



**ACT HUMAN RIGHTS
COMMISSION**

Australian Capital Territory

Submission to

ACT Law Reform Advisory Council

Reform of guardianship arrangements for adult people

Introduction

Thank you for the opportunity to comment on this review. We note that the Terms of Reference include discussion of the ACT *Human Rights Act 2004* and the United Nations Convention on the Rights of Persons with Disabilities (CRPD), but explicitly exclude guardianship-like arrangements for children from this Review.

Therefore, while the ACT Human Rights Commission encompasses three Commissioners across a range of jurisdictions, this submission has been prepared Helen Watchirs, Human Rights and Discrimination Commissioner and Mary Durkin, who is both the Disability and Community Services Commissioner and Health Services Commissioner.

The Commission welcomes this Review, which comes at a critical time for the rights of people with a disability. There has been significant debate about the future of guardianship laws in light of the CRPD, which is particularly relevant in a human rights jurisdiction such as the ACT. Some commentators see the UN General Comments as ‘wanting in key respects’.¹ It is also relevant that this Review comes at a time when the ACT Government is transitioning to the new model of service delivery under the National Disability Insurance Scheme (NDIS). As Gerard Quinn, Professor of Law at NUI Galway, recently commented:

‘The issue of legal capacity reform is probably the most important issue facing the international legal community at the moment. It potentially affects everyone in their own lives – and everyone has a stake in the debate. This is because the issues at stake actually transcend disability and cut to the heart of what we mean to be human.’²

This Review represents both an opportunity and a challenge to the ACT Government and broader community. An opportunity to fully realise our status as a human rights jurisdiction by implementing at a local level some of the most significant changes to the lives and independence for people with a disability contemplated by western democracies; and a challenge not to over-reach or under-invest in such reform, and risk further limiting the human rights of people with disabilities.

A key issue raised in our response to the ACT Government’s recent review of mental health legislation was that the law is only one component of an effective and human-rights compliant system. As Gooding has noted, while the law has the ability to create the ‘power structures, institutions and incentives of disability services “systems”’, appropriate resources are critical to ensure ‘any benefits of using the law for social

¹ Piers Gooding, ‘Navigating the ‘Flashing Amber Lights’ of the Right to Legal Capacity in the United Nations Convention on the Rights of Persons with Disabilities: Responding to Major Concerns’ (2015) 15 (1) *Human Rights Law Review* 45, 47.

² Gerard Quinn, ‘Personhood and Legal Capacity: Perspectives on the Paradigm Shift of Article 12 CRPD’ (Concept Paper presented at HPOD Conference, Harvard Law School, 20 February 2010), 3.

justice in this way are overwhelmed by other powerful forces in society, such as reasonable allocation or wealth disparity'.³

In our view, any reform to guardianship law needs to be coupled with significant resources focused on education and guidance material, and the allocation of funding to critical services to support people with a disability in their decision making. This is timely and all the more important given the significant reforms to the Government and non-government sectors introduced by the NDIS, and proposed changes to the structure of statutory office holders in the ACT which have the potential to decrease visibility of oversight in relation to guardianship issues.⁴

Experiences of Guardianship (Question 1)

The Disability and Community Services Commissioner/ Health Services Commissioner regularly deals with complaints in relation to the functions and actions of guardians in both the disability and mental health spheres. The Human Rights and Discrimination Commissioner also recently held the additional role of ACT Public Advocate for 18 months, and in that capacity, gained direct experience of ACT guardianship law and practice, including as being the Territory's guardian of last resort.

We submit that ACT law should have a presumption that a person has decision making capacity and, just because a person lacks one type of decision making capacity at a particular point in time, then that should not be determinative as to whether they lack decision making capacity in other aspects of their lives.

Issues of particular concern to the Commission are the unregulated use of restrictive practices in relation to people with a disability (see below) and a lack of clarity for guardians and carers regarding their responsibilities when an order is issued. While we welcome the approach of the ACT Civil and Administrative Tribunal (ACAT) not to grant plenary guardianship orders, complaints to the Disability and Community Services Commissioner indicate that some private guardians seek to control all aspects of the lives of people with disability, while others are concerningly absent from decision making for which they should be taking responsibility. For example, some private guardians interpret orders regarding 'welfare' or 'living arrangements' as providing for guardians to make all decisions regarding a person's life, such as what they will eat for dinner and who their friends will be. Compounding this can be situations where multiple guardians are appointed, such as family members, and each has conflicting views on what decisions should be made, often at an inappropriate level of minutiae.

This Review provides an opportunity to not only reform guardianship law, but also the culture and practice that surrounds it, particularly in relation to private guardians in the community. Our suggestion is that, consistent with rights under the HRA and the CRPD, the traditional presumptions and assumptions about guardianship law need to change. Regardless of what form of decision-making orders are adopted, people with disabilities should be presumed to have capacity to make decisions for themselves, and any restrictions on that should be narrowly construed.

We note that the Discussion Paper does not cite the extent of existing guardianship orders in the ACT and comparative data from other jurisdictions. Data collection is a requirement of Article 23 of the CRPD, and such analysis seems critical to any law reform. We submit that an analysis of guardianship data is important to determine:

- Current utilisation of guardianship;
- The nature of the orders and domains they cover;
- How frequently orders are withdrawn;

³ Gooding, above n 1, 48.

⁴ ACT Government Discussion Paper: Designing a model for the effective protection of human rights.

- The profile of current guardians (eg relationship to the person);
- What impact law reform would have on those currently under guardianship.

Interaction with other laws

The Commission also has direct experience of the interaction between guardianship and mental health law gained from the Health Services Commissioner's complaints jurisdiction, and through our extensive involvement in the ACT Government's recent development of new mental health legislation. We also participated as an 'interested party' in an ACAT matter, still on foot, which seeks to address confusion about the interaction between mental health and guardianship law, and how capacity is assessed for guardianship purposes.

That experience highlighted several critical questions about how guardianship law interacts with other ACT laws:

- If a person is assessed to be lacking capacity in one (or more) domain of their life under guardianship legislation, what impact does that have on other assessments of their capacity, including under mental health law?

We submit that consistent with relevant human rights and the CRPD, a person should be presumed to have capacity under existing ACT law until a relevant person can demonstrate otherwise with evidence, as determined by an independent court or tribunal.⁵ As detailed below, the CRPD arguably also creates new obligations on the governments to provide all necessary supports for a person to make decisions for themselves. On this basis, a finding that a person lacks capacity in one domain of their life, (if such assessments were to continue in any new guardianship legislation) should not be determine the assessment of their capacity in other areas.

- How does ACT law currently manage and potentially 'authorise' restrictive practices against people with a disability?

Chan notes that people with a disability who display 'behaviours of concern' are often accommodated in closed environments, placing them at further risk of abuse and restrictive practices, even where such measures are non-therapeutic and increase such behaviour.⁶ The legality of any restrictive practice that limits an individual's rights to liberty and other protected rights in the HR Act is questionable under current legislation. Arguably, only mental health legislation provides a lawful basis for involuntary treatment, and only in a narrow therapeutic sense. Outside this regime, we are particularly concerned that Public Authorities under the Human Rights Act are breaching their obligations if they engage in any form of restrictive practices. Such actions may also constitute a breach of applicable standards under the *Human Rights Commission Act 2005* and disability discrimination under the *Discrimination Act 1991*.

The application of restrictive practices in relation to people with a disability and with mental illness, has been a feature of complaints to the Disability and Community Services Commissioner/Health Services Commissioner. The Commissioner has raised concerns on a number of occasions that restrictive practices have inadequate authority and that the human rights of individuals have potentially been breached.

