2. Conceptual Landscape—the Context for Reform

Contents

Summary

2.1 This chapter discusses the principles, language and theory behind debates about decision-making processes that concern persons with disability. The ALRC considers international human rights law and key concepts in the literature concerning disability and issues of 'capacity'. This provides the conceptual background to the ALRC's recommendations in this Report.

2.2 The 'paradigm shift' in approaches to persons with disability is discussed, outlining the transition from 'best interests' approaches to ones that emphasise the will and preferences of the individual in models of 'supported' decision-making. The tensions around the meaning and application of art 12 of the *United Nations Convention on the Rights of Persons with Disabilities*[1] (CRPD) are analysed in the light of the historical development of decision-making models for people who may require decision-making support. The ALRC identifies significant conceptual confusion that is affecting the development of a focus on support and the

1 *UN Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008).

acknowledgement of the need, at times, for a person to act on behalf of another—particularly in relation to what is called 'substitute' decision-making. In this context, Australia's Interpretative Declaration in relation to art 12 is considered.

2.3 The chapter concludes by summarising the implications for the paradigm shift towards supported decision-making. This provides a prelude to Chapter 3, where the ALRC sets out National Decision-Making Principles as the basis for modelling supported decision-making in Commonwealth laws.

International context

United Nations Convention on the Rights of Persons with Disabilities

2.4 The CRPD was the first binding international human rights instrument to explicitly address disability. Australia was an active participant and leader in its development, contributing greatly to the negotiations of the text of the Convention.[2] Australia was also one of the original signatories when it opened for signature on 30 March 2007.[3] Australia ratified the CRPD in July 2008 and the Optional Protocol in 2009. The CRPD entered into force for Australia on 16 August 2008,[4] and the Optional Protocol in 2009.[5] The CRPD consolidates existing international human rights obligations and clarifies their application to persons with disabilities.[6] It does not create new rights.

2.5 In addition to the general principles and obligations contained in the CRPD,[7] it is art 12, 'Equal recognition before the law', that is of central importance in this Inquiry. It underpins the ability of persons with disability to achieve many of the other rights in the Convention. It recognises the right of persons with disability to enjoy legal capacity 'on an equal basis with others in all aspects of life' and contains five paragraphs:

> 1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
>
> 2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.

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2 Evidence to the Joint Standing Committee on Treaties, *Hansard*, Parliament of Australia, 16 June 2008, 3 (Peter Arnaudo).

3 Prior to the CRPD there were a number of non-binding standards specifically related to disability. See, eg: *Declaration on the Rights of Mentally Retarded Persons*, GA Res 2856, UN GAOR, 3rd Comm, 26th Sess, UN Doc A/RES/2856 (20 December 1971); *Declaration on the Rights of Disabled Persons*, GA Res 3447, UN GAOR, 3rd Comm, 30th Sess, UN Doc A/RES/3447 (9 December 1975); *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, GA Res 48, UN GAOR, 3rd Comm, 48th Sess, Agenda Item 109, UN Doc A/RES/48/96 (20 December 1993).

4 The CRPD entered into force on 3 May 2008, on receipt of its 20th ratification.

5 The Optional Protocol to the CRPD allows for the making of individual complaints to the Committee about violations of the CRPD by States Parties.

6 Such as the *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, UNTS171 (entered into force 23 March 1976).

7 *UN Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) arts 3, 4.

> 3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.
>
> 4. States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.
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> 5. Subject to the provisions of this article, States Parties shall take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit, and shall ensure that persons with disabilities are not arbitrarily deprived of their property.[8]

2.6 By ratifying the CRPD, Australia accepted the obligations to recognise that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life, and to take appropriate measures to provide persons with disability access to the support they may require in exercising their legal capacity.

2.7 Such international instruments do not become part of Australian law until incorporated into domestic law by statute.[9] However, as noted by the High Court in *Minister for Immigration and Ethnic Affairs v Teoh*, a convention can still assist with the interpretation of domestic law:

> The provisions of an international convention to which Australia is a party, especially one which declares universal fundamental rights, may be used by the courts as a legitimate guide in developing the common law. But the courts should act in this fashion with due circumspection when the Parliament itself has not seen fit to incorporate the provisions of a convention into our domestic law.[10]

2.8 Even when an international convention has been incorporated into domestic law, its beneficial impact cannot be assumed. Adam Johnston observed that 'the level of adherence and/or enforcement can rely on many factors':

> The first of these can be political willingness, reflected in the resourcing of relevant agencies. Domestic cultural norms can be important and the broad terms of many conventions can leave much up to an individual reader's interpretation as to what an Article requires. Judicial views, the lobbying of interest groups and the public credibility of international institutions can also play their part.[11]

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8 Ibid art 12.

9 *Minister for Immigration and Ethnic Affairs v Teoh* (1995) 183 CLR 273, 286–8, 315. See also *Kioa v West* (1985) 159 CLR 550.

10 *Minister for Immigration and Ethnic Affairs v Teoh* (1995) 183 CLR 273, 288.

11 A Johnston, *Submission 12*.

2.9 An added complexity with respect to the implementation of the CRPD in Australia is that guardianship and administration issues rest in state and territory law. As the ACT Disability, Aged and Carer Advocacy Service (ADACAS) observed:

> The realities of the Australian federal system are going to create significant challenges for reform, particularly in the nexus between Commonwealth and state law.[12]

2.10 While implementation is clearly a multifaceted challenge, a document like the CRPD can both reflect and propel shifts in thinking. Family Planning NSW commented that the CRPD is 'a powerful statement of what Australia and the world believe are the fundamental rights of people with disability';[13] and ADACAS said that the CRPD 'represents a cultural, identity and legal shift'.[14]

2.11 The CRPD reflects a 'social' model of disability, which describes disability in terms of the interaction between a person's disability and the external world. As the Preamble of the CRPD states:

> Disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others.[15]

2.12 Such an approach is in contrast to a 'medical' approach, in which a diagnosis or categorisation of condition leads to particular consequences for individuals—for example, the imposition of guardianship.[16]

2.13 The Office of the Public Advocate (Qld) said that the CRPD incorporates 'a contemporary approach to disability':

- recognising that disability is an evolving concept and that disability results from the interaction between people with impairments and their surroundings as a result of attitudinal and environmental barriers;
- the right and capacity of people with disability to make valued contributions to their communities; and
- recognising that all categories of rights apply to people with disability, who should therefore be supported to exercise those rights.[17]

2.14 As Professor Gwynnyth Llewellyn of the Centre for Disability Research and Policy, University of Sydney, submitted: 'defining disability as an interaction means that "disability" is *not an attribute of the person*'.[18]

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12 ADACAS, *Submission 108*.
13 Family Planning NSW, *Submission 04*.
14 ADACAS, *Submission 29*.
15 *UN Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) Preamble.
16 Terry Carney, 'Guardianship, "Social" Citizenship and Theorising Substitute Decision-Making Law' in Israel Doron and Ann M Soden (eds), *Beyond Elder Law* (Springer, 2012) 1. See also World Health Organisation and World Bank, 'World Report on Disability' (2011) 3–4; Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law' (2013) 20 *Psychiatry, Psychology and Law* 431, n 3.
17 Office of the Public Advocate (Qld), *Submission 05*.
18 G Llewellyn, *Submission 82*.

2.15 In addition to the general principles and obligations contained in the CRPD,[19] art 12 underpins the ability of persons with disability to achieve many of the other rights under the Convention. It recognises the right of persons with disability to enjoy legal capacity 'on an equal basis with others in all aspects of life'.[20] Article 12 was of central importance to this Inquiry.

2.16 By ratifying the CRPD, Australia accepted the obligation to recognise that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life and to take appropriate measures to provide persons with disability access to the support they may require in exercising their legal capacity. The CRPD also requires that all measures relating to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse.[21]

Other international instruments

2.17 In addition to the CRPD, there are other international instruments of relevance to this Inquiry. The *Universal Declaration of Human Rights* affirms the inherent dignity and the equal and inalienable rights of all people and sets as a common standard the protection of these rights by the rule of law.[22] While the *International Covenant on Civil and Political Rights* (ICCPR) makes no specific reference to persons with disability, it enshrines rights to life, physical integrity, liberty and security of the person, equality before the law and non-discrimination.[23] In addition, the *International Covenant on Economic, Social and Cultural Rights* protects the right to work, social security, family life, health, education and participation in cultural life;[24] and the *Convention on the Rights of the Child* refers specifically to disability.[25]

2.18 The *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment* (CAT)[26] may also be relevant, as there have been suggestions that the use of restrictive practices with respect to persons with disability might contravene the CAT.[27]

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19 *UN Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) arts 3, 4.

