

3. National Decision-Making Principles

Contents

Summary	63
National Decision-Making Principles	64
The equal right to make decisions	66
Support	67
Support Guidelines	69
Will, preferences and rights	75
Will, Preferences and Rights Guidelines	77
Safeguards	86
Safeguards Guidelines	86

Summary

3.1 In this chapter the ALRC recommends a set of National Decision-Making Principles and accompanying Guidelines to provide the first part of the modelling in Commonwealth laws required under the Terms of Reference for this Inquiry. These Principles should guide reform of Commonwealth laws and legal frameworks and the review of state and territory laws.

3.2 The National Decision-Making Principles identify four central ideas in all recent law reform work on capacity. These are that:

- everyone has an equal right to make decisions and to have their decisions respected;
- persons who need support should be given access to the support they need in decision-making;
- a person's will and preferences must direct decisions that affect their lives; and
- there must be appropriate and effective safeguards in relation to interventions for persons who may require decision-making support.

3.3 The Principles reflect the paradigm shift signalled in the *United Nations Convention on the Rights of People with Disabilities*¹ (CRPD) to recognise people with disabilities as persons before the law and their right to make choices for themselves.

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).

3.4 The emphasis is on the autonomy and independence of persons with disability who may require support in making decisions—their will and preferences must drive decisions that they are supported in making, and that others may make on their behalf. The National Decision-Making Principles provide a conceptual overlay, consistent with the CRPD, for a Commonwealth decision-making model that encourages supported decision-making.

National Decision-Making Principles

Recommendation 3–1 Reform of Commonwealth, state and territory laws and legal frameworks concerning individual decision-making should be guided by the National Decision-Making Principles and Guidelines (see Recommendations 3–2 to 3–4) to ensure that:

- supported decision-making is encouraged;
- representative decision-makers are appointed only as a last resort; and
- the will, preferences and rights of persons direct decisions that affect their lives.

Principle 1: The equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

Principle 2: Support

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

Principle 3: Will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

3.5 The National Decision-Making Principles are four general principles that reflect the key ideas and values upon which the ALRC’s approach in relation to legal capacity is based. They are distinct from the framing principles for the Inquiry as a whole (dignity, equality, autonomy, inclusion and participation, and accountability), but reflect and are informed by those principles.

3.6 The National Decision-Making Principles provide a conceptual overlay at a high level. They are drawn from the CRPD, other international models, stakeholder submissions and the work of other bodies and individuals. They are not prescriptive, and are of general application. The Principles are supported by three sets of Guidelines.

3.7 The Terms of Reference require the ALRC to consider ‘how maximising individual autonomy and independence *could be modelled* in Commonwealth laws and legal frameworks’.² The focus of the Inquiry is on the ‘ability to exercise legal capacity’ and equal recognition before the law of people with disability. The ALRC considers this can best be achieved by setting up an overall framework of principles and guidelines that can then be used as the template for specific reforms—both in Commonwealth areas of responsibility included in the Terms of Reference; and at state and territory level, in review of guardianship and related regimes.

3.8 The National Decision-Making Principles³ were strongly supported by stakeholders. The ACT Disability, Aged and Carer Advocacy Service (ADACAS), for example, said that the Principles ‘provide a sound basis for legislative change’.⁴ The Queenslanders with Disability Network (QDN) submitted that

The National Decision-Making Principles and Guidelines developed by the ALRC are a major step forward in creating a unified, progressive approach to empowering people with disability.⁵

3.9 The National Decision-Making Principles will provide the basis for national consistency and ‘could play an important role in creating a framework for reform’ of Commonwealth, state and territory laws concerning decision-making by persons who may require support.⁶ National Disability Services (NDS) supported the

establishment of clearly articulated ‘national decision-making principles’ to guide reform of all Commonwealth, state and territory laws and legal frameworks that affect decision-making of people with disability. This appears to be the most effective strategy for building a more coherent approach to legal capacity. It should, over time, reduce the inconsistency and unnecessary administrative hurdles across different jurisdictions or areas of life that currently face people with disability, their families and service providers.⁷

3.10 The NDS emphasised the importance of the Commonwealth taking the lead in implementing change, and encouraged incremental implementation:

The process of change should roll out slowly, providing opportunities for learning along the way. As indicated by the [ALRC], the Commonwealth may put into practice the various changes prior to states and territories. This will represent a useful opportunity to evaluate the practical ramifications. Similarly, the areas of law that have a clear role in addressing support for legal capacity, such as the National

2 Terms of Reference (emphasis added).

3 As set out in the Discussion Paper: Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Discussion Paper No 81 (2014) Ch 3.

4 ADACAS, *Submission 108*.

5 Queenslanders with Disability Network, *Submission 119*.

6 Law Institute of Victoria, *Submission 129*.

7 National Disability Services, *Submission 92*.

Disability Insurance Scheme (NDIS) Act, the Evidence Act and guardianship laws, may do the detailed work to develop specific legal solutions. These can then be more easily modified or adopted in other areas of law such as electoral, contract, banking and consumer protection.⁸

3.11 The adoption of the National Decision-Making Principles will provide a crucial starting point for change:

The proposed principles should achieve a shift in practice to help embed the right of every adult to make their own decisions and to be provided with the support necessary to do so. They will also help to ensure that any decision made for a person with disability is directed by their will, preferences and rights. This shift will have different practical implications in the various relevant areas of law.⁹

The equal right to make decisions

Principle 1: The equal right to make decisions

All adults have an equal right to make decisions that affect their lives and to have those decisions respected.

3.12 The principal idea in any discussion of legal capacity is that adults have the right to make decisions for themselves. This is frequently expressed in terms of a presumption of legal capacity, which may be rebutted if circumstances demonstrate that the requisite level of capacity is lacking in that context.

3.13 Stakeholders supported the emphasis on the right to make decisions. Some wanted the statement to retain the form of a presumption;¹⁰ others that it should go further. A number of stakeholders also stated that it should be recognised that there are circumstances in which a person may not be able to exercise such a right for themselves—and where another may need to be appointed to act on their behalf.

3.14 In this Report, the ALRC adopts the paradigm shift evident in the language of, and discourse around, the CRPD. The ALRC considers that it is necessary to place the emphasis on the *right* of citizens to make decisions, rather than on the qualification intrinsic in a presumption. The conceptual difficulty in starting with a presumption of legal capacity as an overarching principle is that it already contains a binary classification—of those who have legal capacity, and those who do not.

3.15 This is not to suggest that legal agency may never be found to be lacking—for example through the application of common law doctrines about legal capacity when invoked in reviewing transactions. Nor is it meant to suggest that a person may never

8 Ibid.

9 Ibid.

10 Offices of the Public Advocate (SA and Vic), *Submission 95*.

be appointed to act on behalf of another in making decisions. The ALRC agrees with many stakeholders on these points.¹¹

3.16 The ALRC considered whether the principle should be expressed as applying more broadly than just to adults. The Queensland Law Reform Commission (QLRC) used ‘adult’ in its formulations of principle,¹² but the Victorian Law Reform Commission (VLRC) considered such a principle could have application to young people who are able to satisfy the *Gillick* ‘mature minor’ test endorsed by the High Court in *Marion’s Case*.¹³ The ALRC has sought to avoid confusion in the first principle by confining it to adults. Decision-making principles dealing with children involve a ‘best interests’ standard—a standard deliberately not used in this Inquiry.¹⁴

3.17 This does not mean that the National Decision-Making Principles could not have a broader application, but only that for the purposes of this Inquiry the ALRC has limited the expression to adults—at least as a starting point for reform. The remaining Principles are expressed in terms of ‘persons’.

