

## 3. National Decision-Making Principles

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### Summary

3.1 In this chapter the ALRC proposes a set of National Decision-Making Principles and accompanying Guidelines that 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 and legal frameworks.

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

3.3 The emphasis is on the autonomy and independence of persons with disability who may require support in making decisions—their wishes and preferences must drive decisions that they make, and that others may make on their behalf. The objective of the National Decision-Making Principles is to provide a conceptual overlay, consistent with the CRPD, that is applied in a Commonwealth decision-making model and provides the basis for review of relevant Commonwealth, state and territory laws.

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<sup>1</sup> *UN Convention on the Rights of Persons with Disabilities* Opened for Signature 30 March 2007, 999 UNTS 3 (entered into Force 3 May 2008).

## National Decision-Making Principles

**Proposal 3–1** Reform of Commonwealth, state and territory laws and legal frameworks concerning decision-making by persons who may require support in making decisions should be guided by the National Decision-Making Principles and Guidelines, set out in Proposals 3–2 to 3–9.

3.4 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.

3.5 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 four sets of Guidelines, with more specific detail in each area.

3.6 The Terms of Reference require the ALRC to consider ‘how maximising individual autonomy and independence *could be modelled* in Commonwealth laws and legal frameworks’.<sup>2</sup> 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 reviews of guardianship and related regimes. Application of the National Decision-Making Principles and Guidelines is then considered in a number of the areas set out in the Terms of Reference.

3.7 The National Decision-Making Principles identify the essential ideas in all recent law reform work on capacity. The tendency to suggest lengthy lists of principles may, however, distract from these four key ideas. The ALRC considers that identifying these four central ideas gives greater sharpness and clarity—and power—to the National Decision-Making Principles as reflecting the paradigm shift towards supported decision-making.

3.8 There is also a significant shift in the way these principles are expressed, starting with a right to make decisions, rather than a presumption of capacity.

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2 The Terms of Reference are set out in full on the ALRC website: <[www.alrc.gov.au](http://www.alrc.gov.au)>. Emphasis added.

## The right to make decisions

### **Proposal 3–2 National Decision-Making Principle 1**

Every adult has the right to make decisions that affect their life and to have those decisions respected.

3.9 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.<sup>3</sup>

3.10 In this Inquiry, the ALRC seeks to reflect the paradigm shift evident in the language of, and discourse around, the CRPD, and considers that it is necessary to place the emphasis on the right of citizens to make decisions, rather than the qualification intrinsic to 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.

3.11 This is not to suggest that legal capacity may never be lacking. Rather, it is better considered, in principles of general application, as a matter going to the question of what support is required and the threshold of appointment of others as supporters or representatives in a decision-making process.<sup>4</sup>

3.12 In terms of who has the right expressed in this principle, the ALRC considered whether it should be expressed more generally than applicable to adults. The Queensland Law Reform Commission (QLRC) used ‘adult’, but the Victorian Law Reform Commission (VLRC) considered the 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*.<sup>5</sup> The ALRC has sought to avoid confusion in the first general principle by confining it to adults. The principles dealing with children involve a ‘best interests’ standard—a standard deliberately not used in this Inquiry.<sup>6</sup>

3.13 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 of reform. The remaining Principles are expressed in terms of ‘persons’.

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3 See below.

4 See below.

5 *Secretary, Department of Health and Community Services v JWB and SMB (Marion’s case)* (1992) 175 CLR 218.

6 See Ch 2.

## Support

### **Proposal 3–3 National Decision-Making Principle 2**

Persons 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.

3.14 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’.

3.15 There are two elements: how a person can be supported in his or her 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 who may require decision-making support at the forefront—as the decision-maker—and to include recognition in law for the position of ‘supporters’, both through a mechanism of appointment set out in relevant Commonwealth laws, and through including supporters in ‘information loops’ in certain situations. The ‘supporter’ model is considered in Chapter 4.

3.16 National Decision-Making Principle 2 and the Support Guidelines, set out in Proposal 3–4, reflect the ALRC’s model of a spectrum of decision-making, from fully independent to supported decision-making, including where a person needs to be fully supported. They are underpinned by a conceptualisation of autonomy as empowerment, as noted in Chapter 1.