20 Ibid art 12.

21 Ibid art 12(4).

22 *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd Sess, 183rd Plen Mtg, UN Doc A/810 (10 December 1948). As a non-binding declaration it does not have the same force as a Convention, but forms part of the broader international human rights backdrop to this Inquiry.

23 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, UNTS171 (entered into force 23 March 1976).

24 *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976).

25 *Convention on the Rights of the Child*, opened for signature 20 November 1989, 1577 UNTS 3 (entered into force 2 September 1990) art 2.

26 *Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, opened for signature 10 December 1984, 1465 UNTS 85 (entered into force 26 June 1987).

27 Manfred Nowak, Special Rapporteur, *Interim Report of the Special Rapporteur on Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment*, 63rd Sess, UN Doc A/63/175 (28 July 2008) 9.

2.19 There are also a number of international instruments that specifically protect the rights of women[28] and Indigenous peoples,[29] which are of relevance in considering intersectional discrimination. All of these instruments are reflected in the articles of the CRPD.

Key concepts

The challenge of language

2.20 This Inquiry tackled issues of great significance which contribute to the framing of legal policy responses for persons with disability. The ALRC recognises the importance of carefully defining terms and clarifying how certain concepts are being described. The language concerning disability has shifted significantly over time, for example:

- the distinction between 'lunatics' and 'idiots' in William Blackstone's day in the mid-18th century—'[a]n idiot, or natural fool, is one that hath had no understanding from his nativity' and '[a] lunatic, or *non compos mentis*, is one who hath had understanding, but by disease, grief, or other accident hath lost the use of his reasons';[30]
- the language of 'unsound mind' of the early 20th century, as evident for example in the *Commonwealth Electoral Act 1918* (Cth);[31]
- the use of the terms 'mentally retarded persons' and 'disabled persons' in United Nations Declarations of 1971 and 1975;[32] and
- 'persons with disabilities' in the CRPD in 2007.

2.21 The legal historian Dr John Bennett remarked that '[f]or many centuries ... the law of lunacy was regulated by principles and nomenclature of the Middle Ages'.[33] As words have become associated with negative connotations, or used pejoratively, a new

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28 *Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 18 December 1979, 1249 UNTS 13 (entered into force 3 September 1981).

29 *Declaration on the Rights of Indigenous Peoples*, GA Res 61/295, UN GAOR, 61st Sess, 107th Plen Mtg, Supp No 49, UN Doc A/RES/61/295 (13 September 2007).

30 William Blackstone, *Commentaries on the Laws of England* (1765) vol 1, 292, 294. 'Lunatic' was derived from the Latin 'luna' or moon. As Louise Harmon explains, it embodied the idea that 'like the moon, the insanity of the lunatic waxed and waned. Even a lunatic who appeared permanently insane was presumed potentially curable. He had once lived his life on equal mental footing with others, and there was always that glimmer of hope that he would do so again': Louise Harmon, 'Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment' [1990] *Yale Law Journal* 1, 16.

31 For the historical background see, eg, R Croucher, '"An Interventionist, Paternalistic Jurisdiction"? The Place of Statutory Wills in Australian Succession Law' (2009) 32 *University of New South Wales Law Journal* 674.

32 *Declaration on the Rights of Mentally Retarded Persons*, GA Res 2856, UN GAOR, 3rd Comm, 26th Sess, UN Doc A/RES/2856 (20 December 1971); *Declaration on the Rights of Disabled Persons*, GA Res 3447, UN GAOR, 3rd Comm, 30th Sess, UN Doc A/RES/3447 (9 December 1975).

33 John Bennett, *A History of the Supreme Court of New South Wales* (Law Book Co, 1974) 125.

lexicon has been developed.[34] In its 1989 report, *Guardianship and Management of Property*, the ALRC commented that

> There is a problem of language when dealing with people with disabilities. Some expressions which used to be common are no longer used by those working in the field because they are regarded as having connotations which tend to lower the dignity of people with disabilities.[35]

2.22 The ALRC therefore took an approach in that report which was to adopt usages 'current among people who are disabled and those who work with them'.[36]

2.23 The present Inquiry takes place 25 years later and the language has shifted further in the intervening years. In this Inquiry, the ALRC seeks to frame concepts and choose terms in ways that reflect the framing principles—in particular that of 'dignity'. Consistent with the approach identified by the ALRC in 1989, words and terms should not be used that tend to lower the dignity of people with disabilities. Even where terms have an established usage,[37] the ALRC considers that the development of a new lexicon serves to signal the paradigm shift reflected in the CRPD—the purpose of which is to 'promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'.[38] This Inquiry provided an opportunity to contribute to that process.[39] In particular, the ALRC seeks to place the emphasis in law, and in language, on support.

2.24 The ALRC acknowledges, however, that changes in language, as in law, of themselves, do not effect change:

> Changing laws and implementing new policies regarding legal capacity is only the first step in realising the right to equal recognition before the law for people with disability.[40]

2.25 What is needed is a shift in understanding and commitment—or as some express it, a change in 'culture'. Such a view is summed up in the comments by ADACAS, which said:

> ADACAS fully supports the belief that effective change management requires the development of a new lexicon, and the use of terminology such as fully supported decision making contributes to that goal. Of course, there is a risk associated with a sudden departure from traditional terminology. It may cause confusion at a time when more onerous demands are possibly going to be imposed on supporters. We recognize

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34 A similar shift is evident in relation to the terms applying to children born out of wedlock: from 'bastards', to 'illegitimate' to 'ex-nuptial'.

35 Australian Law Reform Commission, *Guardianship and Management of Property*, Report No 52 (1989) [1.3].

36 Ibid.

37 In the 1989 report the ALRC gave the following example: 'The problem is complicated by the fact that the medical profession has adopted some words as having reasonably precise meanings but the same words are used differently by non-medical people or are regarded as inappropriate': Ibid.

38 *UN Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008) art 1.

39 Support for this approach is evident in, eg, ADACAS, *Submission 29*.

40 PWDA, ACDL and AHR Centre, *Submission 136*.

> that there are implementation issues, but it lays within the power of legislative drafters to mitigate these impacts, possibly through the staged introduction of new requirements. More importantly, a change of culture will not happen simply because legislation is enacted. Intentional community development activities will need to be undertaken to support the broad community to make the change to viewing people with cognitive impairments as having capacity and being valid decision makers.[41]

Definitions of disability

2.26 'Disability' may be defined in different ways and for different purposes. Approaches to defining disability have also shifted over time—particularly from the medical to a social approach. The CRPD does not include detailed definitions of 'disability' or 'persons with disabilities' in its definition section. Rather, art 1 states that

> Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

2.27 For the purposes of this Inquiry, the ALRC is taking a broad encompassing approach to definitions of disability, as reflected in the CRPD.[42] This definition includes: sensory, neurological, physical, intellectual, cognitive and psychosocial disability.

2.28 The social approach to disability, reflected in the CRPD, requires a policy focus on the person and their ability, with the support they require to interact with society and their environment—placing the policy emphasis not on 'impairment' but on 'support'. This approach informs the supported decision-making focus of the ALRC's recommendations in this Report.

Recognition as 'persons'

2.29 The Terms of Reference require a consideration of the recognition of people with disability 'as persons before the law'.[43] This language reflects art 12(1) of the CRPD, that 'States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law'.

2.30 To be recognised 'as persons' is the first question in any consideration of legal capacity. Historically, certain people have been denied recognition of their ability to act in law, or to have 'legal standing', at all.[44] Professor Bernadette McSherry explains that,

> at various times in different societies, certain groups have been viewed as not having legal 'personhood' or standing. The extinction or suspension of legal standing,

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41 ADACAS, *Submission 108*. See also PWDA, ACDL and AHR Centre, *Submission 136*.