Support

Principle 2: Support

Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.

3.18 Decision-making principles should ask what decision-making support is needed so that people can exercise an equal right to make decisions. The emphasis must be on developing supported decision-making if the paradigm shift is to become a reality.

3.19 Support is the central theme in the CRPD. The Terms of Reference require the ALRC to consider:

- ‘how decision making by people with impairment that affects their decision making can be validly and effectively supported’; and
- ‘the role of family members and carers and paid supports ... in supporting people with disability ... and how this role should be recognised by law and legal frameworks’.

11 Disability Discrimination Legal Service Inc and Villamanta Disability Rights Legal Service Inc, *Submission 115*; Max Jackson and Margaret Ryan, *Submission 101*; Offices of the Public Advocate (SA and Vic), *Submission 95*; AGAC, *Submission 91*; B Arnold and 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*. See Ch 2.

12 See Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Final Report R67 (2010) ch 4 (The General Principles).

13 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) 92; *Secretary, Department of Health and Community Services v JWB and SMB (Marion’s case)* (1992) 175 CLR 218.

14 See Ch 2.

3.20 There are two elements: how a person can be supported in their decision-making; and how the law can give recognition to those who are providing the support. The ALRC's approach is to place the person requiring decision-making support at the forefront—as the decision-maker—and to recognise the position of 'supporters' in law, both through a mechanism of recognition set out in relevant Commonwealth laws, and by including supporters in information flows in certain situations. The 'supporter' model is discussed in Chapter 4.

3.21 The National Decision-Making Principles and Guidelines reflect a spectrum of decision-making, from fully independent to supported decision-making, including where a person needs someone else to make decisions on their behalf as a 'representative'. They are underpinned by a conceptualisation of autonomy as empowerment, noted in Chapter 1.

3.22 National Decision-Making Principle 2 (the Support Principle) expresses the concept of support at a high level.¹⁵ The emphasis is on the person as a decision-maker who may require support to exercise their legal capacity—and not as a person with an impairment affecting their decision-making. Such language reflects art 12(3) of the CRPD:

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

3.23 The Support Principle is not prescriptive as to by whom, and how, the support may be given. The Principle reflects a 'general recognition that the focus must now move from the challenges facing a person with disability to the supports that should be provided to enable them to make decisions and exercise their legal capacity'.¹⁶

3.24 The Support Principle includes recognition of communication support.¹⁷ It also reflects some of the general principles contained in the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act)—for example, that persons with disability 'should be supported to participate in and contribute to social and economic life to the extent of their ability'.¹⁸

3.25 Stakeholders strongly endorsed this principle. The Centre for Disability Law and Policy, National University of Ireland, Galway (CDLP Galway) said that the proposal sought to realise the declaration by the United Nations Committee on the Rights of Persons with Disabilities (UNCRPD) that 'supported decision-making must be

15 Compare the formulation by the VLRC that people 'with impaired decision-making ability should be provided with the support necessary for them to make, participate in and implement decisions that affect their lives': Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 21(c). See also the QLRC formulation, 'the adult's right to be given any necessary support and access to information to enable the adult to make or participate in decisions affecting the adult's life': Queensland Law Reform Commission, *A Review of Queensland's Guardianship Laws*, Final Report R67 (2010) rec 7–14(d).

16 Office of the Public Advocate (Qld), *Submission 05*.

17 Compare, eg, *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 2(b); Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 21(g).

18 *National Disability Insurance Scheme Act 2013* (Cth) s 4(2).

available to all'.¹⁹ Justice Connect and Seniors Rights Victoria (Justice Connect) agreed, stating:

We strongly support the proposal to introduce a decision making principle that a person who may require support in decision-making must be provided with the support necessary for them to make, communicate and participate in decisions that affect their lives.²⁰

3.26 In practice, problems may arise from a lack of available supporters. Justice Connect observed:

While it is always preferable for family members and friends with a longstanding relationship and knowledge of the person's wishes and preferences to act as a supporter or representative, there will be instances where a person has no such support available. One of the key risk factors of elder abuse is isolation. In our experience, many vulnerable older people do not have family members or friends willing to take up the role of supporter or representative.

It is in these situations that Kirby J suggests that 'independent, dispassionate, neutral and professional public office holders can be especially useful and even necessary'.²¹

3.27 Justice Connect submitted that in order for a support principle to be meaningful, it would be 'necessary for the Commonwealth to provide funding to a new or existing body to provide assistance to people requiring decision-making support in the absence of available alternatives'. It said that, ideally, an independent body would be provided with sufficient resources and funding to employ suitably qualified people to take on the role 'equivalent to the operation of OPA/State Trustees in the Victorian jurisdiction, and other similar bodies in different states and territories'.²²

3.28 In situations where a person does not have access to support, the state or territory may need to intervene by appointing someone to act as a supporter or representative. The review of state and territory guardianship and administration laws to ensure they are consistent with the National Decision-Making Principles and the Commonwealth decision-making model is discussed in Chapter 10.

Support Guidelines

Recommendation 3–2 *Support Guidelines*

(1) *General*

- (a) Persons who require decision-making support should be supported to participate in and contribute to all aspects of life.

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

20 Justice Connect and Seniors Rights Victoria, *Submission 120*.

21 Ibid. Referring to *Holt v Protective Commissioner* (1993) 31 NSWLR 227.

22 Justice Connect and Seniors Rights Victoria, *Submission 120*. Justice Connect added that volunteer support programs could also be an option, if funding does not support the establishment of a new body.

- (b) Persons who require decision-making support should be supported in making decisions.
- (c) The role of persons who provide decision-making support should be acknowledged and respected—including family members, carers or other significant people chosen to provide support.
- (d) Persons who may require decision-making support may choose not to be supported.

(2) *Assessing support needs*

In assessing what support is required in decision-making, the following must be considered.

- (a) All adults must be presumed to have ability to make decisions that affect their lives.
- (b) A person must not be assumed to lack decision-making ability on the basis of having a disability.
- (c) A person's decision-making ability must be considered in the context of available supports.
- (d) A person's decision-making ability is to be assessed, not the outcome of the decision they want to make.
- (e) A person's decision-making ability will depend on the kind of decisions to be made.
- (f) A person's decision-making ability may evolve or fluctuate over time.

3.29 The ALRC's approach recognises supported decision-making. This goes beyond general statements about the importance of support in the lives of persons with disability, to recommendations for a Commonwealth decision-making model under which supporters can be recognised in law. As discussed in Chapter 2, there is very strong support for legal models that reflect supported decision-making norms and aspirations.