The Commission is not advocating that guardianship law provide an authorising process for guardians to consent to restrictive practices. In her submission to the *Consultation paper about the*

⁵ See in particular s10(2) (right to consent to treatment), s8 (right to equality), s17 (right to liberty) in ACT HR Act.

⁶ Jeffrey Chan, 'Challenges to Realizing the Convention on the Rights of Persons with Disabilities (CRPD) in Australia for People with Intellectual Disability and Behaviors of Concern', [2015] *Psychiatry, Psychology and Law*, 2.

proposal for a National Disability Insurance Scheme Quality and Safeguarding framework, the Disability and Community Services Commissioner specifically noted that a proposal, that guardians could authorise restrictive practices, was not supported. The Commissioner noted that:

‘There are many guardians who, with the best of intentions, would agree to proposals put forward by service providers in the interests only of keeping their sons or daughters safe, and because they have not been informed about alternatives that might exist. They may agree without adequate appreciation for the harm that can accompany well-intentioned un-monitored restriction. Such restrictions may be more intrusive than those that might be duly authorised by a court/tribunal, or considered reasonable by an oversight body’.

The Commissioner argued for such practices to be more transparently reported with a view to minimising or removing their use in conjunction with adequate oversight. The Victorian Senior Practitioner model is one way in which care plans, including restrictive practices, can be recorded and assessed. The Commission submits this model, or another form of regulating and reducing restrictive practice, must be considered.

Powers of Attorney (Question 2)

One of the critical issues discussed at length during the recent review of ACT mental health legislation was how it would interact with powers of attorney, particularly in relation to mental health orders made by the ACAT and advanced agreements and directives made by individuals.

We submit that whatever reforms are suggested by LRAC, some consideration must go into the hierarchy of such orders and agreements, and based on the CRPD (and ALRC) Principles, wherever possible:

- primacy must be given to the wishes and preferences of the person; and
- a person should be supported to articulate those wishes and preferences.

As detailed below, some jurisdictions, such as British Columbia have introduced representative agreements, as an alternative to guardianship. Such agreements appear to be worthy of future consideration. However, as detailed below in relation to guardianship reform, safeguards and protections are vital considerations in any law reform and should be considered in relation to powers of attorney.

CPRD and ALRC National Principles (Question 3)

In many ways, the ALRC Principles and the CRPD itself further articulate the right to equal recognition before the law, enshrined under the Universal Declaration of Human Rights, International Covenant on Civil and Political Rights and s 8 of the ACT HR Act. It also been suggested that because s 31 of the HR Act allows rights to be interpreted with reference to International Law, many aspects of the CRPD may already be effective in the ACT, whether by virtue of the human rights obligations on Public Authorities, or in the application of rights in interpreting other laws under s 30.

We are generally supportive of the ALRC National Decision Making Principles, and their focus on reflecting the CRPD by ensuring people with disabilities are supported to make their own decisions consistent with their will and preferences, including choosing not to receive support. They also contemplate appropriate safeguards, and provide a sound basis from which the ACT should consider reforming guardianship law. One of the most unanimous areas of agreement in academic discussion about the CRPD and General Comment 1, appears to be that it requires states to positively act and invest in supports for people with a disability in order to fulfil their wishes and preferences, something the ALRC Principles also reflect.

However, the primary focus of the ALRC was on Commonwealth laws, which do not include guardianship, and it remains unclear how the principles would be ‘operationalised’ into State and Territory guardianship (and mental health) law and practice. It appears the ACT is amongst the first jurisdictions to review its guardianship legislation in light of the ALRC Report.

While disability and persons with disabilities are not defined in the CRPD, Article 1 states that such persons includes those with long-term physical, mental, intellectual or sensory impairments, which interact with various barriers that may hinder their full and effective participation in society on an equal basis with others.

We suggest that compliance with the CRPD in light of General Comment 1, suggests the ACT must at least reconsider the following elements of the guardianship system:

- Substitute-decision making.
- The ‘best interests test’
- Assessment based on a finding of loss of legal capacity on a medical diagnosis.
- While Article 12 is likely the most relevant Article for the purposes of this Review, other Articles should not be lost in the reform of ACT guardianship law.

An end to Substitute Decision Making?

The Australian Government made an interpretive declaration when ratifying UNCRPD to preserve its right to allow states and territories to retain guardianship as a ‘last resort’. McSherry and Wilson suggest that this means substituted decision-making arrangements will remain in place in Australia, at least in the short term.⁷ They cite Kampf’s opinion that such a declaration contravenes the spirit of the CRPD, who also notes that the statement is a *declaration* not *reservation*. Reflecting this, the ALRC did suggest that this declaration is simply a record of the Australian Government’s understanding at a particular time.⁸ McSherry and Wilson interpret the CRPD as implying that if an interpretative declaration is incompatible with interpretations set out in General Comments, ‘such declarations should not inform law reform endeavours’.⁹

Carney and others also argue that community pressure on governments to change the current substitute decision making regime is growing.¹⁰ The CRPD began this movement, but arguably the release of General Comment 1 by the United Nations Committee on the Rights of Persons with Disabilities on Article 12 (Equality Recognition before the Law) in 2014 sparked this debate in earnest, and in particular paragraph 28:

‘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.’

At any rate, Australia’s interpretative declaration may not be valid, and at any rate, it does not appear to prevent the ACT Government taking law reform measures consistent with the CRPD. The ALRC also suggested in its Final Report that the Declaration was not a barrier to domestic law reform.¹¹

Best Interests Test

As the Principles and Guidelines suggest, states must reconsider the extent of the current model used in guardianship law based on the ‘best interests’ concept. There is significant academic and community support for the approach of the CRPD to place new obligations on the state to no longer apply a ‘best

⁷ McSherry and Wilson, above n 14, 2.

⁸ ALRC, 57.

⁹ McSherry and Wilson, above n 14, 2.

¹⁰ Terry Carney, ‘Supporting People with Cognitive Disabilities with Decision-Making: Any Australian Law Reform Contributions?’, (2015) 2(1) *Research and Practice in Intellectual and Development Disabilities* 6, 2

¹¹ ALRC, 57

interests' substitute decision making test, but rather to 'shore up' legal capacity to assist the person to make and expression decisions for themselves.¹²

Assessing Capacity

Article 12(2) of the CRPD states that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life. In the context of the Australian legal system, there are countless common law authorities on the definition and tests of legal capacity. Arguably, the Convention requires these concepts to be rethought, particularly as many turn on questions of 'sound mind', 'competence' and 'impairment'.¹³

There is increasing recognition that legal capacity is not a binary concept, but rather a continuum of understanding, which must be assessed according to the specific decision in question. Nonetheless, Quinn questions if the current approach is appropriate, which presumes some government intervention if a person's decision making capacity is reduced. The most common intervention, including under current guardianship law, is to appoint someone else to make that decision for the person 'in their best interests'.