42 Other definitions may be found in, eg, Australian Bureau of Statistics, *Disability, Australia, 2009, Cat No 4446.0* (2011); *Disability Discrimination Act 1992* (Cth) s 4(1).

43 The Terms of Reference are set out in full on the ALRC website: <www.alrc.gov.au>.

44 For example, the early laws of marriage in the common law treated the husband and wife as one: the wife's legal personality merged with that of her husband. When the *Statute of Wills 1540* granted the power to devise real estate, an explanatory statute was passed in 1542 to clarify that this power did not extend to married women; nor to infants and 'lunatics'.

> sometimes referred to as 'civil death', was once seen as a necessary consequence of conviction. Similarly, women, children under the age of majority and those with mental and intellectual impairments have been and continue to be viewed in some societies as not having legal standing.[45]

2.31 The shift in language from 'disabled persons' to persons or people 'with disability' reflects an emphasis on personhood, rather than disability. It also reflects a social model of disability.

2.32 In its General Comment on art 12 the United Nations Committee on the Rights of Persons with Disabilities (UNCRPD) emphasised that 'there are no circumstances permissible under international human rights law in which a person may be deprived of the right to recognition as a person before the law, or in which this right may be limited'.[46] In this Report, the ALRC recommends a model that emphasises ability and support to exercise legal agency, consistent with a full recognition of personhood.

'Equal recognition'

2.33 The Terms of Reference state that, for the purposes of this Inquiry, equal recognition before the law and legal capacity are to be understood as they are used in the CRPD, 'including to refer to the rights of people with disability to make decisions and act on their own behalf'. The concept of equality therefore emphasises independent decision-making by persons with disability.

2.34 Professor Terry Carney stated that equality, in the sense used in art 12, 'can be variously formulated':

> It can be expressed as a purely *formal* concept (ie an 'opportunity') or in more substantive terms, as an achievement of distributive equity. It can be conceived as a universal right of citizenship for all, or as a special standard for particular groups (such as the disabled aged). And it also raises notoriously complex issues about respect for diversity and the right to make poor choices (the so-called 'dignity of risk').[47]

2.35 The UNCRPD emphasised that the idea of equality reflected in art 12 is essentially about the exercise of human rights: '[e]quality before the law is a basic and general principle of human rights protection and is indispensable for the exercise of other human rights'.[48] Rather than providing additional rights, art 12 of the CRPD 'simply describes the specific elements required to ensure the right to equality before the law for people with disabilities on an equal basis with others'.[49]

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45 McSherry, Bernadette, 'Legal Capacity under the Convention on the Rights of Persons with Disabilities' (2012) 20 *Journal of Law and Medicine* 22, 23.

46 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [5].

47 Terry Carney, above n 16, 3. See also Terry Carney, 'Participation and Service Access Rights for People with Intellectual Disability: A Role for Law?' (2013) 38 *Journal of Intellectual and Developmental Disability* 59, 66.

48 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [1].

49 Ibid.

2.36 The key element in equal recognition, as understood in the CRPD and the discourse that has developed around it, is the embracing of a supported decision-making paradigm so that persons with disability are acknowledged as having the right to make decisions on an equal basis with others and are supported in exercising that right. The linking of support with equality was made in some submissions. For example, Hobsons Bay City Council said that

> equality should also recognise that in some instances people with disabilities need to be treated with equity in order to create equality. For example, needing additional assistance with some elements of the law in order to fully participate.[50]

Legal capacity

2.37 Article 12(2) of the CRPD provides that 'States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'.

2.38 Capacity in a general sense refers to decision-making ability. Decisions may cover a wide range of choices in everyday life. They may relate to personal matters, financial and property matters, and health and medical decisions. The concept of *legal* capacity in the CRPD contains two aspects: 'legal standing' and 'legal agency'. Legal *standing* is the ability to hold rights and duties—to be recognised as legal persons. Legal *agency* is the ability to exercise these rights and duties to perform acts with legal effects. Dr Mary Donnelly commented that

> A presumption of agency underlies the liberal conception of autonomy. Our choices are autonomous because they are, in a fundamental sense, *our* choices.[51]

2.39 The UNCRPD explains that 'legal capacity to be a holder of rights entitles the individual to the full protection of her rights by the legal system'.[52]

2.40 Legal capacity sets the threshold for individuals to take certain actions that have legal consequences. For example, a range of transactions may involve an age threshold as a benchmark of when a person is regarded as being able to act independently and with binding effect—to have legal agency to make 'legally effective choices'.[53] Legal capacity goes to the validity, in law, of choices and being accountable for the choices made. As Carney states:

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50 Hobsons Bay City Council, *Submission 44*.

51 Mary Donnelly, *Healthcare Decision-Making and the Law—Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, 2010) 24.

52 The right to recognition as a legal agent is also reflected in art 12(5) CRPD, which outlines the duty of States Parties to 'take all appropriate and effective measures to ensure the equal right of persons with disabilities to own or inherit property, to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit and shall ensure that persons with disabilities are not arbitrarily deprived of their property: United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [11]. See also Bernadette McSherry, 'Legal Capacity Under the Convention on the Rights of Persons with Disabilities' (2012) 22 *Legal Issues* 23.

53 Terry Carney and David Tait, *The Adult Guardianship Experiment—Tribunals and Popular Justice* (Federation Press, 1997) 3.

> Those who make the choice should be able to provide valid consent, and make decisions for which they can be held accountable. They should, in short, be legally competent.[54]

2.41 There are examples of tests of legal capacity—in terms of levels of understanding for particular legal transactions—that have been developed through the common law:[55]

> Legal incapacity means that, in law, a person is not competent to enter into legal transactions, such as making a contract, executing a will, or giving a legally-recognised consent, for example to an operation.[56]

2.42 The common law starts from a presumption of legal capacity—'the law's endorsement of autonomy'.[57] Common law definitions of legal capacity are generally invoked after the event, when a transaction is later challenged on the basis of a lack of capacity (in the sense of agency) to rebut the presumption of legal capacity.[58] They are not a general starting point for action, but a retrospective focusing on the nature of the transaction and the level of understanding required for legal agency. The common law—including doctrines of equity—also includes protective doctrines for vulnerable people, such as the doctrines concerning undue influence and unconscionable transactions.[59] Where a lack of the required level of understanding is proven in the particular circumstances, the transaction may be set aside. Such doctrines focus on a transaction and the circumstances surrounding it. They are decision-specific and involve assessments of understanding relevant to the transaction being challenged. Bruce Arnold and Dr Wendy Bonython commented:

> It is axiomatic that in some instances differences in capability will be recognised in law. Lack of capacity is one [of] those instances, and is not inherently discriminatory on the basis of disability.[60]

2.43 Capacity assessments have been made the trigger for formal arrangements for decision-making support through, for example the appointment of guardians and administrators, or the commencement of enduring powers of attorney. They are also made in a range of health care decisions.

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54 Ibid.

55 Contracts: *Blomley v Ryan* (1954) 99 CLR 362. Wills: *Banks v Goodfellow* (1870) LR 5 QB 549. See also Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) ch 7.

56 Australian Law Reform Commission, *Guardianship and Management of Property*, Report No 52 (1989) [1.4].

57 Donnelly, above n 51, 93.

58 For example, in the context of wills, a person is presumed to have the legal capacity to make a will and it is for those who challenge a testator's capacity to bring evidence of incapacity: *Bull v Fulton* (1942) 66 CLR 295. The presumption of capacity arises if the will is rational on its face and is duly executed. See, eg, Gino Dal Pont and Ken Mackie, *Law of Succession* (LexisNexis Butterworths, 2013) ch 2. This was expressed in the legal maxim '*omnia praesumuntur rite et somemniter esse acta*': all acts are presumed to have been done rightly and regularly.

59 See, eg, Dyson Heydon and Mark Leeming, *Cases and Materials on Equity and Trusts* (LexisNexis Butterworths, 8th ed, 2011) ch 14.