3.17 This Principle expresses the concept of support at a high level. The ALRC seeks to place the emphasis on the person as decision-maker not as a person with an impairment affecting their decision-making, but rather as a person who may require support in making decisions. 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.

3.18 The ALRC considers that the emphasis on support should be strong, so the word ‘must’ is used in National Decision-Making Principle 2.<sup>7</sup> It is not prescriptive by

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<sup>7</sup> 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, Queensland Law Reform Commission, *Review of Qld Guardianship Laws*, Final Report (2010) rec 7–14(d).

whom, and how, the support may be given. The Principle reflects, as remarked by the Office of the Public Advocate (Qld),

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.<sup>8</sup>

3.19 National Decision-Making Principle 2 includes the recognition of communication support.<sup>9</sup> It also reflects some of the general principles contained in the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act), that ‘[p]eople with disability should be supported to participate in and contribute to social and economic life to the extent of their ability’.<sup>10</sup>

### Support Guidelines

#### Proposal 3–4 Support Guidelines

- (a) Persons who may require decision-making support should be supported to participate in and contribute to all aspects of life.
- (b) Persons who may require decision-making support should be supported in making decisions.
- (c) The role of families, carers and other significant persons in supporting persons who may require decision-making support should be acknowledged and respected.

3.20 The purpose of support is to enhance the ability of people to make decisions and exercise choice and control—as the decision-maker. The Support Guidelines concern the support that should be provided to persons with disability, who may need support in making decisions.

3.21 The ALRC’s model includes provision for formal recognition of supporters in Commonwealth laws and legal frameworks. This is considered in relation to Commonwealth supporters and representatives, discussed separately in Chapter 4.

3.22 The ALRC’s approach is to provide recognition of supported decision-making. This goes beyond general statements about the importance of support in the lives of people with disability, to the proposal for a model for individual decision-making at Commonwealth level in which supporters can be nominated and recognised. As discussed in Chapter 2, there is very strong support for models that reflect supported decision-making norms and aspirations.

<sup>8</sup> Office of the Public Advocate (Qld), *Submission 05*.

<sup>9</sup> Compare, eg, *Adult Guardianship and Trusteeship Act SA 2008* cA4.2 s 2(b); Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 21(g).

<sup>10</sup> *National Disability Insurance Scheme Act 2013* (Cth) s 4(2).

3.23 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;<sup>11</sup> and
- receive reasonable and necessary supports, including early intervention supports.<sup>12</sup>

3.24 The Support Guidelines reflects the ALRC’s approach that assumptions about ability—and the extent of 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’.<sup>13</sup>

3.25 Stakeholders endorsed the recognition of family as supporters. 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 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.<sup>14</sup>

3.26 Paragraph (c) of the Support Guidelines is consistent with the NDIS Act principle that: ‘The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected’.<sup>15</sup>

## **Will, preferences and rights**

### **Proposal 3–5 National Decision-Making Principle 3**

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

3.27 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 ALRC considers that a principle of general application needs to embody this emphasis.

11 Ibid s 4(4). The principle is focused on choice ‘in the pursuit of their goals and the planning and delivery of their supports’, which are the focus of the NDIS.

12 Ibid s 4(5).

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

14 Mental Health Coordinating Council, *Submission 07*.

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

3.28 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.

3.29 There is a range of formulations of this idea, 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’.<sup>16</sup> 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’.<sup>17</sup>

3.30 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 than does ‘inform’. The ALRC also considers that the principle should not be qualified by words such as ‘to the greatest extent practicable’, which is contained, for example, in the QLRC formulation.

3.31 CRPD art 12(4) uses the formulation ‘rights, will and preferences’. The ALRC formulation follows the logic of the spectrum of decision-making from the will and preferences of a person, underpinned by a human rights focus in circumstances where the will and preferences of a person cannot be determined.

3.32 By placing the emphasis on ‘will and preferences’, the emphasis is clearly shifted from ‘best interests’ approaches. Even in those examples of approaches where ‘best interests’ is defined by giving priority to ‘will and preferences’,<sup>18</sup> the standard of ‘best interests’ is still anchored conceptually in regimes that the ALRC is seeking to distinguish clearly in the National Decision-Making Principles.