If so, the HR Act may already call into question some of the traditional common law concepts of capacity. In light of the CRPD, McSherry and Wilson distinguish *legal* capacity from *mental* capacity. They suggest that legal capacity is akin to legal agency, which is about the ability for an individual to act within the framework of the legal system. The CRPD Committee, in General Comment 1, defined mental capacity as the 'decision making skills of a person'. McSherry and Wilson cite both UK and Australian laws to demonstrate that traditionally this has been assessed according to a person's cognitive abilities, whether through tests based on status, function or outcome.¹⁴ General Comment 1 seeks to refute this approach:

'In most of the State party reports that the Committee has examined so far, the concepts of mental and legal capacity have been conflated so that where a person is considered to have impaired decision-making skills, often because of a cognitive or psychosocial disability, his or her legal capacity to make a particular decision is consequently removed. This is decided simply on the basis of the diagnosis of an impairment (status approach), or where a person makes a decision that is considered to have negative consequences (outcome approach), or where a person's decision-making skills are considered to be deficient (functional approach). The functional approach attempts to assess mental capacity and deny legal capacity accordingly. It is often based on whether a person can understand the nature and consequences of a decision and/or whether he or she can use or weigh the relevant information. This approach is flawed for two key reasons: (a) it is discriminatorily applied to people with disabilities; and (b) it presumes to be able to accurately assess the inner-workings of the human mind and, when the person does not pass the assessment, it then denies him or her a core human right — the right to equal recognition before the law. In all of those approaches, a person's disability and/or decision-making skills are taken as legitimate grounds for denying his or her legal capacity and lowering his or her status as a person before the law. Article 12 does not permit such discriminatory denial of legal capacity, but, rather, requires that support be provided in the exercise of legal capacity.'

Many have argued that this means an end to substitute decision making, at least based merely on a 'diagnosis' of disability.¹⁵ Instead of substitute decision making, the CRPD Committee and the Mental Disability Advocacy Center (MDAC) [sic] based in Hungary, amongst others, contemplate 'facilitated decision-making' for those whose will or preferences cannot be ascertained, which would apply when:

¹² See for example Quinn, above n 2, 13.

¹³ For example, Re C (Adult: Refusal of Medical Treatment) [1994] 1 WLR 290, Marion's Case [1992] 66 ALJR 300, Hunter and New England Area Health Service v A [2009] NSWSC 761

¹⁴ Bernadette McSherry and Kay Wilson, 'The concept of capacity in Australian mental health law reform: Going in the wrong direction?' (2015) 40 *International Journal of Law and Psychology*, 5.

¹⁵ See for example Flynn and Arstein-Kerslake, above n 11, 128

- supports have been exhausted (including creative communication techniques, building relationships, accessible information, etc.) and they have not led to a decision; and
- the individual's will and preferences cannot be clearly and unambiguously ascertained, or there appears to be substantial conflict between preferences as contemporaneously expressed and the best understanding/interpretation of the person's long-term preferences; and
- the individual has not previously expressed his/her will or preferences (for example, in planning documents).

According to MDAC, if 'facilitated decision-making' is used, it should only be used for the minimum period of time which is necessary in the circumstances, with an emphasis on transitioning the person to supported decision-making. Further, States should 'encourage' individuals to detail in advance their will and preferences with respect to key decisions, and to identify preferred supporters for the exercise of their legal capacity.¹⁶

The ALRC Report does not appear to provide a definitive answer on the future of substitute decision making in Australia. The Principles contemplate that where the representative cannot ascertain the person's will and preferences, they should act to promote the person's human rights and act in the least restrictive way. In this sense, these obligations are consistent with those of Public Authorities under the *Human Rights Act 2004*. A representative can only override a person's preferences to prevent harm to the person or others. Similarly, in its discussion of the application of the national principles to State and Territory law, the ALRC did suggest 'some room for fully supported decision making should remain'. This conclusion is, in part, dictated by the reality that some people will always need decisions made for them.' This comment cites the suggestion by the Australian Guardianship and Administration Council (AGAC),¹⁷ that supported decision making cannot 'completely replace substitute decision-making'.

Whether that is both consistent with the CRPD and the ACT Human Rights Act we submit is a fundamental question for LRAC and ultimately the Government. As detailed further below, this is a growing area of academic and community debate, with no clear consensus on how law reform should proceed in light of General Comment 1.¹ McSherry and Wilson suggest it is likely not consistent with the CRPD, but may be more 'palatable' for Australian governments not wishing to undertake more radical reform.¹⁸

The Rest of the CRPD

McSherry and Wilson, are concerned with the sharp focus on Article 12 of the CRPD, which they argue has lead to a lack of consideration of voluntary treatment, particular in relation to mental health, identifying the ALRC Report as one example where the CRPD as a whole should have been further considered.¹⁹ For example, they argue 'other rights, such as the right to health and to independent living, are critical for the realisation of legal capacity.' Such an analysis is consistent with the interrelated, interdependent and indivisible relationship between rights contemplated by the Universal Declaration on Human Rights and confirmed in the Vienna Declaration emanating from the World Conference on Human Rights in 1990, and a message echoed in paragraph (c) of the Preamble to the CRPD.

They also suggest Articles 12 and 14 must be read in light of Article 25, which is essentially a 'right to health', and Article 19, the right to independent living. Their analysis extends from the consensus that Article 12 requires governments to take positive measures to support people with a disability to make decisions. In relation to the right health care, they contend that it extends the range of care and treatments on offer:

¹⁶ Mental Disability Advocacy Center, *Legal Capacity in Europe: A Call to Action to Governments and to the EU*, 2013, 17-18.

¹⁷ AGAC brings together Public Guardians and Trustees from Australian jurisdictions

¹⁸ McSherry and Wilson, above n 14, 6

¹⁹ McSherry and Wilson, above n 7, 1

*'...so that care plans can be individually tailored and targeted with the participation of persons with mental impairments, may have more practical value than the recognition of legal capacity alone.'*²⁰

There is already some human rights jurisprudence regarding rights other than just equality in the application of guardianship law. In *Stanev v Bulgaria*, a man was placed in a social care institution in a remote village way from his home. Conditions were poor and the European Committee for the Prevention of Torture recommended the Government close the institution. Mr Stanev frequently attempted to leave over his eight years of residence, but this was presumed to be a symptom of his mental illness. The European Court of Human Rights found his living conditions amounted to degrading treatment and that his detention was unlawful. His fair trial rights were also infringed because he could not apply himself to have his guardianship order lifted. The Court also found that if Mr Stanev had retained his legal capacity, removed on the basis of his mental disorder, he would not have been deprived of his liberty.²¹

In *Patrick's Case*, Justice Bell of the Victorian Supreme Court applied the CRPD to guardianship and financial decisions made about a person with a disability, and found a breach of a number of his rights, including to equality, and privacy, in the forced sale of his house.²²

Proposed Guidelines for Decision-Making Support (Question 4) & Will, Preferences and Rights (Question 5)

As with the National Principles, the Commission welcomes the Guidelines that underpin them. In some ways, they provide greater detail from which the ACT can draw in reviewing and reforming guardianship law. Their focus on CRPD, which as noted by the list in paragraph 3.67 of the Report, embodies many of the civil and political rights also found in the ACT *Human Rights Act 2004*, is particularly relevant for the ACT. Consistent with the CRPD, they strongly preference the role of supporters over the last resort appointment of representatives. Carney usefully summarises the Reports approach as follows:

'Informed by the Australian Law Reform Commission's five "framing" principles of dignity, equality, autonomy, inclusion and participation, and accountability (2014, para. 1.34), the Commission formulated (and further elaborates as guidelines) four decision-making principles: the right of all persons to make and have decisions respected; to be supported to make decisions; for supported decisions to be directed by the "will, preferences and rights" of the person; and for provision of appropriate safeguards. These principles would inform two kinds of possible appointments where autonomous decision making or informal assistance was inadequate: appointment of a "supporter" or, as a last resort, appointment of a "representative".'

The role of 'plan nominees' under the NDIS was also considered by AHRC, and while perhaps outside the scope of this Review, the relationship between state guardianship schemes and the NDIS remains unclear. Carney notes that in NSW there have been 85 guardianship appointments requested in the NSW trial site by late 2014, likely due to the 'considerable overlap and intersecting relationships between the NDIS and traditional guardianship'.²³ In contrast, the Victorian Office of the Public Advocate received just 7 such appointments, perhaps based on that office's preference to utilise its advocacy role rather than formal guardianship.²⁴ The ALRC generally recommended that NDIS (and related) nominees under Commonwealth law be replaced, likely by supporters who Carney suggests would presumably be appointed and terminated by the person.²⁵ The Report also recommends that State and Territory tribunals be approached before the chief executive appoints a NDIS representative.