60 B Arnold and W Bonython, *Submission 38*.

2.44 The common law presumption is embodied in some guardianship legislation.[61] In the Commonwealth context, the *National Disability Insurance Scheme Act 2013* (Cth) includes an assumption of capacity:

> People with disability are assumed, so far as is reasonable in the circumstances, to have capacity to determine their own best interests and make decisions that affect their own lives.[62]

2.45 Legal capacity is a different concept from 'mental capacity' and should not be confused with it.[63] The UNCRPD commented that the CRPD 'does not permit perceived or actual deficits in mental capacity to be used as justification for denying legal capacity'.[64]

2.46 Stakeholders emphasised the distinction between legal capacity and mental capacity. For example, People with Disability Australia, the Australian Centre for Disability Law and the Australian Human Rights Centre commented that any proposal for a uniform approach to legal capacity

> must remove any notion that the assessment of mental capacity is also an assessment of legal capacity, that assessing mental capacity is a mechanism through which to limit legal capacity, and that the existence of a cognitive impairment creates a limit to the exercise of legal agency. Concerns with the provisions in, and operation of, legislation ... cannot be ameliorated or rectified without an acceptance of this premise.[65]

2.47 This reflects two concerns: first, that legal capacity should not simply be *equated* with mental capacity; and, secondly, that people with cognitive impairment should not be assumed to have limited legal capacity, in the sense of being able to exercise legal agency.

2.48 Similarly, stakeholders pointed to the danger of defining legal capacity on the basis of disability—of those who *have* legal capacity; and those who *have not*. Such a 'binary model' does not reflect how legal capacity should be represented. Arnold and Bonython submitted that

> [Legal capacity] may be context-dependent, and fluctuate, rather than static and permanent. In many instances, the primary focus of the law is not whether the individual has a disability; rather, it considers whether that disability impairs the individual's ability to act as a legally recognized entity, with the powers and obligations such recognition attracts. A person who is physically disabled, therefore, is entitled to exactly the same presumption of capacity at law as someone without a

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61 See, eg, *Guardianship and Administration Act 2000* (Qld) sch 1 cl 1; *Guardianship and Administration Act 1990* (WA) s 4(3).

62 *National Disability Insurance Scheme Act 2013* (Cth) s 17A(1). See also *Mental Capacity Act 2005* (UK) s 1, which addresses this explicitly by providing that individuals are assumed to have capacity to make decisions unless otherwise established.

63 See, eg, the distinction between medical and legal perspectives in Terry Carney, above n 16.

64 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [12].

65 PWDA, ACDL and AHR Centre, *Submission 66*.

> physical disability. ... For many disabled people, the question of capacity is no more relevant to them than it is [to] the remainder of society.[66]

2.49 What is clearly not appropriate in the context of the CRPD is a disqualification or limitation on the exercise of legal capacity *because of* a particular status, such as disability. As National Disability Services remarked, '[t]he crux of the issue is seen in historic legal frameworks that place constraints on the exercise of legal capacity based solely on disability status'.[67] The approach should therefore be on the support needed to exercise legal agency, rather than an assumption or conclusion that legal agency is lacking because of an impairment of some kind.

2.50 Even the word 'capacity' may carry some of the connotations of previous times. 'Capacity' is regularly confused with 'legal capacity', and 'legal capacity' is regularly conflated with 'mental capacity'. To avoid such confusion and to direct reform towards supported decision-making, the ALRC uses the word 'ability'[68]—and emphasises that the focus should be on assessing how the individual can be supported to exercise their ability.

Supported and substitute decision-making

2.51 In this Report, the ALRC recommends shifting away from 'substitute decision-making' to 'supported decision-making'. There is an important distinction between them and it is the key issue in the discussion surrounding the meaning and effect of art 12 of the CRPD. It is also the point at which most confusion has arisen.

2.52 Decision-making arrangements for persons with disability take many forms along a spectrum, including:

- informal arrangements—usually involving family members, friends or other supporters;
- formal pre-emptive arrangements—anticipating future loss of legal capacity through appointment of a proxy, for example in enduring powers of attorney (financial/property), enduring guardianships (lifestyle) and advance care directives (health/medical);[69] and
- formal arrangements—where a court or tribunal appoints a private manager or guardian, or a state-appointed trustee, guardian or advocate to make decisions on an individual's behalf (guardians and administrators).[70]

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66 B Arnold and W Bonython, *Submission 38*.

67 National Disability Services, *Submission 49*. See also PWDA, ACDL and AHR Centre, *Submission 66*.

68 Others talk about 'capability', such as Amartya Sen and Martha Nussbaum. See discussion in Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar for the Future' (2006) 34 *Syracuse Journal of International Law and Commerce* 429.

69 Sometimes referred to collectively as 'living wills'. See, eg, Rosalind Croucher and Prue Vines, *Succession: Families, Property and Death* (LexisNexis Butterworths, 4th ed, 2013) [4.3].

70 In some cases, such as emergency medical decisions, there are statutory hierarchies of those who may authorise certain actions—'generic lists of suitable proxies in the legislation': Carney and Tait, above n 53, 4.

2.53 Formal arrangements may also include recognition of support by family, friends or others—for example, where provision is made for the designation of a 'nominee' for particular purposes.[71] Banks may provide facilities for co-signing, allowing designated others to conduct banking along with the account holder.

2.54 The formal appointment of guardians and administrators in Australia occurs under state and territory laws. Guardians and administrators are vested with power to make decisions on behalf of persons assessed to be unable to make decisions for themselves.

2.55 In the literature discussing support for people who may require decision-making assistance there is an evident tension in the way that the labels of 'supported decision-making' and 'substitute decision-making' are used. The discourse around art 12, and particularly the General Comment on art 12 when published as a draft in 2013,[72] has exacerbated this tension.

2.56 General Comments are provided by way of guidance and are different from legally binding obligations as reflected in the CRPD itself. The Rules of Procedure of the UNCRPD provide that it may prepare General Comments 'with a view to promoting its further implementation and assisting States Parties in fulfilling their reporting obligations'.[73] Some of the tension arising from the discussion about models of decision-making is evident in the submissions made in response to the UNCRPD's General Comment on art 12.

2.57 Australia has set out its understanding about art 12 in one of three Interpretative Declarations.[74] In relation to art 12, Australia declared its understanding:

> Australia recognizes that persons with disability enjoy legal capacity on an equal basis with others in all aspects of life. Australia declares its understanding that the Convention allows for fully supported or substituted decision-making arrangements, which provide for decisions to be made on behalf of a person, only where such arrangements are necessary, as a last resort and subject to safeguards.[75]

2.58 This Declaration was made in the light of the contentiousness of guardianship in the discussions surrounding the development of the text of the CRPD and the criticism of what was described as 'substituted' decision-making. A number of other countries

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71 Eg, Centrelink 'correspondence nominees'. See Ch 4.

72 United Nations Committee on the Rights of Persons with Disabilities, *Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law*, 2013. The final General Comments No 1 and No 2 were adopted by the UNCRPD on 11 April 2014.

73 UNCRPD, *Rules of Procedure* (5 June 2014) r 47.

74 An 'Interpretative Declaration' is a unilateral statement made by a State or an international organisation, in which that State or organisation purports to specify or clarify the meaning or scope of a treaty or of certain of its provisions, outlining the State's understanding of obligations under the CRPD, without purporting to exclude or modify its legal effects: International Law Commission, *Guide to Practice on Reservations to Treaties* (2011) [1.1]–[1.3].

75 *Convention on the Rights of Persons with Disabilities: Declarations and Reservations (Australia)*, opened for signature 30 March 2007, 999 UNTS 3 (entered into force 3 May 2008). There were also Interpretative Declarations in relation to arts 17 and 18.

made similar declarations that the CRPD permits substitute decision-making in certain limited circumstances and subject to appropriate safeguards.[76]

2.59 There are differing views about the effect of Australia's Interpretative Declaration, particularly in relation to the role of substitute decision-making. The ALRC considers that this is driven by conceptual confusion that is impeding reform. To appreciate the significance of this tension, and to provide the context for the formulation of legal policy responses in this Inquiry, the following section explores some key concepts and the emergence of the concepts of 'supported' and 'substitute' decision making.