3.30 The Support Guidelines reflect the Inquiry's framing principles of dignity, autonomy, and inclusion and participation. They are consistent with the general principles of the NDIS Act, that people with disability should be supported to:

- exercise choice, including in relation to taking reasonable risks;²³ and
- receive reasonable and necessary supports, including early intervention supports.²⁴

23 *National Disability Insurance Scheme Act 2013* (Cth) s 4(4). The principle is focused on choice 'in the pursuit of their goals and the planning and delivery of their supports', which is the focus of the NDIS.

24 *Ibid* s 4(5).

3.31 The Support Guidelines reflect the ALRC's approach that assumptions about the extent of decision-making support should not be based on a person's disability. As one stakeholder commented, '[a]ssumptions should ... not be made that a person with physical disability will require supported decision-making or substitute decision making assistance'.²⁵

Paragraph (1)

3.32 Paragraph (1)(a) is framed broadly and applies beyond support in decision-making. The OPA (SA and Vic) suggested that it 'confuses the concept of decision-making support with support for participation and contributing to society, which may require a wider range of support services'.²⁶ The ALRC acknowledges this concern, but considers the provision sits appropriately within the aspirational framework of the National Decision-Making Principles.

3.33 The purpose of support is to enhance the ability of people to make decisions and exercise choice and control—as decision-makers. That control includes the choice to have a supporter and choose the supporter, or to decline support. Stakeholders suggested that the latter needs to be made clear,²⁷ and this is incorporated in paragraph (1)(d).

3.34 The ALRC's model includes formal recognition of supporters in Commonwealth laws and legal frameworks. Paragraph (1)(c) of the Support Guidelines reflects this and is consistent with the NDIS Act's general principle that: 'the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected'.²⁸ None of this detracts from the vital and continuing role that *informal* support plays in the lives of persons with disabilities. The model is designed to provide a channel for formal validation of such support, where the person chooses it, consistent with the Terms of Reference. Paragraph (1)(c) embraces both informal and formal support.

3.35 A 'supporter' is distinguished from a 'representative'. Where a person is being supported in decision-making, the decision is their own, but made with support. Where a representative is appointed, the decision is made on behalf of the person, but involving the person to the greatest extent possible. How supporters and representatives are to act is considered in Chapter 4. The Support Guidelines reflect the recognition of family members, carers or other significant people as supporters at a high level. How they are recognised and how they may act is discussed in Chapter 4.

Paragraph (2)

3.36 The second paragraph of the Support Guidelines reflects an approach to assessing the support needed to exercise legal agency that is functional (ability to make the particular decision in question), not outcomes-based (the result or wisdom of the

25 Physical Disability Council of NSW, *Submission 32*.

26 Offices of the Public Advocate (SA and Vic), *Submission 95*.

27 Centre for Disability Law and Policy NUI Galway, *Submission 130*; F Beaupert, P Gooding and L Steele, *Submission 123*; Offices of the Public Advocate (SA and Vic), *Submission 95*; AGAC, *Submission 91*.

28 *National Disability Insurance Scheme Act 2013* (Cth) s 4(12).

decision), or status-based (because of a condition). A functional approach of this kind ‘seeks to maximise the circumstances in which the right of autonomy is protected’.²⁹

3.37 The Terms of Reference require the ALRC to consider ‘presumptions about a person’s ability to exercise legal capacity’ and ‘how a person’s ability to independently make decisions is assessed’. The ALRC considers that assessments of ‘ability to exercise legal capacity’ need to be refocused, by making the primary inquiry about the assessment of the support a person needs to exercise legal capacity, or agency. The second paragraph of the Support Guidelines reflects this approach.

3.38 The starting point in any assessment of support needs is a presumption of ability.³⁰ Paragraph (2)(a) reflects the object of CRPD art 12(2) ‘that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of their lives’. It also reflects the ALRC’s framing principles, particularly of equality and autonomy. A presumption of capacity is also the starting point of the common law, as discussed in Chapter 2. It places the onus on those who want to contest that a person has decision-making ability with respect to a particular transaction, or generally.

3.39 Legislative statements of this presumption often use the word ‘capacity’ and include the qualification ‘unless it is established that he or she lacks capacity’. The ALRC’s formulation keeps the qualification out of the Guidelines, reflecting the rights emphasis of the CRPD. The focus needs to be on assessment of the support necessary to exercise legal agency. The VLRC similarly recommended that a person ‘should not be considered to lack the capacity to make a decision if it is possible for them to make that decision with appropriate support’.³¹ An assessment of ability in terms of support acts to encourage support, enhancing a person’s ability. Similarly, the *Mental Capacity Act 2005* (UK) provides that ‘[a] person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success’.³²

3.40 The formulation in paragraph (2)(b) departs from status-based assessments. It reflects comments by the UNCRPD in its General Comment on art 12, and its criticism of conflating legal and mental capacity:

Legal capacity and mental capacity are distinct concepts. Legal capacity is the ability to hold rights and duties (legal standing) and to exercise these rights and duties (legal agency). It is the key to accessing meaningful participation in society. Mental capacity

29 Mary Donnelly, *Healthcare Decision-Making and the Law—Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, 2010) 92. In recommending such an approach that was subsequently incorporated in the *Mental Capacity Act 2005* (UK), the Law Commission of England and Wales deliberately rejected status-based assessments: Law Commission, *Mental Incapacity*, Report No 231 (1995) [3.5]–[3.6]. In that inquiry, the Law Commission received a ‘ringing endorsement’ of the functional approach: [3.6].

30 See, eg, Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 26. Examples: *Mental Capacity Act 2005* (UK) s 1(2); *Adult Guardianship and Trusteeship Act 2008* (Alberta) s 2(a); *Guardianship and Administration Act 2000* (Qld) ss 5–7, sch 1; *National Disability Insurance Scheme Act 2013* (Cth) s 17A. See also: NCOSS, *Submission 26*; Mental Health Coordinating Council, *Submission 07*; Office of the Public Advocate (Qld), *Submission 05*.

31 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 27(e).

32 *Mental Capacity Act 2005* (UK) s 1(3).

refers to the decision-making skills of a person, which naturally vary from one person to another and may be different for a given person depending on many factors, including environmental and social factors. ... Under article 12 of the Convention, perceived or actual deficits in mental capacity must not be used as justification for denying legal capacity.³³

3.41 Bruce Arnold and Dr Wendy Bonython submitted that stereotyping detracts from equality, and prevents the ‘flourishing’ of people with disability:

Ultimately equality is a pernicious abstraction unless it fosters flourishing. Equality is significant because inequality is associated with discrimination, in particular the non-recognition of capabilities on the basis of stereotypes and the retention of barriers to the fulfilment of both people with disabilities and people around them.³⁴

3.42 Paragraphs (2)(d)–(e) reflect a functional assessment of ability. These Guidelines may apply to a decision, or types of decision, depending on the circumstances. As the Council of Social Service of NSW (NCOSS) submitted:

Determinations about capacity must be made not only on a person-by-person basis, but also about every separate decision for each person, because people may have different capacity to make different decisions at different times.³⁵

3.43 As the Law Commission of England and Wales concluded in a review of ‘mental incapacity’ in 1995, status-based assessments should be rejected as being ‘quite out of tune with the policy aim of enabling and encouraging people to take for themselves any decision which they have capacity to take’.³⁶

3.44 In the context of the Support Guidelines, the functional approach is directed towards an assessment of the support needs of the person who requires decision-making support. In other specific contexts, this approach may also inform decisions about the need to appoint another to assist or represent the person.