3.33 The inclusion of ‘rights’ is the crucial backdrop. 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 particular decision to be made.

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

17 Queensland Law Reform Commission, *A Review of Queensland’s Guardianship Laws*, Report No 67, 2010 recs 7–14 (b), (c).

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

## Will, Preferences and Rights Guidelines

### Proposal 3–6 Will, Preferences and Rights Guidelines

- (a) *Threshold*: The appointment of a representative decision-maker should be a last resort and not as a substitute for appropriate support.
- (b) *Appointment*: The appointment of a representative decision-maker should be limited in scope, be proportionate, and apply for the minimum time.
- (c) *Supporting decision-making*:
  - (i) a person’s will and preferences, so far as they can be determined, must be given effect;
  - (ii) where the person’s will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters; and
  - (iii) if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person’s human rights and act in the way least restrictive of those rights.

3.34 The Will, Preferences and Rights Guidelines address the determination of will and preferences and what happens when the ‘will and preferences’ of a person who needs decision-making support cannot, or no longer can, be ascertained.

3.35 These Guidelines provide detail around the limits on the appointment and mode of operation of representative decision-makers that are consistent with the CRPD. Any supported decision-making model should reflect the Guidelines.

### Representative Decision-Making Guidelines

3.36 Paragraph (a) of the Wills, Preferences and Rights Guidelines contains several elements. First, there is an acknowledgment that a person may need to be appointed to act for another when that other does not have legal capacity to make decisions for themselves. Secondly, the person who is appointed is described as a ‘representative decision-maker’. Thirdly, the appointment is expressed in limited terms.

3.37 By including such a threshold the ALRC acknowledges that there are times when a person may need to be appointed to act for another, beyond supporting a person who remains as the primary decision-maker. The ALRC has chosen a new term to reflect the role of the person appointed, to embody the model being proposed in this Discussion Paper. By choosing the word ‘representative’ the ALRC seeks to signal that the role is not as a ‘substitute’ for the person who requires support. Whatever the

understanding of the concept of ‘substitute decision-maker’,<sup>19</sup> the ALRC considers that it is better to create some distance from any controversy surrounding this usage and to find a new term.<sup>20</sup>

3.38 The limitation of the appointment of a representative decision-maker reflects the safeguards provision in art 12(4) of the CRPD.

3.39 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 the threshold needs to be defined in terms which emphasise the *ability* of a person and proposes Representative Decision-Making Guidelines reflecting this approach.

### **Proposal 3–7 Representative Decision-Making Guidelines**

Any determinations about a person’s decision-making ability and any appointment of a representative decision-maker should be informed by the following guidelines:

- (a) An adult must be presumed to have ability to make decisions that affect their life.
- (b) A person has ability to make a decision if they are able to:
  - (i) understand the information relevant to the decision and the effect of the decision;
  - (ii) retain that information to the extent necessary to make the decision;
  - (iii) use or weigh that information as part of the process of making the decision; and
  - (iv) communicate the decision.
- (c) A person must not be assumed to lack decision-making ability on the basis of having a disability.
- (d) A person’s decision-making ability is to be assessed, not the outcome of the decision they wish to make.
- (e) A person’s decision-making ability will depend on the kinds of decision to be made.
- (f) A person’s decision-making ability may evolve or fluctuate over time.

<sup>19</sup> See Ch 2.

<sup>20</sup> ‘Representative’ has some established record of usage in the context of deceased estates, where a legal personal representative, as executor or administrator with the will annexed, ‘represents’ the will of the deceased and must carry out the terms of the will. See, eg, Rosalind Croucher and Prue Vines, *Succession: Families, Property and Death* (LexisNexis Butterworths, 4th ed, 2013) [16.1]. [16.4].

- (g) A person’s decision-making ability must be considered in the context of available supports.
- (h) In communicating decisions, a person is entitled to:
  - (i) communicate by any means that enables them to be understood; and
  - (ii) have their cultural and linguistic circumstances recognised and respected.