The emergence of 'substitute' decision-making

2.60 Any discussion of substitute decision-making needs to distinguish two separate issues: the first is the *appointment* of a person to act on behalf of another and the scope of the person's powers; the second is the *standard* by which that appointee is to act. They are entirely separate points, but often confused. The appointee may be chosen by the person themselves, or by a court or tribunal. The standard is the test by which any decision-making by the appointee is to occur. To explain the distinction, it is constructive to set out a little of the history.

2.61 Traditional guardianship laws have been described as exceedingly paternalistic,[77] protecting the estate of the person under protection, and not promoting their autonomy, especially where plenary forms were used involving a complete vesting of authority in another person. The disability rights movement of the 1960s led to increasing pressure to move away from such models, championing a social, rather than a medical, model of disability.[78]

> The principles of new legislation were fairly consistent: the least restrictive option (with guardianship as a last resort), promoting maximum autonomy, encouraging habilitation and living as 'normally' as possible, and a preference for family over state proxies. This meant keeping orders as short and limited as possible. Generally 'private' arrangements were to be preferred to public ones, and a 'substituted judgement' principle was to be used rather than a 'best interests' one, where these came into conflict.[79]

2.62 Such efforts sought to limit the scope of appointment of substitute decision-makers, such as guardians, to achieve the 'least restrictive option'. But they also focused on the standard by which the appointee was to act: 'best interests' standards, as suggested in this quote, were ones that preceded, and were to be contrasted with, a 'substituted judgment' approach. The 'best interests' principle was seen to reflect the idea of 'beneficence'—a dominant theme in medical ethics, in which the 'primary imperatives were for doing good for the patient, the avoidance of harm and the

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76 Eg, Norway, Estonia and Canada: see Australian Government Attorney-General's Department, *Submission 113*.

77 Eg, Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) [6.95]–[6.96].

78 Ibid [2.8].

79 Carney and Tait, above n 53, 17–18. Citations omitted.

protection of life'.[80] A 'best interests' standard 'requires a determination to be made by applying an objective test as to what would be in the person's best interests'. A 'substituted judgment' standard is 'what the person would have wanted',[81] based for example on past preferences. Substitute decision-making can therefore apply in two broadly different ways—one involves an objective 'best interests' standard, the other involves a focus on what the person wants or would have wanted ('substituted judgment').

2.63 In a report in 1995, Robin Creyke described the emergence of a 'common core of principles' to guide substitute decision-makers as '[o]ne of the most remarkable developments in this area of law'. It involved an appreciation that disability

> is not an absolute state and that individuals' capacities to reason and to make decisions continue, or can be developed, in some areas, albeit they are lost, or cannot be exercised without assistance or training in others. This awareness, coupled with the growing focus on people's rights as individuals, led to the notion that the powers given to substitute decision-makers should be restricted and tailored to the special needs of the individual for whom assistance is needed.[82]

2.64 The 'guiding philosophies' that became 'strongly entrenched in Australian laws for guardians, financial managers or administrators' by the 1990s were: the presumption of competence; normalisation; the least restrictive option; respect for autonomy; and fostering self-management.[83] So when a 'substitute' was appointed to act on behalf of another, their powers were to be restricted and the standard by which they were to act was increasingly one of 'substituted judgment', based on what the person would have wanted.

2.65 Even in a reformed context of being committed to advancing individuals' rights, however, 'best interests' standards were still retained, in language and in form. The Australian Guardianship and Administration Council described the approach of state and territory appointments as being 'governed by three principles, variously expressed', that:

> (a) an appointment must promote as far as possible the person's freedom of decision and action (sometimes called the 'least restrictive alternative' or 'autonomy' principle); and
>
> (b) an appointment promotes the person's best interests; and
>
> (c) the person's wishes are given effect to, wherever possible.[84]

2.66 'Best interests' and the person's wishes are both used—a combination of subjective and objective. Some 'best interests' standards have also been expressed in terms of prioritising the wishes and preferences of the person. For example, the *Mental*

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80 Donnelly, above n 51, 11. Donnelly refers to the Hippocratic Oath.
81 Explanatory Notes, *Mental Capacity Act 2005* (UK) [28].
82 R Creyke, *Who Can Decide? Legal Decision-Making for Others*, Aged and Community Care Service Development and Evaluation Reports, No 19, Department of Human Services and Health, Aged and Community Care Division (1995) 38.
83 Ibid 40.
84 AGAC, *Submission 51*.

Capacity Act 2005 (UK) s 4(6) requires a person making a determination of 'best interests' to consider, 'so far as is reasonably ascertainable':

> (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),
>
> (b) the beliefs and values that would be likely to influence his decision if he had capacity, and
>
> (c) the other factors that he would be likely to consider if he were able to do so.[85]

2.67 In addition, s 4(7) requires the decision-maker to take into account, 'if it is practicable and appropriate to consult them', the views of:

> (a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,
>
> (b) anyone engaged in caring for the person or interested in his welfare,
>
> (c) any donee of a lasting power of attorney granted by the person, and
>
> (d) any deputy appointed for the person by the court,
>
> as to what would be in the person's best interests and, in particular as to the matters mentioned in subsection (6).

2.68 Of such a hybrid standard, Dr Mary Donnelly writes that it 'attempts to mitigate the consequences of a loss of capacity while staying within a best interests framework'.[86] The overall question is an objective one, but it is informed by past and present wishes and the opinion of others as to what would be in the person's best interests.

Shift towards supported decision-making

2.69 By the second decade of the 21st century, the approach advocated is described as 'supported decision-making', which places the person who is being supported at the front of the decision-making process. The decision is *theirs*. As Carney summarises:

> Supported decision-making encompasses a range of processes to support individuals to exercise their legal capacity, and these consist of:
>
> - effective communication, including in the provision of information and advice to a person and through ensuring that a person is able to communicate their decisions to others;
> - spending time to determine a person's preferences and wishes;
> - informal relationships of support between a person and members of their social networks;
> - agreements or appointments to indicate that a relationship of support exists; and
> - statutory relationships of support—whether through private or court/tribunal appointment.[87]

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85 A similar model is included, for example, in the Mental Health Bill 2013 (WA), pt 2 div 3, 'Best interests of a person'.

86 Donnelly, above n 51, 203. This approach, she writes, is 'not without difficulties': 203.

87 Carney, above n 47, 60.

2.70 Supported decision-making emphasises the ability of a person to make decisions, provided they are supported to the extent necessary to make and communicate their decisions. It focuses on what the person *wants*.

2.71 In the context of developing—and championing—'supported decision-making', however, 'substitute' is often equated with 'guardianship' and both are assumed to represent a standard that is not consistent with the rights of persons with disability. The fact that someone is appointed as a substitute becomes problematic of itself, rather than focusing upon *how* the substitute is to act.

2.72 Interwoven in the discussion about 'substitute' and 'supported' decision-making is a lack of conceptual clarity about the role that a person's wishes and preferences play when another acts for them as a 'substitute' decision-maker; and the role that a 'supporter' plays in assisting a person to make decisions. Conceptual confusion is also exacerbated when models use 'best interests' language, but expressed in terms of giving priority to the person's wishes and preferences. Given the tensions around the usage and understanding about 'substitute' decision-making—and the blurring between 'substituted judgment' and 'substitute decision-making'—the ALRC considers that it might be preferable to move away from this language altogether. The terms the ALRC recommends are 'supporter' and 'representative' contained in the Commonwealth decision-making model set out in this Report.

Substitute decision-making and the CRPD

2.73 An important issue to clarify is whether the CRPD permits substitute decision-making at all, or in what form. This also raises the questions of what is meant by substitute decision-making in the CRPD context, how is it different from supported decision-making and what are the implications of this analysis in informing reform recommendations.

2.74 The ALRC considers that the issue of the appointment of a person to act needs to be clearly differentiated from the standard by which the appointee—or substitute—is to act. The danger in analytical terms is to condemn the appointment of a person to act on behalf of another simply by virtue of the appointment, presupposing that the appointee will not act in a way that places the individual at the centre of the decision-making process. The ALRC considers that much of the conceptual confusion lies in a failure properly to distinguish these two things. As noted above, substitute decision-making can apply an objective 'best interests' standard or can use a 'substituted judgment' standard of what the person wants or would have wanted.