3.45 There are concerns that functional tests of ability may present inappropriate barriers to the exercise of legal agency. However, it is not practicable to completely do away with some functional tests of ability that have consequences for participation in legal processes. For example, the integrity of a criminal trial (and, arguably, the criminal law itself) would be prejudiced if the defendant does not have the ability to understand and participate in a meaningful way. It may also breach the person’s human rights by denying them a fair trial, implicating arts 12 and 13 of the CRPD.

33 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 [13].

34 B Arnold and W Bonython, *Submission 38*. The submission of NCOSS to the NDIS Rules also strongly rejected decisions based on stereotyping, referred to in its submission to this Inquiry: NCOSS, *Submission 26*.

35 NCOSS, *Submission 26*.

36 Law Commission, *Mental Incapacity*, Report No 231 (1995) [3.3].

3.46 Other law reform bodies have endorsed the functional approach.³⁷ In its extensive inquiry on Queensland’s guardianship laws, the QLRC commented that the functional approach is a ‘widely accepted modern capacity model’,³⁸ and observed that

It has been suggested that one of the advantages of the functional approach is that it ‘best accommodates the reality that decision-making capacity is a continuum rather than an endpoint which can be neatly characterised as present or absent’. In contrast to the status model, there is no requirement for the presence of a particular type of disability or condition. The relevant question is whether the adult lacks capacity for making a decision about a given matter, for whatever cause and for whatever reason.³⁹

3.47 The ALRC notes some criticism by the UNCRPD of what it described as a functional approach in its General Comment on art 12:

The functional approach attempts to assess mental capacity and deny legal capacity accordingly. ... 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.⁴⁰

3.48 When the General Comment was in draft form, the emphasis in this paragraph was softened by a later comment that ‘functional tests of mental capacity, or outcome-based approaches that lead to denials of legal capacity violate Article 12 *if they are either discriminatory or disproportionately affect the right of persons with disabilities to equality before the law*’.⁴¹ However, the final form of the General Comment dropped these words. The ALRC considers that, with appropriate safeguards, and a rights emphasis, there is no ‘discriminatory denial of legal capacity’ necessarily inherent in a functional test—provided the emphasis is placed principally on the support necessary for decision-making and that any appointment is for the purpose of protecting the person’s human rights.

37 See, eg, Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 27(a); Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity*, NSW Parliament (Report 43, 2010) [4.56]. With respect to para (f), compare, eg, Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 27(b); Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Final Report R67 (2010) rec 7–14(d). See also Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity*, NSW Parliament (Report 43, 2010) rec 1.

38 Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Final Report R67 (2010) [7.105].

39 *Ibid* [7.103]. Citing Law Reform Commission of Ireland, *Vulnerable Adults and the Law*, Report No 83 (2006) [2.28].

40 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 [15].

41 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 [21] (emphasis added).

3.49 Paragraph (2)(d) rejects an outcomes-based approach and captures what is described as ‘the dignity of risk’, which is underpinned by the framing principle of autonomy. As Dr Mary Donnelly explains,

Respect for the liberal principle of autonomy requires that external factors, including the outcome of the decision reached and the degree of risk assumed, are irrelevant to the determination of capacity. ... [R]espect for autonomy is premised on allowing each individual to determine for herself what is good. Therefore, whether or not a person’s decision complies with other people’s perception of ‘the good’ is irrelevant to whether the person has capacity. In the words of the Law Commission [of England and Wales], according a role to the nature of the decision reached is inappropriate because it ‘penalises individuality and demands conformity at the expense of personal autonomy’.⁴²

Will, preferences and rights

Principle 3: Will, preferences and rights

The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.

3.50 The Terms of Reference direct the ALRC to consider ‘how maximising individual autonomy and independence’ can be modelled in Commonwealth laws and legal frameworks. The emphasis on the will and preferences of a person who may require support in making decisions is at the heart of the paradigm shift away from ‘best interests’ standards, as discussed in Chapter 2. Given that the focus on will and preferences is such a key idea in all the discussions, the ALRC considers that it needs to be identified as a general principle. It reflects the framing principles of dignity, equality, autonomy, and inclusion and participation.

3.51 There are a range of formulations of this concept, including those of the VLRC and the QLRC in their reports on guardianship. In its list of ‘new general principles’, the VLRC included the principle that ‘people with impaired decision-making ability ... have wishes and preferences that should inform decisions made in their lives’.⁴³ The QLRC recommended that emphasis should be placed on promoting and safeguarding ‘the adult’s rights, interests and opportunities’ and ‘the importance of preserving, to the greatest extent practicable, the adult’s right to make his or her decisions’.⁴⁴

3.52 The ALRC has chosen ‘must’ in the formulation of National Decision-Making Principle 3, to signal that this general principle has an important role in modelling Commonwealth laws. The word ‘direct’ should also be used, rather than a word like ‘inform’, as ‘direct’ attaches more weight to their will and preferences than does ‘inform’. The ALRC also considers that the principle should not be qualified by words

42 Donnelly, above n 29, 101. Quoting Law Commission, *Mental Incapacity*, Report No 231 (1995) [3.4].

43 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 21(d).

44 Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Final Report R67 (2010) recs 7–14 (b), (c).

such as ‘to the greatest extent practicable’, which is contained, for example, in the QLRC formulations.⁴⁵ What happens when a person’s will and preferences cannot be determined is considered as a separate issue in the Guidelines.

3.53 Article 12(4) of the CRPD uses the formulation ‘rights, will and preferences’. The ALRC formulation follows the spectrum of decision-making based on the will and preferences of a person, through to a human rights focus in circumstances where the will and preferences of a person cannot be determined. The inclusion of ‘rights’ is the crucial safeguard. In cases where it is not possible to determine the will and preferences of the person, the default position must be to consider the human rights relevant to the situation as the guide for the decision to be made.

3.54 The emphasis should be shifted from ‘best interests’ to ‘will and preferences’ approaches. Even in those examples of approaches where ‘best interests’ are defined by giving priority to ‘will and preferences’,⁴⁶ the standard of ‘best interests’ is still anchored conceptually in regimes from which the ALRC is seeking to depart.

3.55 Stakeholders strongly supported this approach.⁴⁷ For example, QDN said that ‘[t]his is an important development in acknowledging the rights of an individual who is unable to make a decision independently’.⁴⁸ The Australian Research Network on Law and Ageing welcomed

the emphasis of the Principles on the human rights of the person to whom the decision relates. In particular we note the importance of looking beyond the concept of promoting the personal autonomy of persons, to include the wider right of respect for the person’s dignity. It has been recognized that dignity is a wider concept than autonomy, and a universal value to which all persons are entitled. It therefore has special relevance for those whose capacity is compromised, either because of conditions producing fluctuating capacity, or for more chronic situations.⁴⁹

3.56 Principle 3 applies to both supporters and representatives. In the ALRC’s model, where a person appoints a supporter, as set out in the Commonwealth decision-making model,⁵⁰ decisions remain those of the person, not of the supporter. The concern is to describe the relationship between the person being supported and the supporter,⁵¹ and establish the expectations of a formal supporter role. Chapter 4 discusses the duties of supporters and representatives.