²⁰ McSherry and Wilson, above n 7, 8.

²¹ See also decisions about standing to engage judicial system such as *Winterwerp v Netherlands* 2 ECHR Rep 387.

²² *PJB v Melbourne Health & Anor* (Patrick's case) [2011] VSC 327

²³ Carney, above n 10, 9.

²⁴ *Ibid.*

²⁵ *Ibid.*, 10

However, as Carney has noted, the Commonwealth has limited constitutional responsibility for guardianship and so the Report was not focussed on the practical implementation of the CRPD to State and Territory schemes. Further, the appointment of representatives by Commonwealth bureaucrats is 'left hanging' in the absence of an appropriate national tribunal to consider such appointments.²⁶ The remainder of this Submission refers to applicable literature and human rights standards to determine how such reform might take place in the ACT.

The ALRC Report was preceded by the Victorian Law Reform Commission's 2012 Report, which also predated General Comment 1. Amongst its most critical and relevant recommendations were that the Victorian Civil and Administrative Tribunal make appointments of co-decision makers and supported decision makers, prior to utilising substitute decision making as a last resort.²⁷

The Commission submits that while this review did not have the benefit of considering General Comment 1, it remains the most recent and relevant state-based review of current guardianship regimes in a human rights context and so must be seriously considered.

A move to Supported Decision Making?

We note that the term supported decision making is used throughout the LRAC Discussion Paper, but is not defined, although a broad definition is used in paragraph (1) of the ALRC Guidelines. It would be useful for LRAC's Final Report to define what it means by 'supported decision making', including how this may fit into to other options in new capacity legislation, or other law reform that may arise from this process.

Blanck and Martinis suggest that while there is no single model of supported decision making, it 'generally occurs when people use one or more trusted friends, family members, professionals, or advocates to help them understand the situations and choices they face so they may make their own informed decisions'.²⁸ In this way, it seeks to mirror how adults make daily decisions in all domains of their lives.

Browning, Bigby and Douglas have contrasted 'supported decision-making' from 'support with decision-making'. Support *with* decision making constitutes broader measures to assist people make decisions outside the context of directly exercising legal capacity, which may indirectly assist a person exercise legal capacity, such as providing plain language information or self-advocacy training.²⁹ Davidson et al have undertaken a comprehensive analysis of SDM around the world, and provide an excellent analysis of the various models that could be considered.³⁰

For the purposes of our submission, we will use this term generally as it is used in General Comment 1 of the CRPD Committee, which was to contrast alternatives to the substitute decision making model used in many jurisdictions including in the ACT. MDAC, drawing on Concluding Observations in relation to China and Austria by the CRPD Committee, suggests that a system of supported decision-making must include:

- Recognition of everyone's legal capacity and right to exercise it;
- Accommodations (adjustments) and access to support where necessary to exercise legal capacity;
- Regulations to ensure that support respects the person's will and preferences, including the establishment of feedback mechanisms to ensure that support is meeting the person's needs; and
- Arrangements for the promotion and establishment of supported decision-making.

²⁶ Ibid, 10.

²⁷ Victorian Law Reform Commission, *Guardianship: Final Report*, 18 April 2012.

²⁸ Blanck and Martinis, above n **Error! Bookmark not defined.**, 26.

²⁹ Cited in Gooding, above n 1, 51.

³⁰ Gavin Davidson, Berni Kelly, Geraldine Macdonald, Maria Rizzo, Louise Lombard, Oluwaseye Abogunrin, Victoria Clift-Mathews and Alison Martin, 'Supported decision making: A review of the International literature', (2015) 38 *International Journal of Law and Psychiatry*, 61, 62

MDAC submits this means that governments should develop new legislation and structures that:

- Recognise that supported decision-making is built on relationships of trust;
- Assign clear roles to supporters to provide information to help people with a disability to make choices, and to assist them to communicate their choices to third parties (such as banks, doctors, employers, etc.); and
- Prevent and remedy exploitation, violence and abuse, as detailed in Article 16 of the CRPD.³¹

Gooding also notes that the CRPD criteria would encompass pass SDM and ‘support with decision making’ and broader support to exercise legal capacity across a range of law, policy and practice.³² It is worth noting, that for the purposes of the Victorian Law Reform Commission Report, supported decision making was a more defined category of decision making, along a spectrum which included co-decision making.

We welcome both the broader definition of SDM contemplated by the CRPD Committee, and the more nuanced spectrum of decision making options contemplated by the Victorian report. However, we are also cautiously supportive of SDM as this still requires some level of oversight. We are already concerned about restrictive practices not having a clear lawful basis. Even in the ACT, where Public Authorities have obligations in relation to human rights, there is still a lack of understanding that measures can only be taken with lawful basis. The *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* is welcome, but we submit to have a meaningful impact it, and applicable human rights, as well as the law reform of other jurisdictions, should inform the development of restrictive practice legislation in the ACT.

Proposed Safeguards Guidelines (Question 6)

While the Commission is strongly supportive of reform to the current substitute decision making paradigm, we also recognise there are challenges and barriers to this transition. One critical question is what safeguards are necessary to overcome such challenges. The ALRC Report attempted to deal with these issues in its proposed Safeguards Guidelines.

Barriers and Challenges

In reviewing a range of international studies, Davidson et al note that implementing SDM ‘takes time and resources, and may require a shift in attitudes of some care providers and in some service users themselves’.³³ Their analysis includes issues of informed consent (often impeded by staff attitudes), communication limitations, methodology used by supporters, law reform not leading to cultural change in institutions, and the consistent application of good practice SDM across all settings.³⁴

Blanck and Martinis cite a 2012 meeting of stakeholders in New York, including representatives from the American Bar Association, United States Department of Justice and National Guardianship Association. The meeting sought to discuss how to move away from the substitute decision making model. It identified a number of issues that had to be considered and addressed:

- Revise guardianship standards to emphasise supported, independent decision-making;
- Set standards and expectations for supporters; and

³¹ MDAC, Above n 16, 13

³² Gooding, above n 1, 52.

³³ Davidson et al, above n 30, 64.

³⁴ Ibid, 66.

- Prevent abuse and undue influence, without denying legal capacity.³⁵

The first issue may very well be the easiest to change in the ACT context, through legislative reform, while the other matters are likely to be more difficult.

Potential Safeguards

Article 12(4) of the CRPD contemplates certain safeguards applying generally to protect people with disabilities, which the ALRC emphasised including:

- Prevention of abuse in accordance with international human rights law;
- respect for the rights, will and preferences of the person;
- freedom from conflict of interest and undue influence;
- decisions are proportionate and tailored to the person's circumstances;
- restrictions apply for the shortest time possible;
- decisions are subject to regular review by a competent, independent and impartial authority or judicial body; and
- restrictions are proportionate to the degree to which such measures affect the person's rights and interests.

The ALRC's Safeguards Guidelines reflect these requirements, and provide useful principles for how the issues should be approached at the Territory level.