2.75 In its General Comment on art 12, finalised in April 2014,[88] the UNCRPD said that 'support' is a broad term—'that encompasses both informal and formal support

88 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014.

arrangements, of varying types and intensity'.[89] It then spelled out its understanding of the difference between a 'support' model and a 'substitute' one.

2.76 A *supported* model comprises 'various support options which give primacy to a person's will and preferences and respect human rights norms' and, while supported decision-making regimes 'can take many forms', 'they should all incorporate key provisions to ensure compliance with article 12'.[90] Supported decision-making processes prioritise personal autonomy and recognise that individuals should be empowered with information to make decisions—even bad ones (acknowledging the dignity of risk).[91]

2.77 A *substitute* decision-making regime has different characteristics and can also take many forms. The common defining elements, as understood by the UNCPRD, are where

> (i) legal capacity is removed from a person, even if this is just in respect of a single decision; (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will or (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective 'best interests' of the person concerned, as opposed to being based on the person's own will and preferences.[92]

2.78 The General Comment was prompted by what the UNCRPD described as 'a general misunderstanding of the exact scope of the obligations of States Parties under Article 12'.[93] The UNCRPD suggested that substitute decision-making regimes should be abolished and replaced by supported decision-making regimes and the development of supported decision-making alternatives. Most importantly, the Committee commented that '[t]he development of supported decision-making systems in parallel with the retention of substitute decision-making regimes *is not sufficient to comply with Article 12*'.[94] What is required is '*both* the abolition of substitute decision-making regimes and the development of supported decision-making alternatives'.[95]

2.79 The UNCRPD commented on Australia's Interpretative Declaration in its concluding observations on the initial report of Australia to the Committee in September 2013. The Committee noted the referral to the ALRC of this Inquiry, but expressed concern 'about the possibility of maintaining the regime of substitute decision-making, and that there is still no detailed and viable framework for supported decision-making in the exercise of legal capacity'.[96]

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89 United Nations Committee on the Rights of Persons with Disabilities, *Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law*, 2013 [15].

90 Ibid [25].

91 Bernadette McSherry, above n 52, 26.

92 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [23].

93 Ibid [3].

94 Ibid [24]. Emphasis added.

95 Ibid. Emphasis added.

96 Committee on the Rights of Persons with Disability, 'Concluding Observations on the Initial Report of Australia, Adopted by the Committee at Its Tenth Session (2-13 September 2013)' (United Nations, 4 October 2013) 9, [24].

2.80 The ALRC acknowledges that there is considerable tension about what is described as 'substitute decision-making'. As noted above, the so-called 'substitute judgment' approach was anchored in the will and preferences of the person—the significant conceptual shift related to how the appointed substitute was to act, namely *away* from an objective 'best interests' standard.

2.81 Stakeholders pointed to art 12(4) and its requirements of safeguards, implicitly acknowledging measures that may be regarded as 'substitute' models. The Office of the Public Advocate (SA) observed that the protections of art 12(4) 'make sense as protections for substitute decision making as a "measure relating to exercising capacity"'.[97] The Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance noted that Australia's Interpretative Declaration reflected this safeguards approach in relation to substitute decision-making arrangements,

> where decision-making support may extend to decisions being made by a third party on behalf of the person with the impairment, but where such arrangements should be put in place only when they are necessary in order to enable the exercise of legal capacity and only where there are sufficient safeguards in place.[98]

2.82 While substitute decision-making models that reflect the constraints identified in such comments may technically not be contrary to the CRPD, '[t]here is still considerable debate over the significance of the [CRPD] for guardianship'.[99] Is 'guardianship' compatible with the CRPD? Or is it rather a question of *what kind of* guardianship (or whatever other label is used) is incompatible with it—namely, only guardianship where decisions are made without reference to the wishes and preferences of the person under protection?

2.83 Australia welcomed the initiative to clarify the scope of States Parties' obligations under art 12 and noted 'the Committee's perception of a general failure of States Parties to recognise that the human-rights based model of disability implies a shift from the substitute decision making paradigm to one that is based on supported decision-making':

> Australia acknowledges the importance of supporting decision-making where this is possible, but considers that a human rights-based model of disability does not preclude all substituted decision-making. Such decisions should only be made on behalf of others where this is necessary, as a last resort, and subject to safeguards.[100]

2.84 Australia considered the discussion of art 12(1) and (4) 'particularly helpful',[101] but was critical of the characterisation of art 12(3) 'as never permitting substituted decision-making',[102] and that the General Comment did not acknowledge

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97 Office of the Public Advocate (SA), *Submission 17*. See, also, Caxton Legal Centre, *Submission 67*.

98 Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*.

99 John Chesterman, 'The Future of Adult Guardianship in Federal Australia' (2013) 66 *Australian Social Work* 26, 31.

100 Australian Government, Submission to the UN Committee on the Rights of Persons with Disabilities, *Draft General Comment on Article 12 of the Convention–Equal Recognition before the Law*, 2014 [5].

101 Ibid [8].

102 Ibid [5].

> Situations where no amount of support will assist, such as where a person may have a severe cognitive or psychiatric impairment and is unable to understand, make or communicate a decision. It is unfortunate that the complexities of this issue are not acknowledged and discussed in the current draft.[103]

2.85 Australia reiterated the position under art 6 of the ICCPR, in cases of medical emergency where a person is not able to consent to treatment, it is permissible to provide such treatment where this is necessary for life-saving purposes.[104]

> Australia considers the same principle to be relevant to persons with disabilities, and that the exclusion of any form of substituted decision making in relation to persons with disabilities would be incompatible with these other international human rights obligations.[105]

2.86 Australia expressed concern that the draft General Comment was characterising the entirety of art 12 'in absolute terms',[106] although art 12 itself is not expressed in this fashion:

> Australia considers that while it is important that the legal capacity of persons with disabilities is respected to the fullest extent possible, there are circumstances in which substituted decision-making may be the only available option. Australia considers that guidance from the Committee on the most human rights compatible approach in situations where a person does not have, either temporarily or permanently, the capacity to make or communicate a decision, would be useful to States Parties.[107]

2.87 Australia argued that, in a number of respects, the draft General Comment sought to extend the scope of art 12 beyond that of existing expressions of both equality before the law and 'legal capacity' in international human rights law. It stated that the most significant example of this is 'the characterisation of art 12 as requiring supported decision-making and not permitting substituted decision-making in any circumstances':

> The statement that there are no circumstances permissible in which a person may be deprived of the right to recognition as a person before the law, or to have this right limited, relates to article 16 of the ICCPR, rather than article 12 of the Convention. The ICCPR provides for this in article 4(2), which states that no derogation from that right is permissible even in times of public emergency. The Convention does not contain a similar provision. However, Australia accepts that this is applicable in relation to article 12(1).[108]

2.88 Australia reiterated that it did not consider art 12 required the abolition of all substitute decision-making regimes and mechanisms.[109] Other States Parties expressed similar concerns with the language of the draft General Comment.[110]

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103 Ibid [9].
104 Ibid [11].
105 Ibid.
106 Ibid [13].
107 Ibid [16].
108 Ibid [21].
109 Ibid [24].
110 See submissions to the UNCRPD on the draft General Comment from, eg, Denmark, New Zealand and Norway: Australian Government Attorney-General's Department, *Submission 113*.

2.89 There are distinct threads in these responses. First, that an approach of supporting decision-making is paramount; secondly, that any appointment of a person to act on behalf of another should be limited, a last resort and subject to safeguards compatible with human rights; and thirdly, that the CRPD does not prohibit the appointment of a person to act on behalf of another. What is *not* clearly disentangled, however, is separating the fact of an appointment in certain circumstances and how the person is to act. Both are subsumed in the argument that, in some limited circumstances, 'substitute decision making' may be appropriate, without closely interrogating what substitute decision-making means. The argument is therefore expressed in terms of 'supported' *versus* 'substitute' decision-making.

