, rec 5–2.

57 Victorian Law Reform Commission, above n 34, 364–5.

58 Communities, Disability Services and Domestic and Family Violence Prevention Committee, above n 52, 152. See also Law Reform Committee, above n 52, 236.

59 Australian Law Reform Commission, *Elder abuse – A National Legal Response*, above n 27, 181.

60 Legislative Council Select Committee into Elder Abuse, Parliament of Western Australia, *'I Never Thought it Would Happen to Me': When Trust is Broken* (2018)

61 Council of Attorneys-General, *Implementation Plan to Support the National Plan to Respond to the Abuse of Older Australians 2019-2023* (2019).

62 For a good discussion on this topic, see Victorian Law Reform Commission, above n 34, chpt 16.

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