3.40 The Representative Decision-Making Guidelines sit within the Wills, Preferences and Rights Guidelines. They are set at a fairly high, general, level. They should guide the assessment of decision-making ability, although the exact definition of ability and the way in which it is assessed will vary depending on the particular context in which the assessment is being made. More fine-grained assessments will depend on the kinds of decision to be made. As one stakeholder commented, a tool is needed to assess capacity and it should include

clear legal definitions to determine capacity, and appropriate training on how to use the tool, to reduce the risk of incorrect conclusions relating to an individual’s capacity<sup>21</sup>

3.41 The ALRC acknowledges that capacity assessments are part of a process of ‘gatekeeping’—and a complement to respect for autonomy. As Dr Mary Donnelly explains,

Where the right of autonomy is recognised, the law has relied on the requirement for capacity to act as gatekeeper for the application of the right. Thus, while respect for autonomy provides the principled foundation for the law’s approach to decision-making, the question of whether or not each individual’s decision will actually be respected is dependent on whether she meets the legal standard for capacity in respect of the decision in question.<sup>22</sup>

3.42 Because assessments of capacity have served this gatekeeping role, they ‘sort’ people:

People with capacity represent the norm. Those who do not are defined in contrast to this norm; they are, in this sense, the ‘other’.<sup>23</sup>

3.43 Although this sorting has negative connotations, the ALRC recognises that some form of ‘sorting’ is inescapable in a number of cases. As Donnelly acknowledged, ‘[w]hile capacity is a flawed gatekeeper, it is nonetheless probably the best way of sorting decisions’.<sup>24</sup> What the ALRC proposes is, however, that the place of such assessments be reconsidered—and, in particular, that it is not a starting point in an

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

22 Mary Donnelly, *Healthcare Decision-Making and the Law—Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, 2010) 2.

23 *Ibid* 3.

24 *Ibid* 273.

expression of principle. The starting point, as National Decision-Making Principle 1, is the *right* to make decisions. Any assessment should be seen as much further along a spectrum, with the focus being squarely on supporting decisions, rather than assessing whether or not a person can make a decision.

3.44 By proposing Representative Decision-Making Guidelines, the ALRC seeks to foster a nationally consistent approach. In the Issues Paper the ALRC asked whether there should be a nationally consistent approach to defining capacity and assessing a person's ability to exercise their legal capacity; and, if so, what was the most appropriate mechanism and what should the key elements be?<sup>25</sup> Stakeholders supported strongly the idea of a nationally consistent approach. For example, the Mental Health Coordinating Council said that it agreed

with the Law Council of Australia that a nationally consistent approach to the assessment of capacity in the context of substitute decision-making 'is highly desirable in order to promote greater clarity and ultimately, to more effectively provide protection and foster individual autonomy as circumstances require'.<sup>26</sup>

3.45 The Representative Decision-Making Guidelines reflect an approach to ability that is functional (ability to make the particular decision in question), not outcome-based (the result or wisdom of the 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'.<sup>27</sup> 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'.<sup>28</sup> In that inquiry, the Law Commission received a 'ringing endorsement' of the functional approach.<sup>29</sup>

3.46 In its extensive inquiry on Queensland's guardianship laws, the QLRC commented that the functional approach is a 'widely accepted modern capacity model':<sup>30</sup>

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

25 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Issues Paper No 44 (2013) Question 4.

26 Mental Health Coordinating Council, *Submission 07*. The submission refers to The Law Council Australia, Submission 056 to the House Standing Committee on Health and Ageing, *Inquiry into Dementia: Early Diagnosis and Intervention* (2012) item 21.

27 Donnelly, above n 22, 92. In recommending such an approach that was subsequently incorporated in the *Mental Capacity Act 2005* (UK), the Law Commission was deliberately rejecting status-based assessments: Law Commission, *Mental Incapacity*, Report No 231 (1995) [3.5]–[3.6].

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

29 *Ibid* [3.6].

30 Queensland Law Reform Commission, Queensland Law Reform Commission, *Review of Old Guardianship Laws*, Final Report (2010) [7.105].