2.90 The ALRC considers that the focus of analysis needs to be on how support is translated into a principles-based model that may guide law reform. How should support be articulated as the principal idea—consistent with the Convention and the concerns of the UNCRPD? What is the standard by which supporters and anyone appointed to act on behalf of another are to act? What is the standard to apply when the will and preferences of a person are not evident and cannot be determined? What is a human rights compatible approach? The standing and impact of Australia's Interpretative Declaration in relation to art 12 is relevant to these matters.

Implications for law reform

2.91 In September 2013, Australia appeared before the 10th session of the UNCRPD.[111] In its concluding observations, the UNCRPD recommended that Australia review its Interpretative Declarations in order to withdraw them.[112]

2.92 The ALRC asked what impact the Interpretative Declaration regarding art 12 had on (a) the provision for supported or substitute decision-making arrangements; and (b) the recognition of people with disability before the law and their ability to exercise legal capacity.[113] In the Discussion Paper, the ALRC suggested that, in view of concerns identified by the UNCRPD and some stakeholders, the time was opportune to review it, with a view to withdrawing it.[114]

2.93 The ALRC considers that the clear momentum is towards supported decision-making and supporting the ability to communicate wishes and preferences with respect to decision-making. Australia was a leader in advocating the CRPD and is well placed to continue this role. The developments at the Commonwealth level, particularly through the introduction of the National Disability Insurance Scheme and the decision-making model recommended in this Report provide a template and a catalyst for propelling reform federally. In such a context, the Interpretative Declaration may be seen, perhaps, to be unnecessary.

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111 Office of the High Commissioner for Human Rights, *10th Session of the Committee on the Rights of Persons with Disabilities* (12 November 2013).

112 Committee on the Rights of Persons with Disability, above n 96.

113 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Issues Paper No 44 (2013) Question 1.

114 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Discussion Paper No 81 (2014) Proposal 2–1.

2.94 In its present form it may also be considered unclear or as representing an overabundance of caution. While Interpretative Declarations can be modified at any time,[115] they may also be understood as essentially historical notes, marking a government's understanding at a particular time. As noted above, other States Parties made similar declarations at the time.

2.95 In this context, the ALRC considered whether to recommend that the Interpretative Declaration in relation to art 12 be withdrawn. Some would advocate this because they see the Declaration as hindering 'Australia's reform efforts and its continued leadership in the field of promoting equal recognition before the law for persons with disabilities'.[116] On the other hand, the Australian Government Attorney-General's Department submitted that 'this focus on the Interpretative Declaration is unhelpful, as of itself the United Nations Convention on the Rights of Persons with Disabilities has no effect in domestic law in the absence of laws or policies adopted by the Australian Parliament'.[117]

2.96 Insofar as the 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. The ALRC also considers that the UNCRPD was principally condemning a best interests approach, not a will and preferences approach. As set out in Chapter 4, the ALRC uses the term 'representative' in such cases and sets out a standard which embodies the 'will and preferences' approach.

2.97 The ALRC concludes that there is an opportunity to send a clear message and to provide conceptual clarity in place of any confusion, or negative messaging,[118] arising out of the Interpretative Declaration. If the Declaration remains as it is, or without further explanation, it may be seen to create 'a sense of complacency';[119] and may 'substantially diminish Australia's progress in disability rights and undermine its position as a State committed to advancing the inclusion, participation and wellbeing of people with disabilities, in our country and overseas'.[120]

2.98 However the ALRC acknowledges that there are many ways to do this—regardless of whether the Declaration itself remains.[121] For example, in Australia's

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115 International Law Commission, *Guide to Practice on Reservations to Treaties* (2011) [2.4.8].

116 Centre for Disability Law and Policy NUI Galway, *Submission 130*.

117 Australian Government Attorney-General's Department, *Submission 113*.

118 A point made in a number of submissions: eg, Disability Discrimination Legal Service Inc and Villamanta Disability Rights Legal Service Inc, *Submission 115*; Scope, *Submission 88*; Carers Alliance, *Submission 84*; NMHCCF and MHCA, *Submission 81*; WWDA, *Submission 58*; National Disability Services, *Submission 49*; Disability Advocacy Network Australia, *Submission 36*; Cairns Community Legal Centre, *Submission 30*.

119 Office of the Public Advocate (SA), *Submission 17*.

120 Disability Advocacy Network Australia, *Submission 36*.

121 The ALRC also acknowledges the comments of the Australian Government Attorney-General's Department that, where there are complaints under the Optional Protocol alleging violations of art 12, the Interpretative Declaration provides the basis for responding in setting out the understanding of obligations that Australia has accepted under the CRPD: Australian Government Attorney-General's Department, *Submission 113*.

Initial Report to the UNCRPD greater clarification of Australia's understanding of obligations under art 12 were set out:

> Australia strongly supports the right of persons with disabilities to legal capacity. In some cases, persons with cognitive or decision-making disabilities may require support in exercising that capacity. In Australia, substituted decision-making will only be used as a measure of last resort where such arrangements are considered necessary, and are subject to safeguards in accordance with article 12(4). For example, substituted decision-making may be necessary as a last resort to ensure that persons with disabilities are not denied access to proper medical treatment because of an inability to assess or communicate their needs and preferences. Australia's interpretive declaration in relation to article 12 of the Convention sets out the Government's understanding of our obligations under this article. Australia's guardianship laws and the safeguards contained in them aim to ensure abuse, exploitation and neglect does not occur, consistent with article 16 of the Convention.[122]

2.99 The adoption by the Australian Government of the National Decision-Making Principles and the Commonwealth decision-making model set out in this Report will provide impetus for the further reform of laws nationally to promote better compliance with the CRPD.

2.100 Submissions revealed distinct, and at times conflicting, themes:

- ambiguity in the Declaration—particularly about the meaning of fully supported or substitute decision-making arrangements;[123]
- concerns about the standard by which the person is to act, rather than about the appointment of a representative in itself;[124] and
- discomfort with the idea of 'substitute decision-making' altogether.[125]

2.101 The ALRC considers that the crucial issue is how to advance, to the extent possible, supported decision-making in a federal system—a matter also pointed out by the UNCRPD in its concluding observations on Australia.[126] This 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. Insofar as the Interpretative Declaration is asserting this, it is not incorrect as a matter of law, despite the somewhat confusing terminology in which it is expressed. The focus, in policy terms, then falls

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122 *Australia's Initial Report under the Convention on the Rights of Persons with Disabilities*, 3 December 2010 [55].

123 Disability Discrimination Legal Service Inc and Villamanta Disability Rights Legal Service Inc, *Submission 115*; Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*; Office of the Public Advocate (SA), *Submission 17*; Mental Health Coordinating Council, *Submission 07*.

124 Disability Discrimination Legal Service Inc and Villamanta Disability Rights Legal Service Inc, *Submission 115*; Offices of the Public Advocate (SA and Vic), *Submission 95*; B Arnold and Dr W Bonython, *Submission 38*; NSW Council for Intellectual Disability, *Submission 33*; Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*.

125 F Beaupert, P Gooding and L Steele, *Submission 123*.

126 Committee on the Rights of Persons with Disability, above n 96.

on the *limits* surrounding the appointment of another to act in a person's stead and also upon the *standard* by which the person is to act. These are the safeguards central to art 12(4). The consequence, in a federal system in which guardianship laws are state based, is to propel a critical evaluation of all decision-making models, by whatever name.

2.102 There are also dangers in action that is not anchored in a strong conceptual framework, and tested in implementation. The Caxton Legal Centre pointed out that

> A number of writers comment that insufficient research has been done on both supported decision making models and guardianship itself, and warn against inviting a 'bricolage' of experimental models resembling a 'young child's pocketful of melted lollies on a hot summer's day'.[127] The task is complex and highly nuanced and as Terry Carney suggests, perhaps the best recommendation is to marshall the evidence and debate which is the least imperfect of the policy options at the disposal of the law.[128]

2.103 Two key policy issues are how far 'support' can really go without attracting criticism of being a legal fiction;[129] and the need to underpin change in practice by evidence.