3.57 To provide greater clarity about the distinction between a supporter and a representative and full emphasis to will and preferences in decision-making, the Will, Preferences and Rights Guidelines (below) refer to both roles.⁵² The Principle has a

45 See *Ibid* ch 4 (The General Principles).

46 For example, *Mental Capacity Act 2005* (UK). See discussion in Ch 2.

47 Justice Connect and Seniors Rights Victoria, *Submission 120*; Queenslanders with Disability Network, *Submission 119*; ADACAS, *Submission 108*; Australian Research Network on Law and Ageing, *Submission 102*; Offices of the Public Advocate (SA and Vic), *Submission 95*.

48 Queenslanders with Disability Network, *Submission 119*.

49 Australian Research Network on Law and Ageing, *Submission 102*.

50 See Ch 4.

51 See, eg, Justice Connect and Seniors Rights Victoria, *Submission 120*.

52 See Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Discussion Paper No 81 (2014) Proposal 3–6.

role in embodying the move away from objective ‘best interests’ approaches, which is most necessary when a person is appointed to make decisions on behalf of another. In the ALRC’s model, this occurs when another person is appointed as a ‘representative’. The significant shift is in the decision-making standard by which that person must act, and the constraints on the appointment of a representative in the first place. Given that such appointments are made under state and territory law, the full implementation of the ALRC’s recommendations will be dependent on reform of state and territory legislation.

Will, Preferences and Rights Guidelines

Recommendation 3–3 *Will, Preferences and Rights Guidelines*

(1) *Supported decision-making*

- (a) In assisting a person who requires decision-making support to make decisions, a person chosen by them as supporter must:
 - (i) support the person to express their will and preferences; and
 - (ii) assist the person to develop their own decision-making ability.
- (b) In communicating will and preferences, a person is entitled to:
 - (i) communicate by any means that enable them to be understood; and
 - (ii) have their cultural and linguistic circumstances recognised and respected.

(2) *Representative decision-making*

Where a representative is appointed to make decisions for a person who requires decision-making support:

- (a) The person’s will and preferences must be given effect.
- (b) Where the person’s current will and preferences cannot be determined, the representative must give effect to what the person would likely want, based on all the information available, including by consulting with family members, carers and other significant people in their life.
- (c) If it is not possible to determine what the person would likely want, the representative must act to promote and uphold the person’s human rights and act in the way least restrictive of those rights.
- (d) A representative may override the person’s will and preferences only where necessary to prevent harm.

3.58 The Will, Preferences and Rights Guidelines begin by clearly differentiating between supported and representative decision-making.⁵³ The starting point, in both cases, is that decisions must be directed by the will and preferences of the person needing decision-making support.

3.59 Paragraph (1) defines the meaning of supported decision-making, in terms of the role of the supporter and the right of the person being supported to express their will and preferences.

3.60 Paragraph (2) sets the standard for representative decision-making. Importantly, the Will, Preferences and Rights Guidelines address what should happen when the current will and preferences of a person cannot be determined. The focus should be on what the person's will and preferences would likely be. In the absence of a means to determine this, a new default standard is advocated—expressed not in terms of 'best interests', but in terms of human rights.

3.61 Paragraph (2)(a) provides that a person's will and preferences must be given effect, which is central to the paradigm shift signalled in the CRPD and involves an emphasis on participation and communication.

3.62 Paragraph (2)(b) provides the standard for how a representative should act, in circumstances where the supported person's will and preferences cannot *currently* be determined. The representative must seek to ascertain what the person would likely have wanted in the particular circumstances. This is essentially a past preferences approach.⁵⁴ It requires a consideration of past information about decision-making choices. A key source of such information is likely to be the person's family members, carers and other significant people in their life.

3.63 The *Mental Capacity Act 2005* (UK) includes a list of those who could provide such information.⁵⁵ Similar lists have been included in, for example, the *Mental Health Act 2014* (Vic);⁵⁶ and the *Mental Health Bill 2013* (WA).⁵⁷ Consulting family members and others provides a further avenue for recognising the role of family members and carers.

3.64 Stakeholders endorsed the recognition of family as supporters who can provide relevant information regarding will and preferences. For example, the Mental Health Coordinating Council submitted:

The role of family members and carers should be recognised in Commonwealth laws. The supporting policy frameworks must reflect that those assessing capacity and supporting decision-making must listen to, learn from and act upon communications from the individual and their carers about what is important to each individual. This

53 This was also suggested by Offices of the Public Advocate (SA and Vic), *Submission 95*.

54 See Ch 2.

55 *Mental Capacity Act 2005* (UK) s 4(6), (7). See also: *Guardianship and Administration Act 1993* (SA) s 5; *Guardianship and Management of Property Act 1991* (ACT) ss 4, 5A; *Adult Guardianship and Trusteeship Act 2008* (Alberta) cA4.2, s 2(d).

56 For example, s 71(4).

57 For example, pt 2 div 4, 'Wishes of a person'.

involves acknowledging each individual is an expert on their own life and that their ‘recovery’ and care involves working in partnership with individuals and their carers to provide support in a way that makes sense to them and that assists them realise their own hopes, goals and aspirations.⁵⁸

3.65 Paragraph (2)(c) embodies a human rights approach, where the will and preferences *cannot* be determined by any means. The underlying idea in this guideline is that the default position should not be expressed in terms of a ‘best interests’ standard.

The ‘best interests’ principle is not a safeguard which complies with article 12 in relation to adults. The ‘will and preference’ 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.⁵⁹

3.66 The move away from a best interests standard was also strongly supported by stakeholders.⁶⁰ There are different ways that this shift can be expressed. The VLRC, for example, recommended that the ‘promotion of the personal and social wellbeing of the person’ replace ‘best interests’.⁶¹ The QLRC recommended that powers should be used in a way that ‘promotes and safeguards’ and is ‘least restrictive’ of an adult’s ‘rights, interests and opportunities’.⁶²

3.67 The kinds of human rights encompassed by the Guideline include the various matters set out in the CRPD, including:

- respect for inherent dignity—preamble and art 3;
- non-discrimination—art 5;
- liberty and security—art 14;
- freedom from torture or cruel, inhuman or degrading treatment or punishment—art 15;
- physical and mental integrity—art 17;
- liberty of movement—art 18;
- independent living—art 19;
- respect for privacy—art 22;
- respect for home and family—art 23; and
- participation in political and public life—art 29.

58 Mental Health Coordinating Council, *Submission 07*.

59 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.

60 Eg, Centre for Disability Law and Policy NUI Galway, *Submission 130*; Justice Connect and Seniors Rights Victoria, *Submission 120*; Queenslanders with Disability Network, *Submission 119*; Australian Research Network on Law and Ageing, *Submission 102*; Offices of the Public Advocate (SA and Vic), *Submission 95*; Mental Health Coordinating Council, *Submission 94*.