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.<sup>31</sup>

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 functional approach is flawed for two key reasons. The first is that it is discriminatorily applied to people with disabilities. The second is that it presumes to be able to accurately assess the inner-workings of the human mind and to then deny a core human right—the right to equal recognition before the law—when an individual does not pass the assessment. In all these 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.<sup>32</sup>

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*’ (emphasis added).<sup>33</sup> 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’.

3.49 The starting point of any list of Representative Decision-Making Guidelines needs to include a presumption of ability.<sup>34</sup> It 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 above. It places the onus on those who wish to contest that a person has decision-making ability with respect to a particular transaction, or generally.

3.50 Legislative statements of this presumption often use the word ‘capacity’ and include the rider ‘unless it is established that he or she lacks capacity’. The ALRC proposes keeping the rider out of the Guidelines, reflecting the rights emphasis of the CRPD, rather than its qualification.

3.51 Paragraph (b) of the Representative Decision-Making Guidelines focuses on *having* ability, rather than not having it:

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

32 United Nations Committee on the Rights of Persons with Disabilities, *General Comment No 1 (2014) on Article 12 of the Convention—Equal Recognition before the Law* [13].

33 United Nations Committee on the Rights of Persons with Disabilities, *Draft General Comment on Article 12 of the Convention—Equal Recognition before the Law and Draft General Comment on Article 9 of the Convention—Accessibility* [21].

34 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 SA 2008 cA4.2* 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*.

- (b) A person has ability to make a decision if they are able to:
- (i) understand the information relevant to the decision and the effect of the decision;
  - (ii) retain that information to the extent necessary to make the decision;
  - (iii) use or weigh that information as part of the process of making the decision; and
  - (iv) communicate the decision.

3.52 There are many other comparable provisions.<sup>35</sup> The VLRC, for example, includes both ‘Defining Capacity’ and ‘Defining Incapacity’, which are mirror images of each other.<sup>36</sup> The ALRC proposes to keep the focus on the affirmation of ability, rather than its converse.

3.53 The formulation in paragraph (c) of the Representative Decision-Making Guidelines is suggested to get away from status-based assessments:

- (c) A person must not be assumed to lack decision-making ability on the basis of having a disability.

3.54 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 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.<sup>37</sup>

3.55 The ALRC has deliberately omitted any qualification, such as ‘solely on the basis of disability’ in the proposed guideline.

3.56 Arnold and 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.<sup>38</sup>

35 See, eg, *Mental Capacity Act 2005* (UK) s 1(3); New South Wales, Attorney General’s Department, *Capacity Toolkit: Information for Government and Community Workers, Professionals, Families and Carers in New South Wales* (2008).

36 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) recs 24, 25.

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

38 B Arnold and Dr 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*.

3.57 Paragraphs (e)–(f) of the Representative Decision-Making Guidelines reflect a functional assessment of ability:

- (e) A person’s decision-making ability will depend on the kinds of decision to be made.
- (f) A person’s decision-making ability may evolve or fluctuate over time.

3.58 These Guidelines may apply to a decision, or types of decision, depending on the circumstances. As 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.<sup>39</sup>

3.59 Other law reform bodies have reached similar conclusions.<sup>40</sup> The New South Wales Legislative Council Standing Committee on Social Issues recommended, for example, that

the legislative definition in NSW should define ‘capacity’ with reference to the ability to understand, retain, utilise and communicate information relating to the particular decision that has to be made, at the particular time the decision is required to be made, to foresee the consequences of making or not making the decision and to separate the concepts of ‘incapacity’ and ‘disability’.<sup>41</sup>

3.60 Paragraph (d) of the Representative Decision-Making Guidelines rejects an outcomes-based approach:

- (d) A person’s decision-making ability is to be assessed, not the outcome of the decision they wish to make.

3.61 Paragraph (d) captures what is described as ‘the dignity of risk’, which is underpinned by the framing principle of autonomy. As 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, 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’.<sup>42</sup>

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39 NCOSS, *Submission 26*.

40 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, Queensland Law Reform Commission, *Review of Qld Guardianship Laws*, Final Report (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.

41 Legislative Council Standing Committee on Social Issues, *Substitute Decision-Making for People Lacking Capacity*, NSW Parliament (Report 43, 2010) [4.57].