Nonetheless, Gooding and others have noted that a common 'critique' of SDM proposals are that they 'open the possibility of manipulation and unchecked abuse', including where SDM strays into the area of *de facto* substitute decision-making.³⁶ In this context, it is worth noting that the draft General Comment 1 was criticised for not including enough discussion on 'undue influence' and this was expanded in the final, including a definition of undue influence as being 'where the quality of the interaction' between the individual and a supporter includes 'signs of fear, aggression, threat, deception or manipulation'.³⁷

Similarly, there are suggestions that SDM might lead to supporters acting in a differential manner to those that support them, effectively deferring their will to that of the supporter. Kohn et al cite the research showing older adults tend to prefer trusting a surrogate decision-maker, rather than expressing treatment preference themselves, and note the lack of research into how SDM relationships would influence such deference.³⁸

Gooding rebuts some of this critique on the basis that all adults are subject to influence and pressure from those around them, and may at times defer to the opinions of those circles of support. He questions why those standards should change when the state is intruding into the decision making of a person with disability. He also notes that safeguarding in the current substitute decision making framework has also been challenging.³⁹ Nonetheless, he suggests that states must clarify this definition and design measures to ensure interactions between supporter and supported are not subject to undue influence, and points to existing thresholds in contract and probate law as worthy of consideration.

³⁵ Blanck and Martinis, above n 10, 27

³⁶ Gooding, above n 1, 55 - 57.

³⁷ Para 22.

³⁸ Nina A Kohn, Jeremy A Blumenthal and Amy T Campbell, 'Supported Decision Making: A Viable Alternative to Guardianship?', 117(4) *Penn State Law Review* 1111, 1138.

³⁹ Gooding, above n 1, 54-57.

MDAC, in its Call to European Governments document, highlights some of these requirements in suggesting that a supported decision making system would safeguard and structures which:

- recognise the right to legal capacity;
- respect the will and preference of the individual;
- provide the opportunity to challenge and modify support arrangements;
- recognise that supported decision-making is built on relationships of trust;
- assign clear roles to supporters to provide information to help the person with a disability to make choices, and to assist the person to communicate these choices to third parties (such as banks, doctors, employers, etc.);
- accommodate individuals who communicate unconventionally;
- prevent and remedy exploitation, violence and abuse, as outlined in Article 16 of the CRPD;
- carefully structure and monitor these provisions and safeguards to ensure that they do not over-regulate the lives of the individuals utilising them and become invasive and burdensome;
- ensure that third parties give legal recognition to the role of support people and to decisions made with support;
- collect comprehensive data on individuals subject to legal capacity restrictions and support;
- initiate pilots to develop a wide variety of support measures; and
- ensure any law reform should include training for all relevant stakeholders, including civil servants, judicial officers and public officials on consulting and cooperating with people with disabilities, including on the human rights model of disability and recognition of legal capacity.⁴⁰

A Legal Basis?

One safeguard may be to legislate supported decision making in reformed guardianship law, as was contemplated by the Victorian Law Reform Commission. General Comment 1 by the CRPD Committee does contemplate giving support to exercising legal capacity as encompassing a broad spectrum, some of which may engage legal mechanisms.⁴¹

Carney questions if legislating a 'supported decision making' system is indeed the right step:

*'Supported decision-making may or may not require engaging the law at all. Circles of support, micro-boards, or friendship networks may better be cultivated purely within civil society, overseen simply by the advocacy, service protocols, health and welfare professional standards, and other processes of the myriad of informal community, self-help, non-government, and government human services agencies. However inadequate due to cost and other barriers, accountability of informal supporters may better be left to education and information strategies, or the abuse mandate of Offices of the Public Advocate (Chesterman, 2013; Feigan, 2011), in order to avoid the more egregious social policy cost of formalisation having a chilling effect on willingness to offer support, or of rendering the work of supporters less "visible".'*⁴²

⁴⁰ MDAC, Above n 16, 17-19. .

⁴¹ Para 25.

⁴² Carney, above n 23, 15.

The Commission finds it difficult to contemplate how the cultural change demanded by the CRPD, with corresponding safeguards, is possible without significant law reform. Gooding for example questions if the benefits of using the law for social change will be ‘overwhelmed by other powerful sources in society’, but nonetheless notes:

‘...it is generally agreed that the law authoritatively creates the power structures, institutions and incentives of disability service ‘systems’, which directly shape the lives of people with disabilities, their families and others.’⁴³

Similarly, Flynn and Arstein-Kerslake suggest that it is ‘difficult to imagine how supported decision-making could be implemented and formally recognised without statutory language’.⁴⁴ Therefore, we tend to favour this approach in contrast to that of Carney, although we do appreciate Sir Anthony’s Mason words regarding the perils of rushing into law reform without a sound evidence base:

‘...[a]s things currently stand, [current] proposals seem to reflect little more than ideals that have not been carefully thought through, with the risk that they will result in experimental law-making.’⁴⁵

Bach and Kerzner suggest that such a legislative basis would include three categories of decision making, each with corresponding levels of legal oversight and supports:

- autonomous decision making
- supported decision making; and
- facilitated decision making.

Supports would include mechanisms to help a person develop decision-making capabilities, and facilitation whereby a supporter is appointed to make decisions based on the best interpretation of will and preference.⁴⁶ This model echoes the spectrum of supports envisaged by the VLRC, although Gooding notes there are questions as to how criteria for determining which category a person falls into will be determined, without falling into the discriminatory diagnosis or functional testing that is currently contrary to the CRPD and General Comment 1.

There has been criticism of General Comment 1 in this respect,⁴⁷ on the basis it is unclear how states should proceed. As Gooding notes, ‘only a very small number of commentators have explored this possibility beyond the abstract.’⁴⁸

Alternatives to Current Assessments

In order to avoid the current models of assessing capacity, which is criticised in General Comment 1, a coalition of Australian non-government organisations have proposed that the law should focus on the supports provided to a person to meet their requirements to make and communicate a decision. In doing so, the question would become if a person cannot currently communicate their views, what changes are needed to supports to ensure that they can.⁴⁹

⁴³ Gooding, above n 1, 48.

⁴⁴ Flynn and Arstein-Kerslake, above n **Error! Bookmark not defined.**, 137.

⁴⁵ Carney, above n 10, 9.

⁴⁶ Bach and Kerzner cited in Gooding, above n 1, 58.

⁴⁷ See for example the Canadian Association of Community Living, and Bach and Kerzner, who both suggest that functional assessment of mental capacity are necessary to identify how individuals exercise their legal capacity.

⁴⁸ Gooding, above n 1, 60.

⁴⁹ Gooding, above n 1, 60 citing Discussion Paper Submission from People with Disabilities Australia, The Australian Centre for Disability Law and the Australian Human Rights Centre

As Gooding notes, the Centre for Disability Policy and Law have proposed similar legislative amendments, which would focus on the point at which a person's will and preference is unknown or unclear. Flynn and Arstein-Kerslake suggest a paradigm of support should be provided by the state that adapts to a sliding scale of abilities.⁵⁰ However, Gooding submits that such proposals are 'in the early stages of conceptual development and their practical application to legislation would constitute a profound shift away from centuries of capacity jurisprudence'.⁵¹

Similarly, Carney notes that a consequence of new non-discriminatory capacity tests could be so-called 'net-widening', where persons not currently judged to lack capacity, including those with disabilities, are determined to require decision making support under new assessments. Such an outcome could be perceived as both a benefit and risk in a new system.⁵²

The cessation of capacity testing therefore appears to be a critical area for further consideration and research. It is far from settled as to how state parties will implement General Comment 1 and provide a spectrum of supports and protections without undertaking *discriminatory* capacity testing. As noted elsewhere in our Paper, this is therefore an exciting and challenging time for the ACT to be considering new guardianship law.

Resources, Training and Guidance Material

Even with a legal basis, complete with a nuanced suite of safeguards, there seems to be consensus that the success of any type of law reform in this area will be contingent on the resources that governments invest. Inclusion International suggests the realisation of a new fundamental right to make decisions will require a range of reforms, including the way supports are provided by governments and community, and that legal reform 'must go hand in hand with strategies for building community supports'.