61 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) 536 n 83.

62 Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Final Report R67 (2010) [5].

3.68 While the ALRC has sought distance from the ‘best interests’ standard of previous eras, the Law Council of Australia submitted that

the ‘best interests’ of an individual should be consistent with their will and preferences in the majority of circumstances. If these are inconsistent, or if one is unable to be ascertained, the objective and subjective elements of each approach can be balanced by reference to appropriate international human rights standards.

The Law Society of New South Wales advises that ‘best interests’ standards should be retained as a last resort for people with disabilities whose will and preferences cannot be determined, for example, to prevent elder abuse.⁶³

3.69 Some have suggested the retention of the ‘best interests’ approach as a fallback.⁶⁴ Part of the issue with the ‘best interests’ standard was said to be that it was poorly understood. The Office of the Public Advocate (Qld) observed that

what is in a person’s best interests has often been conflated with ‘medical judgement’ or another professional’s judgement. Such determinations do not take into account the particular views, wishes and needs of the person.

‘Best interests’ is often applied in an unsystematic way without any unpacking of relevant considerations, including the values and principles applied in the decision-making process.⁶⁵

3.70 The OPA (Qld) also argued that, without ‘careful guidance, education, training and advice’, a rights-based approach could be similarly fraught and that the ‘kind of cultural change that needs to be achieved will be difficult to effect without a holistic strategy’.⁶⁶

[S]upporters and other decision-makers must be provided with guidance about how to apply a rights-based approach, including how to evaluate and weigh different considerations. Formal guidelines or codes of practice under the relevant legislation should also be provided to guide decision-makers in implementing a rights-based approach.⁶⁷

3.71 The importance of developing codes of practice was also emphasised by the Mental Health Coordinating Council:

Whilst we agree that there needs to be a consistent approach to the assessment of capacity in the context of representative decision making, promoting individual autonomy as circumstances require, it is important that the process does not become too proscriptive and therefore run the risk of leading to, for example, harm or neglect. At the end of the day the legislation must have an underpinning code of practice that provides the key framework and principles of best practice.⁶⁸

63 Law Council of Australia, *Submission 142*.

64 Eg, the NSWCID submitted that ‘[t]here should also be caution about completely dispensing with the best interests approach—it has weaknesses but it also has the strength of being able to flexibly accommodate the unique and fluctuating circumstances of an individual’: NSW Council for Intellectual Disability, *Submission 33*.

65 Office of the Public Advocate (Qld), *Submission 110*.

66 *Ibid.*

67 *Ibid.*

68 Mental Health Coordinating Council, *Submission 94*.

3.72 In its General Comment on art 12, the UNCRPD suggested that, if the will and preferences of a person could not be determined, the new standard to replace ‘best interests’ should be the ‘best interpretation of will and preferences’.⁶⁹

3.73 CDLP Galway referred to this ‘best interpretation’ approach in submitting that,

Whereas good efforts should be made to determine the will and preference of the relevant person, where the ‘best interpretation’ arrived at leads to a conflict of human rights (eg right to health in conflict with right to self-determination), it may be better for outside decision-makers to adhere to subjective guidance and follow the principle of ‘best interpretation’ rather than setting forth ‘objective’ rules which would allow the representative to decide which balance of human rights to achieve.⁷⁰

3.74 CDLP Galway also referred to amendments to Irish legislation, which inserted the following definition of ‘best interpretation’:

the interpretation of the relevant person’s past and present communication (using all forms of communication, including, where relevant, total communication, augmented or alternative communication, and non-verbal communication, such as gestures and actions) that seems most reasonably justified in the circumstances.⁷¹

3.75 It was suggested that ‘this language could be used to guide the ALRC in its development of final recommendations on how will and preferences may be determined in situations of last resort’.⁷² Such an approach may sometimes be instructive in terms of how current and past will and preferences are determined under paragraphs (2)(a) and (b) of the Will, Preferences and Rights Guidelines.

3.76 Consistently with the CRPD, it is important to leave the ‘best interests’ language behind in advancing supported decision-making in Australian laws and legal frameworks. However, it is not clear that the ‘best interpretation’ approach should necessarily be the default standard when a person’s will and preferences are not known, nor are capable of being made known. Judges have developed other approaches in such contexts, for example:

- what a reasonable and ordinary man might do in the position of a ‘lunatic’ with respect to the disposition of his surplus income—the standard developed by Lord Eldon LC in the leading case concerning the ‘substituted judgment’ approach;⁷³ and

69 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]. This paragraph was added between the draft and the final form of the General Comment on art 12, with respect to art 12(4).

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

71 *Ibid.* Quoting the From Mental Capacity to Legal Capacity (Amendment) (No 2) Assisted Decision-Making (Capacity) Bill (2013) [2.1.5].

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

73 *Ex Parte Whitbread, in the Matter of Hinde, a Lunatic* (1816) 2 Mer 99, 35 ER 878. See William Thompson and Richard Hale, ‘Surplus Income of a Lunatic’ (1894) 8 *Harvard Law Review* 472, 474–475. The authors then trace the application of Lord Eldon’s principle in later cases. See also 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.

- the ‘wise and just husband and father’ approach in relation to family provision litigation.⁷⁴

3.77 The danger in such approaches is that they reveal a certain blurring of the subjective and objective in the creation of a ‘legal fiction’.⁷⁵ They also run the risk of contradicting other principles advocated by the UNCRPD in its General Comment, in particular that

All forms of support in the exercise of legal capacity (including more intensive forms of support) must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests.⁷⁶

3.78 The ALRC considers that it is better to use human rights standards as the benchmark, accompanied by appropriate guidelines, codes of practice and other explanatory material, developed over time. Such material should be accompanied by appropriate training and guidance.

3.79 Where a representative is appointed, the decision-making standard to be applied is, therefore, to give priority to the will and preferences of the person but, if these *cannot* be determined, decision-making must emphasise the human rights of the person, particularly as articulated in the CRPD. Decisions must also be made on the basis of the least restrictive option—a point included specifically in the Safeguards Guidelines.⁷⁷ This approach uses objective standards—because the subjective cannot be determined.

3.80 The NSW Council for Intellectual Disability (NSWCID) questioned whether human rights provide an adequate basis for decisions where a person’s will and preferences cannot be ascertained. The NSWCID noted that there is limited understanding of human rights and there are many international instruments. Different rights may point to different outcomes ‘so that quite complex balancing exercises are required to make a decision’.

The result of all this might be that only highly educated people were qualified to make representative decisions. We are concerned about the prospect of removing from eligibility as representatives down to earth practical family members who have a lifetime’s knowledge of a person with disability.⁷⁸

3.81 The NSWCID preferred the standard recommended by the VLRC—that representatives be required to exercise their powers ‘in a manner that promotes the personal and social wellbeing of the person’, with guidance from a list of relevant factors.

74 See, eg, Rosalind Croucher, ‘The Concept of Moral Duty in the Law of Family Provision—A Gloss or Critical Understanding?’ (1999) 5 *Australian Journal of Legal History* 5.

75 See Louise Harmon, ‘Falling off the Vine: Legal Fictions and the Doctrine of Substituted Judgment’ [1990] *Yale Law Journal* 1, 22.