2.104 The policy impetus is clearly away from models that, in substance, form or language, appear as ones that are not reflective of the individual as decision-maker, based on their wishes and preferences to the greatest extent possible. Although some have queried whether reformed law will have the desired effect *in practice*, and may be understood by stakeholders as 'little different from its predecessor', a shift to supported decision-making has great 'symbolic significance':[130]

> It can be argued that at the very least a shift towards supported decision making sends two important symbolic messages regarding: (i) rejection of avoidable paternalism; and (ii) repositioning the state as an *adjunct to* (or facilitator of) civil society.[131]

2.105 The issue for policy reform, and law reform, is how to express this in a way that clearly reflects the paradigm shift in approach and thinking to the levels of support needed for those who require decision-making support. In this respect there is force in the UNCRPD's observations about a lack of a 'detailed and viable framework for supported decision-making in the exercise of legal capacity'.[132] As the Caxton Legal Centre submitted:

> The task is a tremendous one. The greatest challenges to ensuring equality before the law and the exercise of legal capacity for persons with disability involve the political will to endorse change to reflect consistency with a social model of disability, to provide sufficient education to the entire community, to stakeholders including all

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127 Citing Terry Carney and Fleur Beaupert, 'Public and Private Bricolage—Challenges Balancing Law, Services and Civil Society in Advancing CRPD Supported Decision-Making' (2013) 36 *University of New South Wales Law Journal* 175, 177.

128 Caxton Legal Centre, *Submission 67*. Citing Terry Carney, above n 16, 15. Carney and Beaupert, above n 118, 177. Carney and Beaupert, above n 117, 177.

129 Harmon, above n 30. See also Donnelly, above n 51, 185–187.

130 Carney, above n 47, 62.

131 Terry Carney, above n 16, 12.

132 Committee on the Rights of Persons with Disability, above n 96, [24].

> levels of employment and management, and to institutions and to implement the supply side and demand side reforms to ensure that supported decision making can effectively operate.[133]

2.106 Legal and policy reform must also include consideration of when 'it is not practicable to determine the will and preferences of an individual'.[134] It is in such cases, where the appointment of someone to make decisions is needed, that the *standard* by which they act and the nature of their appointment become the critical focus. As Denmark urged, in its response to the Draft General Comment on art 12,

> Above all, the general comment should take into account that there will be individuals, such as those who are unconscious, who are living in a persistent vegetative state, have very advanced dementia, or have the most profound intellectual disabilities, who will not be in a position to understand that there is a decision to be made, the nature of that decision, or the consequence of any apparently expressed will or preference. If substitute care and treatment decisions are not made for these individuals, they will run the risk of being exploited, neglected, or even left to die. To assume that no one would ever require someone else to make a decision on their behalf would against this background not only be flagrantly wrong but ultimately irresponsible.[135]

2.107 In other words, *some* system of appointment of others to act is a necessary human rights backstop. The Offices of the Public Advocate (South Australia and Victoria) identified the danger that an 'overemphasis' on a person's autonomy may be 'to the detriment of protection for people who need guardianship *as a rights enhancing mechanism*'.[136] They argued that 'guardianship, *properly done*, is a positive use of state power that enhances the inclusion and legal personhood of the represented person'.[137]

2.108 Such concerns were also expressed by the NSW Council for Intellectual Disability:

> Even with a comprehensive national strategy there will continue to be a need for a backstop of a substitute or fully supported decision-making system. In the absence of such a system, there will be no way to resolve many situations:
>
> - in which people with intellectual disability are being neglected, abused, exploited or overprotected on an ongoing basis and are unable to recognise these breaches of rights or and assert themselves in responding to the breaches.
> - in which there are disputes within families or between families and service providers or others about what decisions should be made about where a person should live, about health care or services or other lifestyle decisions.[138]

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133 Caxton Legal Centre, *Submission 67*.

134 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 on Article 12 of the Convention—Equal Recognition before the Law*, 2014 [21].

135 Denmark, Submission No 19 to the UN Committee on the Rights of Persons with Disabilities, *Draft General Comment on Article 12 of the Convention–Equal Recognition before the Law*, 2014.

136 Offices of the Public Advocate (SA and Vic), *Submission 95*. Emphasis added.

137 Ibid. Emphasis added. 'Guardians need to be properly resourced and the person's wishes must be paramount in all decisions'.

138 NSW Council for Intellectual Disability, *Submission 33*.

2.109 The need for support, and appropriate policy responses, is likely to increase as Australia's population ages.[139] Justice Connect and Seniors Rights Victoria observed that, as Australia's population is ageing, both the number of older people and their proportion of the population are increasing:

> It has been estimated that in the 30 years from 2007, the number of Australians aged over 65 years will more than double, increasing from 2.7 to 6.3 million and will constitute 24% of the population. An increase in the incidence of age-related disability, in particular dementia, is expected to accompany the ageing of the population. The ageing population together with the rising incidence of dementia amongst that population has led to a concerning rise in applications for guardianship and administrative appointments outside the more traditional scope of intellectual disabilities.[140]

2.110 Where institutional mechanisms of support cannot be avoided, 'new priorities, processes and language' are needed.[141] The legal and policy issues must focus on key questions:

- When is it appropriate to appoint someone to act on behalf of another?
- What test is used to determine when this should happen?
- What should this be called?
- What standard should guide the actions of a person appointed to act on another's behalf?
- What accountability mechanisms need to be in place?

2.111 These questions necessarily focus on guardianship laws and the impact of the CRPD in moulding future reforms. As Barbara Carter observed:

> Guardianship is the 'elephant in the room' of Art 12 and the debate continues to rage about whether guardianship is allowable under the Convention. This debate is effectively stymying considered discussion of how the Convention, in its totality should be implemented in domestic guardianship legislation.[142]

2.112 John Chesterman suggests that

> What is clear is that the Convention obliges countries to use guardianship as little as possible, and to limit as much as possible the powers that guardians have. Moreover, the Convention obliges us to utilise other processes, particularly now supported decision-making, wherever possible. In this way, the Convention is promoting some degree of uniformity, and will continue to do so as jurisdictions review their guardianship systems.[143]

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139 Demographic shifts were outlined in the ALRC's report: Australian Law Reform Commission, *Access All Ages—Older Workers and Commonwealth Laws*, Report No 120 (2013) ch 2.

140 Justice Connect and Seniors Rights Victoria, *Submission 120*. See also NSW Council for Intellectual Disability, *Submission 131*; Caxton Legal Centre, *Submission 67*.

141 ADACAS, *Submission 29*.

142 Barbara Carter, 'Adult Guardianship: Human Rights or Social Justice?' (2010) 18 *Journal of Law and Medicine* 143, 145.

143 Chesterman, above n 99, 31.

2.113 The ALRC considers that the focus of reform initiatives needs to be towards providing greater clarity around the expectations of persons with disability, their families and carers, and the courts and tribunals involved in appointing those to assist in decision-making where it is required. The policy pressure is clearly towards establishing and reinforcing frameworks of support in law and legal frameworks, and through funding of support models. The momentum is also towards building the ability of those who may require support so that they may become more effective and independent decision-makers.

2.114 There will also be a need for thorough research. The Caxton Legal Centre submitted that

> models of supported decision making need to be thoroughly researched and evaluated particularly given the implications of profound change—the paradigm shift—across institutions, agencies, services and the community generally. The suggestion has been made that there is little evaluative research into the efficacy and acceptability of guardianship systems, and this too should be remedied. At the very least, guardianship should not continue on the basis of 'business as usual'. And as a number of writers have observed, legislative change without equal attention to supply side and demand side reforms, including adequate resourcing of free legal services for persons with disability, will only be as useful as the paper it is printed on.[144]

2.115 For many, resourcing is a key issue:

> There is no escaping the reality that realising the right to equal recognition before the law for all people in our community requires resourcing from the grassroots up, as well as the top down.[145]

2.116 The most difficult policy challenges in this area concern those who require the most support—where a person's will and preferences are difficult, or impossible to determine and they need someone else to make decisions on their behalf. These hard cases should not, however, be treated as a barrier to building law and legal frameworks that signal the paradigm shift of the CRPD towards supported decision-making in practice, as well as in form.

144 Caxton Legal Centre, *Submission 67*.
145 PWDA, ACDL and AHR Centre, *Submission 136*.