*'Simply eliminating all forms of substitute decision making without providing the necessary support for decision making would in effect deprive people with an intellectual disability of the power to make decisions.'*⁵³

Flynn and Arstein-Kerslake state that a human rights approach to this reform suggests there can be no limit to the level of support provided for a person to be supported.⁵⁴ The South Australian Public Advocate reported in its trial of SDM the importance of adequate resourcing.⁵⁵ The ALRC Report itself notes submissions from a number of stakeholders, including the Queensland OPA, that argued with 'careful guidance, education, training and advice' a rights-based approach to decision making could be fraught with the same issues as currently existing practices, and advocated for codes of practice to guide decisions makers.⁵⁶

In terms of training material, the Autistic Self Advocacy Network (ASAN) has released 'An Act Relating to the Recognition of a Supported Healthcare Decision-Making Agreement for Adults with Disabilities', and accompanying educative material, including a toolkit providing information for health care providers on liability.⁵⁷

⁵⁰ Flynn and Arstein-Kerslake, above n 11, 131.

⁵¹ Gooding, above n 1, 60.

⁵² Ibid, 66.

⁵³ Inclusion International, *Independent but Not Alone: A Global Report on the Right to Decide*, 2014, xiii.

⁵⁴ Citing Articles 12(4) and 16

⁵⁵ South Australian Office of the Public Advocate's Annual Report, cited in Gooding, above n 1, 63.

⁵⁶ ALRC, Page 80.

⁵⁷ Autistic Self Advocacy Network, *Model Legislation: An Act Relating to the Recognition of a Supported Health Care Decision-Making Agreement for Adults With Disabilities*, 9.

It seems probable that governments will want cost benefit analysis regarding the introduction of SDM, but Gooding advocates that such an assessment must also consider the comparative costs of the current system.⁵⁸ Governments must also consider adequately resourcing advocacy groups that represent people with a disability and oversight agencies. This remains an ongoing issue in the rollout of the NDIS and cannot be underestimated as a key issue for the ACT Government to consider in any reform to guardianship law.

Monitors

Gooding submits that informal efforts by people with disability, their families and others should not replace government resourcing. The Victorian trial of SDM offers a reasonable compromise, as it seeks to mobilize citizen volunteers utilising a paid facilitator, to develop relationships around isolated persons and build social capital in the community.⁵⁹ The concept of independent monitors is a common feature of SDM, at least found in both the South Australian trial and the British Columbia representative agreement models. The monitor is someone to oversee the supporter, and seems worthy of further investigation as part of ACT trials and law reform.

Those for Whom Wishes and Preferences Cannot be Ascertained or Supported

One of the most discussed aspects of General Comment 1 and Article 12 is how it relates to those whose will and preferences may be very difficult to decipher. These could include people who have been institutionalised, those in a 'persistent vegetative state',⁶⁰ or coma.⁶¹ Quinn notes that there are dangers that 'at some point the supports and assistants will end up making decisions *for* and not *with* those individuals'.⁶² He argues that a return to substitute decision making is not the answer for this group. Instead, he submits that Article 12.3 requires the state to take additional steps, including advancing research that provides the possibility, even if remote, that a person's brain can be read to detect preferences. In relation to those whose social connectedness has been severed due to institutionalisation, then the state should create social conditions to kindle some 'kernel or preference'.

Nonetheless, Quinn accepts that for some individuals, decisions will need to be made 'for' them and that the State and law must be honest about this. Quinn suggests the role of the law remains vital for this group, as there are risks that the community around that person might ascribe to him or her a will or preference based on the community or culture in which they live. In doing so, the 'right to be different' would be smothered.⁶³

Similarly, Gooding questions how new regimes of SDM would apply to those in 'a coma' or who have no relationships of trust, and/or there is not enough intention expressed to guide decision making. Like Quinn, he agrees there are 'clear risks to stretching the meaning' of SDM to where decisions are ultimately made *for* the person.

In General Comment 1, the Committee contemplates a system that has been labelled 'facilitated decision making', in which the 'best interpretation' by friends or family, or if necessary, public officials, is used to determine a person's wishes and preferences based on the person's life story, values and beliefs.⁶⁴ The Committee suggests that such a system must be based on the protections in Article 12(4), including respect for the person's rights, will and preferences.

⁵⁸ Gooding, above n 1, 63.

⁵⁹ Gooding, above n 1, 65.

⁶⁰ Quinn, above n 2, 16

⁶¹ Gooding, above n 1, 51.

⁶² Quinn, above n 2, 16

⁶³ Above n 2, 15.

⁶⁴ As summarised in Gooding, above n 1, 54.

*'The 'best interests' principles is not a safeguard which complies with article 12 in relation to adults. The 'will and preferences' paradigm must replace the 'best interests' paradigm to ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others.'*⁶⁵

Flynn and Arstein-Kerslake submit that even where a person has impairments that significantly affect communication, such a shift is possible. They suggest a support should do everything they can to still enable that person to exercise their legal capacity. This could include spending time learning their communication methods (including movements of eyelids, hand squeezing and smiling), researching past communications and speaking to those who know the person well to ascertain their values and belief systems.⁶⁶ This would be very time-consuming as well as worthwhile, but it is worth noting that this would require the allocation of further resources at least in the case of public guardianship, as the current Public Advocate's office is guardian of last resort for about 150 Canberrans.

However, Gooding identifies that State parties may struggle to implement such an approach for certain individuals, particularly for a person who is 'non-verbal, requires intensive support and has no financial experience or apparent preference regarding personal finance'. As Gooding notes, prior to the release of General Comment 1, the Victorian Law Reform Commission recommended that in exceptional circumstances, the overarching goal should be to promote the personal and social wellbeing of the supported person, with other principles applied to support this, including how a 'prudent person' would administer a person's finances. While worthy of consideration, such goals and principles Gooding submits are indistinguishable from the 'best interests standard'.⁶⁷

Gooding proposes somewhat of a hybrid of the VLRC model and that envisaged in General Comment 1, in which the best interpretation by supporters remains the principle driver, even as the other guiding principles advanced by VLRC are applied. In the situation of a person who is non-communicative, supporters could reasonably presume that a person wishes to be free from harm and vulnerability, and therefore prefer secure and stable investments. Even then, Gooding submits 'robust mechanisms' would be required to prevent exploitation, as would arbitration procedures, such as by ACAT, to resolve disputes.⁶⁸

The respect for the rights of such individuals is considered by the ALRC Report, which suggests where a person's will and preferences cannot be determined, representatives must act to uphold the person's right and in a way least restrictive of those rights, a protection consistent with both the ACT Human Rights Act and Article 12 (4).⁶⁹

Even with this combination of protections, Gooding notes that there are still scenarios where such a framework will require greater clarity or safeguards:⁷⁰

- When is it 'not possible' to determine a person's preferences, who decides, how do they decide; and what is the extent of supports that must be attempted/provided in advance;
- Instances where an individual's rights are perceived to conflict with a representatives;
- Where a person's will may conflict with their preference, using the example of a person with anorexia whose preference may be not to eat, but has the will to live. Gooding notes that attempting to undertake a 'best interpretation of will and preferences' in such situations would be 'fraught'. Instead, Gooding submits that further consideration must go into the 'emergency' situations where legal agency can be overridden and the way in which that can occur in a non-

⁶⁵ General Comment 1, para 21.

⁶⁶ Flynn and Arstein-Kerslake, above n 11, 8-9.

⁶⁷ Gooding, above n 1, 54 citing VLRC at 398.

⁶⁸ Ibid.