76 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 [29](b).

77 See, eg, *Mental Capacity Act 2005* (UK) s 1(6); *Adult Guardianship and Trusteeship Act 2008* (Alberta) cA4.2, s 2(c); *NSW Trustee and Guardian Act* s 39(b). See also: Mental Health Coordinating Council, *Submission 07*; Office of the Public Advocate (Qld), *Submission 05*.

78 NSW Council for Intellectual Disability, *Submission 131*.

3.82 Autonomy is a key principle of the CRPD, but a human rights approach places autonomy in a much wider context. As Donnelly suggests, a human rights framework ‘provides a mechanism within which to deal with questions of limitations on the right of autonomy’:

The contribution of the CRPD is likely to be most significant in providing human rights support for the development of legal obligations to empower patients, in the context of capacity assessment, decision-making on behalf of people lacking capacity and treatment for a mental disorder.⁷⁹

3.83 The human rights approach is also reflected in the paragraph 2(d) of the Will, Preferences and Rights Guidelines, which provides that a representative may override the will and preferences of a person only where necessary to prevent harm. This is consistent with the CRPD in that, for example, art 17 of the CRPD may require the representative to make a decision that protects the person’s ‘physical and mental integrity’, notwithstanding the decision conflicts with the person’s expressed will and preferences. A qualification of this kind tests the limits of autonomy, particularly where the limitation concerns harm to oneself. Examples are seen usually in the context of mental health legislation: to save a patient’s life, or to prevent a patient from seriously injuring themselves or others. Safeguards may be included in terms of ensuring that the course of action proposed is the ‘least restrictive’ option.⁸⁰ The latter approach is captured in the Safeguards Principles, considered below.

3.84 Whenever a limit is included, considerable care is needed in translating it into practice. A provision that a person’s will and preferences may be overridden based on the outcome of a decision—in this case, harm—runs contrary to a focus on ability that is not outcomes-based.⁸¹ However, it is not necessarily inconsistent with a principle of autonomy, as autonomy is not an absolute concept. The classical conceptualisation of autonomy, by John Stuart Mill, recognised some limit—that it may be limited in order ‘to prevent harm to others’.⁸² He gave the example of a wayfarer, summarised by Donnelly as follows:

Mill describes a wayfarer approaching a dangerous bridge in circumstances in which it is uncertain whether she is aware of the danger. He states that it is permissible to stop the wayfarer and warn her of the dangers ahead but if, following the warning, the wayfarer still wishes to proceed, she should be permitted to do so. Mill also recognised that interference with individual freedom could be justified in order ‘to prevent harm to others’. However, this justification does not allow a wholesale overriding of individual freedom. While acknowledging that ‘no person is an entirely isolated being’, Mill argued that a person can be stopped from doing something only if, in doing that thing, she would ‘violate a distinct and assignable obligation’ to others.⁸³

79 Donnelly, above n 29, 277.

80 See, eg, *Mental Health Act 2014* (Vic) s 71(3) concerning treatment decisions for patients who either do not have capacity to give informed consent, or who do not give informed consent.

81 See above.

82 John Stuart Mill, *On Liberty* (London, 1859) in John Gray (ed) *On Liberty and Other Essays* (Oxford University Press, 1991) 14.

83 Donnelly, above n 29, 21. Citing John Stuart Mill, *On Liberty* (London, 1859) in John Gray (ed) *On Liberty and Other Essays* (Oxford University Press, 1991) 107, 14, 88 respectively.

3.85 Overriding will and preferences on the basis of preventing harm to others is one aspect of a harm principle; another concerns the issue of preventing harm to oneself. Arnold and Bonython defended the need to make decisions on behalf of people in some contexts and suggested that this is consistent with human rights law and with ‘accepted bioethical standards and with the practicalities of both health care and social activity’:

It is axiomatic that all Australians, with or without disabilities, may experience life-threatening circumstances in which a decision should be made by a medical practitioner or other recognised decision-maker within a coherent and transparent legal framework to preserve the life of the individual. From a human rights perspective it is also axiomatic that interventions that are contrary to the will of some individuals will be necessary in order to both preserve the life of those individuals and the lives of the intimates or other associates of those individuals.⁸⁴

3.86 Intervening to preserve the life of a person against their will and preferences is what CDLP Galway described as one of the ‘hard cases’. They give the example of a person with anorexia:

Many people with anorexia express a will to live, but a preference to not eat. In these cases, an outside decision-maker may be involved, but would still be restricted from making a decision that was contrary to the individual’s expressed will and preference. PEG feeding, for example, would only be allowed if the individual agreed to it. These situations will always be difficult—they are difficult under ‘best interests’ determinations and they will continue to be difficult under an approach that prioritises will and preference.⁸⁵

3.87 While emphasising the support paradigm and the paramountcy of will and preferences, CDLP Galway said that this ‘does not mean that vulnerable individuals who are having difficulty expressing their will and preference are going to be left by the wayside in emergency situations’:

For example, in a situation in which an individual is displaying behaviours of serious self-harm, the support paradigm does not leave the individual to perish. Instead, it asks support people around the person to closely examine what is happening and to support the individual by taking actions that will facilitate her or his decision-making ability to a point at which she or he can clearly express her or his will and preferences. This could mean a variety of things, including but not limited to assisting the individual in stopping the self-harming behaviour and interacting with the individual in a caring and understanding manner and/or attempting to create an environment that the individual feels safe and comfortable in to allow her or him to be in an optimal decision-making scenario. Throughout any interaction, the goal remains of arriving at the will and preference of the individual. Further, according to the terms of the CRPD, any emergency interventions must adhere to the principle of non-discrimination by ensuring that criteria for crisis interventions do not discriminate on the basis of disability (for example, by using mental health diagnosis or mental capacity assessments).⁸⁶

3.88 How does one achieve an intervention which is both respectful of will and preferences, but is also least restrictive of the person’s human rights? CDLP Galway

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

85 *Centre for Disability Law and Policy NUI Galway, Submission 130* (citations omitted).

86 *Ibid.*

argued that permitting intervention in the way they described is not the same, nor should it be, ‘equated to substitute decision-making systems that currently exist’:

There are clear distinctions, which are 1) using ‘will and preference’ as the guiding paradigm as opposed to ‘best interest,’ 2) not denying legal capacity to individuals with disabilities on a different basis, and 3) not imposing outside decision-makers against the will of the individual.