⁶⁹ Rec 3-3(2)(d)

⁷⁰ Gooding, above n 1, 54-63.

discriminatory way, including by consideration of existing principles in international law including because of ‘public order’.

The need for future research

A notable barrier to the introduction of supported decision making systems is the lack of research into the various aspects and impact of their use. Carney suggests ‘some reform caution is warranted, as international evidence of exactly what forms of assisted decision making regimes work in practice is lacking. Key areas of knowledge that academics have noted include:

- How it applies depending on personal characteristics (such cultural preferences for ‘collaboration’); and
- Which categories of people with cognitive impairment are best suited to the model, such as people with dementia from alcohol abuse.

Gooding submits that further research is needed to inform how states should define ‘undue influence’, how to identify and address when it occurs, and the limits of the law in entering such interpersonal relationships.⁷¹ Kohn, Blumenthal and Campbell also suggest more evidence is needed to demonstrate that SDM in practice will empower persons with disabilities to make decisions for themselves, as opposed to having ‘the opposite effect’.⁷² As Gooding puts it:

‘Certainly, the gap in the empirical and social science literature on how to effectively realise a support decision-making regime does little to assuage the concerns of policymaker, academics, families and others about the concept.’⁷³

In undertaking a review of the experiences of SDM from 2001 to 2011, Davidson et al concluded more research is required, noting that ‘the available evidence on implementation and impact is limited, and mainly comes from the areas of intellectual disabilities and end-of-life care.’⁷⁴

Similarly, Kohn et al raise concerns about the lack of clarity about how decisions are made in supported decision making relationships, the effect of such relationships on the individual’s involvement and the quality of the decisions that result. They also find a lack of material on demographic information about principals, supporters or monitors (those who oversee supporters). They also suggest more work is needed on substantive outcomes, including on the psychological impacts of SDM on principals and supporters, congruency between wishes and decisions, and quality of decisions, including the effect on outcomes.⁷⁵

‘...there is currently insufficient empirical evidence to know the extent to which (or the conditions under which) it can remedy the problems posed by surrogate decision-making process.’⁷⁶

However, it must also be noted that there is a lack of empirical research into the current dominant form of guardianship regime used in many jurisdictions. This is a point made by several commentators, including those who remain unconvinced about SDM.⁷⁷ As Blanck and Martinis note, this is likely because guardianship has been assumed to be ‘benevolent and protective’ of people with disability.⁷⁸ Gooding similarly questions

⁷¹ Gooding, above n 1, 57.

⁷² Ibid, 67.

⁷³ Ibid, 68.

⁷⁴ Davidson et al, above n 30, 66.

⁷⁵ Kohn et al, above n 38, 1142-1144.

⁷⁶ Ibid.

⁷⁷ See discussion in Gooding, above n 1, 68

⁷⁸ Blanck and Martinis, above n 10,25.

if existing substitute decision making laws are ‘under-researched’.⁷⁹

A necessary ‘safeguard’ then for the ACT appears to be to continue trials locally, and research those occurring in other jurisdictions fully, prior to legally embedding such a system in the longer term. This should not necessarily be used as an excuse to retain current laws indefinitely. In light of the CRPD and corresponding General Comments, there are clear human rights issues arising from the current law.

How do we judge success?

One of the most complex issues regarding reform to the way the law (and society) treats decision making capacity is how success of such reform is measured. As Quinn has noted, most human beings, most of the time, think and act irrationally. While actions and reasoning may be ‘cloaked’ in a ‘garb of rationality’ the ‘wellsprings of both thought and action often run much deeper.’ He notes the importance of the ‘dignity of risk’ principle, but this must be about process as much as outcome.

‘Dignity of risk, I suggest, doesn’t just mean allowing freedom in order to enable people to learn and alter behaviour – it is valuable in itself because it allows for dignity in taking risk.’⁸⁰

Quinn notes that the test of decision-making applied to people with a disability has been ‘exceedingly high’ where poor choices and decision making is not tolerated to such an extent that people without disability would have difficulty surmounting it.⁸¹

Transition

Finally, reflecting the barriers and issues identified above, while law reform is needed to make the current laws more human rights compatible, any transition to new regimes must be done carefully, systematically and in consultation with people with a disability and their carers. Even the most robust and appropriate regime of safeguards will be undermined by a rushed introduction of a new model.

Other Approaches to Supported Decision Making (Question 7)

As detailed above, we would welcome more research, evidence and evaluation on the various ways SDM and related reforms from the CRPD could be implemented. The VRLC suggestions of a spectrum of co-decision making, as well as SDM particularly seem worthy of further investigation. Such an approach is also endorsed by Davidson et al’s review of the international literature.

‘SDM should be considered as an important part of a continuum of decision making from autonomous decision making through to substitute decision making. Law, policy and practice have tended to focus on either end of the spectrum and have sometimes approached decision making as if people are either globally capable or incapable, but most people require some level of support with decision making.’⁸²

Flynn and Arstein-Kerslake have undertaken in 2014 a review of law reform across various jurisdictions:⁸³

⁷⁹ Gooding, above n 1, 68.

⁸⁰ Quinn, above n 2, 8

⁸¹ Quinn, above n 2, 14.

⁸² Davidson et al, above n 30, 1.

⁸³ Flynn and Arstein-Kerslake, above n 11, 135-136.

Northern Ireland: Assisted Decision-Making (Capacity) Bill, which they note ‘presents an interesting mix of supports (including the option of entering binding assisted decision-making agreements and co-decision making agreements) and substitute decision making (such as decision-making representatives and informal decision makers). They are concerned that the model is premised on a ‘standard’ of mental capacity as a prerequisite for retaining legal capacity.⁸⁴ Certainly the position of the ACT Human Rights Commission is that the ACT *Human Rights Act*, particularly the right to equality (s 8) and consent to medical treatment (s10(2) read in light of the CRPD mean that there should be a presumption of capacity unless that is demonstrated otherwise.

India has a draft Rights of Persons with Disabilities Bill 2011 and amendments to the National Trust Act, which include the proposed abolition of plenary guardianship and transition of those currently under plenary guardianship to a new limited form of guardianship. While supportive of change based on Article 12, Flynn and Arstein-Kerslake nonetheless raise concerns that this model may still function like a substitute decision making regime.

Canada: British Columbia have existing laws in place that allows individuals to chose representatives under agreements and types of decisions, although these are limited and do not include refusing life-saving treatment, placing the person in an institution, limiting contact with others or consenting to treatment over the individual’s objection.⁸⁵ While noting a lack of research in this area, Kohn et al suggest that women are more likely to be principals than men under the BC model, and non-relatives appear to be frequently selected as alternative representatives. This model also includes the selection of ‘monitors’ to oversee the representatives, and in these cases approximately 30% of monitors are other family members and equally 30% are friends. Kohn et al submit that if supported decision is likely to occur primarily with families, then the dynamics inherent in such relations can be both positive and negative.⁸⁶ Bach and Kerzner have also written extensively on how the CRPD could be adopted into Canadian law, including submissions to the Ontario Law Reform Commission.⁸⁷

United States: Booth Glen has also written of the extensive academic work underway in the United States, including a new National Centre for Supported Decision Making, a draft supported decision-making Bill in Texas, and the work of Autistic Self Advocacy Network (ASAN) in developing model legislation.⁸⁸ ASAN has released ‘An Act Relating to the Recognition of a Supported Healthcare Decision-Making Agreement for Adults with Disabilities’, and accompanying educative material.

Sweden and Saskatchewan: Kohn et al notes the so called ‘good man’ court appointment co-decision making process used in current Swedish and Saskatchewan law.⁸⁹

How can a person’s need for support be balanced with that person’s right to independent decision making? (Question 8)

We have addressed this question above in relation to the Safeguard Principles. Again, it seems clear that education and resources for all persons participating and supporting are critical, based on evidence-based research. The Government must be prepared to invest in this area, particularly in the transition and trial periods, if law reform is to succeed.