However, there are times in which a decision needs to be made and the relevant individual is not able to make a decision or needs assistance in making the decision. The foregoing explanation is meant to show that Article 12 can and does address these situations without the need for substituted decision-making. However, it is also important to stress that these solutions are ONLY intended to apply to the ‘hard cases’, and should not encroach into cases where an individual is expressing a will and preference—even where the will and preference of the individual is contrary to medical advice or to advice of mental health professionals. It should also not be used to impose an outside decision-maker on a person who is expressing an unpopular or unorthodox decision. The solutions proposed for these ‘hard cases’ only apply at the end of a process where there is a genuine inability to understand a person’s will and preference or where it is impossible to realise the person’s will and preferences without breaching some other aspect of the law.⁸⁷

3.89 The Australian Guardianship and Administration Council (AGAC) submitted similarly that,

in certain circumstances, the views of the person might lead to outcomes that are significantly detrimental to the person’s health and welfare. In these circumstances, recognition of the representative’s authority to make decisions contrary to the wishes of the person is essential.⁸⁸

3.90 CDLP Galway said that, while intervention ‘in some exceptional cases which conflicts with the individual’s will and preferences should be permissible’, they need to be ‘disability-neutral and not justified on the basis of an individual’s decision-making ability’.⁸⁹

3.91 The development of codes of practice, guidance and accountability measures will, over time, lead to a shift in ‘culture’ and practice. An important aspect of this cultural shift arises in decisions where the person involved has expressed will and preferences that are likely to be financially detrimental. The issue is captured in the phrase ‘dignity of risk’. While the UNCRPD has referred to the need to protect people from ‘undue influence’, it has also said that protection must ‘respect the rights, will and preferences of the person, including the right to take risks and make mistakes’.⁹⁰

87 Ibid.

88 AGAC, *Submission 91*.

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

90 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 [22].

Safeguards

Principle 4: Safeguards

Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may require decision-making support, including to prevent abuse and undue influence.

3.92 The Terms of Reference require the ALRC to consider whether ‘the powers and duties of decision-making supporters and substituted decision-makers’ are ‘effective, appropriate and consistent with Australia’s international obligations’. The Terms of Reference also ask the ALRC to consider mechanisms to review decisions about the assessment of a person’s ability ‘to independently make decisions’.

3.93 Article 12(4) of the CRPD sets out safeguards obligations. The article requires that all measures relating to the exercise of legal capacity provide for appropriate and effective safeguards. In particular, it requires that such safeguards:

- prevent abuse in accordance with international human rights law;
- 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;
- are subject to regular review by a competent, independent and impartial authority or judicial body; and
- are proportional to the degree to which such measures affect the person’s rights and interests.⁹¹

3.94 The Safeguards Principle and Guidelines reflect these requirements.

Safeguards Guidelines

Recommendation 3–4 *Safeguards Guidelines*

(1) *General*

Safeguards should ensure that interventions for persons who require decision-making support are:

- (a) the least restrictive of the person’s human rights;

⁹¹ *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 12(4).

- (b) subject to appeal; and
- (c) subject to regular, independent and impartial monitoring and review.
- (2) *Support in decision-making*
 - (a) Support in decision-making must be free of conflict of interest and undue influence.
 - (b) Any appointment of a representative decision-maker should be:
 - (i) a last resort and not an alternative to appropriate support;
 - (ii) limited in scope, proportionate, and apply for the shortest time possible; and
 - (iii) subject to review.

3.95 These Guidelines capture the essential elements of safeguards that should be incorporated in laws and legal frameworks that deal with decision-making by people who need support to make decisions.

3.96 Stakeholders generally supported the ‘least restrictive’ intervention and ‘last resort’ appointment approaches. These are consistent with the position of the Australian Government as set out in the Interpretative Declaration on art 12 of the CRPD, discussed in Chapter 2.

3.97 The Law Council referred to some current good practice examples of requirements on guardians ‘to restrict as little as possible the freedom of decision making and action of a person in need of, or under, guardianship’⁹² and of reluctance to make guardianship orders in the first place. The QDN, for example, emphasised that it is ‘critical that appointments of representatives and supporters be time and task specific’.⁹³

3.98 Paragraph (2)(a) reflects the need for safeguards to be directed to the potential problem of conflict between a supporter or representative and the person being supported. Stakeholders identified this as an issue. For example, CDLP Galway submitted:

It is vital to recognize the role of the family as a natural support system, and the crucial role of carers and others in supporting persons who may require decision-making support. However, this principle must always be accompanied by safeguards in order to minimize conflicts of interest which inevitably arise. While the family should be recognized as a natural support system, they should only be assigned the

92 Law Council of Australia, *Submission 142*. Referring to the NSW Civil and Administrative Tribunal website and restrictions in the *Guardianship Act 1987* (NSW).

93 Queenslanders with Disability Network, *Submission 119*.

role of the support in cases where the person gives consent to family members assuming such a role.⁹⁴

3.99 Similarly, Justice Connect said that:

One concern with appointing a supported or substitute decision maker is the level to which that person is able to divorce themselves from their own bias and concerns, and act in accordance with the will and preferences of the supported person.⁹⁵

3.100 The circumstances in which representative decision-makers are appointed need to be reviewed, and should be central to review of state and territory legislation in the light of the National Decision-Making Principles and the Commonwealth decision-making model. Implementing paragraph (2)(b) of the Safeguards Guidelines should result in more constraint in the appointment of representative decision-makers.

3.101 The ALRC recognises that this is an iterative process that will take some time. The goal is for supported decision-making to become the dominant model—not only in aspiration, but also in practice. The OPA (Qld) submitted:

Regardless of views about the compatibility of guardianship laws with the Convention, there is general recognition that the focus must now move from the challenges facing a person with disability to the supports that should be provided to enable them to make decisions and exercise their legal capacity. This means that the appointment of a substitute decision-maker should not preclude efforts to support a person to make their own decisions.⁹⁶

3.102 CDLP Galway acknowledged that paragraph (2)(b) sets out an ‘important safeguard’, but said that ‘there should be something to distinguish it from the already existing safeguards in the antiquated substituted decision-making regimes’. As observed by the UNCRPD in its General Comment, the ‘most important safeguard for a decision-making regime is respect for the rights, will, and preferences of the relevant person’.⁹⁷

3.103 In the National Decision-Making Principles, respect for the will and preferences of the person is embodied in the standard by which a representative is to act, as set out in Will, Preferences and Rights Guidelines. To distinguish the old approach from the new, it is also necessary to move away from status-based assessments of legal capacity and to emphasise the role of support, as reflected by the Support Guidelines.

3.104 Stakeholders acknowledged that access to appeal and review mechanisms is an important safeguard.

Safeguards should not just respect due process or judicial review of the interventions that restrict legal capacity. There is a need for checks and balances in order to respect the process as well as the autonomy of the relevant person. For example, monitors could be appointed in certain support agreements to ensure that significant decisions are made on the basis of the relevant person’s will and preference. Also, the infrastructure at Commonwealth and State or Territory levels established to oversee

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

95 Justice Connect and Seniors Rights Victoria, *Submission 120*.

96 Office of the Public Advocate (Qld), *Submission 05*.

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

and implement new legislation in this arena will be crucial, and accessible complaints mechanisms must be established within the implementing bodies to ensure ease of access for those using support to exercise legal capacity, as well as the usual recourse to the courts ... Additionally, there should be training and support for the supporters to ensure that they fully understand their role and the scope of their powers. Lastly, there should be an appeal process to an independent and impartial tribunal or court for instances when the relevant person is unable to choose his or her own representative and where an outside decision-maker is appointed to make particular decisions.⁹⁸

3.105 This statement illustrates how safeguards need to be considered at all relevant points along the spectrum of decision-making support, and in relation to all persons and organisations involved in the particular category of decision.

98 Ibid.