⁸⁴ Flynn and Arstein-Kerslake, above n 11, 135

⁸⁵ Representation Agreement Act of 1996.

⁸⁶ Kohn et al, above n 38.

⁸⁷ As discussion in Kristin Booth Glen, ‘Supported Decision-Making and the Human Right of Legal Capacity’, (2015) 3 Inclusion 2, 7-8.

⁸⁸ Ibid, 8.

⁸⁹ Kohn et al, above n 38.

SDM Trials (Question 9)

The Commission is aware of the recent ADACAS supported decision making trial, and has been consulted by the Community Service Directorate about another trial due to commence shortly. Our feedback has been informed by research of other trials interstate and overseas.

Nonetheless, Carney suggests Australia has been slow to legislate supported-decision making, compared to Canada or Sweden.⁹⁰ Blanck and Martinis note that in the United States, Texas and Virginia have passed laws authorising and studying the use of supported decision-making. MDAC also cites new laws introduced in the Czech Republic, Ireland and Latvia.⁹¹ As Carney puts it:

*'Australian pilot studies of difference models of assistance are few in number, small in scale, and unable to afford a rigorous evaluation design....they also concentrate on assessing the more extensive forms of assistance to the neglect of the more routine or ordinary situations where assistance may be needed.'*⁹²

In light of the Victorian Law Reform Commission's proposals for reform to that State's guardianship laws, the Victorian Government introduced legislation in 2014 to facilitate supported decision making, although Carney submits that these reforms 'fell short' of the VLRC's proposals and were poorly drafted.⁹³ Carney does however welcome that the Bill would have obliged appointees to do a range of things, and while arguably falling short of the CRPD standard, it would have given substance to international suggestions that reformed guardianship law can enshrine "person-centred" principles. The law would have required appointees to give:

- practicable and appropriate support to enable that person to participate in decisions affecting the person as much as possible in the circumstances ;
- give all practicable and appropriate effect to the represented person's wishes ;
- take any steps that are reasonably available to encourage the represented person to participate in decision making, even though the represented person does not have decision making capacity (cl. 7(b)(ii)); and
- act in a way that promotes the personal and social wellbeing of the represented person.

The Bill also elaborated promotion of personal and social wellbeing as including recognising a person's "inherent dignity", having regard to his or her "existing supportive relationships, religion, values and cultural and linguistic environment" and respect for confidential information.⁹⁴

Nonetheless, Carney cautions against the very narrowness of the gap between substitute and supported decision-making options, which risks confusing public understanding. He is also critical of the Bill's adoption of an expedited avenue for the appointment of a parent as guardian of an adult, which does indeed appear to be the test of capacity rejected by the CRPD, with an unclear justification. In contrast, Carney submits the criteria proposed by VLRC Report was a 'more sophisticated' suite of protections, requiring one of the following to be shown:

(a) a need for a decision to be made 'now or reasonably soon', which decision 'would not be able to be made' without an appointment, or the person's 'personal and social wellbeing can best be promoted' by such an appointment; or

⁹⁰ Carney, above n 10, 2

⁹¹ MDAC, Above n 16, 13.

⁹² Carney, above n 10, 3

⁹³ Ibid, 2

⁹⁴ Carney, above n 10, 7.

(b) that there are 'ongoing decisions to be made in relation to the person's lifestyle or finances', and/or his or her 'personal and social wellbeing can best be promoted'

(c) decision-making 'is so significantly impaired and enduring that they are unlikely at any time in the future to make their own decisions, even with significant support' and people are and have been making similar decisions for a 'significant period of time', and there is a 'broad consensus among carers and others' that the role is appropriate, and that if able to communicate his or her wishes, the person would not object.

Apparently contrary to the presumption of capacity detailed above, the original Bill would also have encourage VCAT to make an order where notified parties did not object or failed to respond, absent other factors, such as the quality of the documentation. Carney contrasts this to the VLRC proposed expanded pre-hearing process which could include mediation, planning, investigation and other options.

The legislation lapsed at the subsequent State election in 2014.

The Victorian Parliament has passed amendments to its Powers of Attorney Act, to action the VLRC's recommendation that, wherever feasible, the appointment of supports be made by the person. Carney submits that a welcome step in this legislation is that the capacity standard for appointment of a supporter is lower than that for executing a valid enduring power of attorney, being that:

- the person understands the enabling or facilitating role of a supporter;
- that the person chooses the supporter;
- that decision remains that of the person;
- and the person retains control over the beginning and ending of the relationship.⁹⁵

Other Matters (Question 12)

There are a range of other related matters that should be considered in reform to guardianship law.

Firstly, the criminal law is one area worthy of further investigation in light of the CRPD. Flynn and Arstein-Kerslake note current criminal law concepts of consent and mens rea (or the mental elements of offences) may be particularly influenced by the requirements of the Convention.⁹⁶ Already, the Australian Human Rights Commission noted in its 2014 Report, *Equal Before the Law*, that there are a range of issues for people with a disability in the justice system.

In Response to this Report, the Commission continues to advocate that the ACT Government implement many of its proposals in the form of a Disability Justice Plan, the development of which should include consultation with people with a disability in the local ACT community.

As detailed above, the issue of restrictive practices is a matter of concern. There remains confusion over whether guardians can 'consent' to restrictive practices (locks on doors, etc), and we submit that to be consistent with human rights, new legislation should clarify this issue. There also needs to be a comprehensive consideration of how restrictive practice should be monitored and regulated in the ACT.

Finally, since the review of the ACT's mental health legislation, General Comments under the CRPD have been released and subjected to significant discussion, much of it focussed on mental health law. That Bill was always intended as a 'bridge' to new legislation based even more so on capacity questions. It is doubtful

⁹⁵ Carney, above n 10, 6.

⁹⁶ Flynn and Arstein-Kerslake, above n 11, 143.

there is community or Government support for such a significant review so soon after the introduction of new mental health law, but this is an area worthy of ongoing consideration.

Conclusion

As our submission demonstrates, the application of International human rights and best practice to guardianship law and practice is a controversial and evolving area. It seems clear however that the current ACT Guardianship Act and accompanying service system is out of step with these standards, and in particular, has an over reliance on substitute decision making. At a minimum, new legislation that reduces substitute decision making to an absolute last resort, and enabling supported decision making to develop along a continuum, must be prioritised.

The challenge for the ACT is how far to strive in this law reform effort. As a human rights jurisdiction, the ACT has an opportunity to lead Australia in the implementation of the most significant reforms required under the CRPD. However, reforms such as moving to cease substitute decision making, would have a profound impact on people with a disability and their carers, and cannot be rushed or progressed without significant investment of resources. In particular, the situation of those whose wishes cannot be ascertained or supported needs to be given careful consideration.

Much planning and consultation with the community would be required before a gradual change to such a system were implemented. Part of this consultation must include the development of appropriate safeguards and transitional support.

The Commission welcomes the opportunity to work with the Government on such reform if there were a clear mandate from the community to do so, and the Government invested significantly in such efforts. Such measures truly would likely make the ACT's guardianship law amongst the best, and improve the lives of people with disabilities. But to be the first to implement such change would also inevitably involve learning from mistakes. To rush such reform without adequate investment, would likely only further limit the rights of people with a disability.

That is the challenge for this Review, and the Government's response to it – on the one hand, to attempt only incremental change, which fails to achieve the full spectrum of rights fulfilment contemplated by the CRPD, or on the other, strive for the most significant reform to the legal treatment of people with a disability possible.