42 Donnelly, above n 22, 101. Citing Law Commission, *Mental Incapacity*, Report No 231 (1995) [3.4].

3.62 Paragraph (g) of the Representative Decision-Making Guidelines reflects the second of the National Decision-Making Principles concerning support:

(g) Decision-making ability must be assessed in the context of available supports.

3.63 The VLRC recommended, similarly, 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’.<sup>43</sup> An assessment of ability in terms of support incorporates the encouragement of supporting—and thereby enhancing—a person’s ability. The *Mental Capacity Act 2005* (UK) s 1(3) provides, for example, 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’. Donnelly describes this provision as ‘one of the most striking innovations’ in the UK Act.<sup>44</sup>

3.64 Paragraph (h) of the Representative Decision-Making Guidelines focuses on communication:

(h) In communicating decisions, a person is entitled:

- (i) to communicate by any means that enables him or her to be understood; and
- (ii) to have his or her cultural and linguistic circumstances recognised and respected.

3.65 The Terms of Reference require the ALRC to consider ‘the use of appropriate communication to allow people with disability to exercise legal capacity’. Comparable examples include:

- for (i), the QLRC recommendation that ‘a person is not to be regarded as unable to understand the information relevant to a decision if he or she is able to understand an explanation of it given to the person in a way that is appropriate to his or her circumstances (using simple language, visual aids or any other means)’;<sup>45</sup> and
- for (ii), the VLRC recommendation that ‘[p]eople with impaired decision-making ability ... ‘should have their cultural and linguistic circumstances recognised and respected by others’.<sup>46</sup>

## Appointment

3.66 Paragraph (b) of the Will, Preferences and Rights Guidelines provides that:

The appointment of a representative decision-maker should be limited in scope, be proportionate, and apply for the minimum time

3.67 This proposed guideline reflects CRPD art 12(4)—a safeguards provision stipulating that ‘all measures that relate to the exercise of legal capacity provide for

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

44 Donnelly, above n 22, 113.

45 Queensland Law Reform Commission, Queensland Law Reform Commission, *Review of Qld Guardianship Laws*, Final Report (2010) rec 7–14(c).

46 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) rec 21(j). See, also, *National Disability Insurance Scheme Act 2013* (Cth) s 5(d).

appropriate and effective safeguards to prevent abuse in accordance with international human rights law'. The measures referred to relate to decision-making support, and can apply to appointment of representative decision-makers, who must be 'free of conflict of interest and undue influence'. The appointments covered by art 12(4) must also be 'proportional and tailored to the person's circumstances, apply for the shortest time possible'. A further aspect of art 12(4) is the provision that the 'measures' should be 'subject to regular review by a competent, independent and impartial authority or judicial body'. The ALRC includes this aspect of art 12(4) in the Safeguards Guideline, considered below.

3.68 The Guideline also reflects that, in some circumstances, another person may be needed to act for a person who requires full decision-making support.

### **Supporting decisions**

3.69 Paragraph (c) of the Will, Preferences and Rights Guidelines provides:

(c) Supporting decision-making:

- (i) a person's will and preferences, so far as they can be determined, must be given effect;
- (ii) where the person's will and preferences are not known, the representative must give effect to what the person would likely want, based on all the information available, including communicating with supporters;
- (iii) if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

3.70 This Guideline is a key element in the National Decision-Making Principles and reflects the importance of the autonomy of the individual. Decisions for those who may require support in making decisions must be directed by the will and preferences of the individual. The Office of Public Advocate (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.<sup>47</sup>

3.71 The challenge in advancing a supported decision-making approach is, as Donnelly suggests, 'to provide meaningful protection for autonomy notwithstanding incapacity'.<sup>48</sup> She wrote that there are two broad ways 'to protect the autonomy of a person lacking capacity':

The first involves the preservation of the autonomy of the once capable person (sometimes described as precedent autonomy), either through formal advance decision-making mechanisms or the less formal means of taking account of past views, preferences and opinions in the decision-making process. The second involves

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

48 Donnelly, above n 22, 192.

supporting people lacking capacity so as to enable them to participate to the maximum degree possible in decision-making. The first of these is most consistent with the traditional liberal approach to decision-making for people lacking capacity while the second is more in line with the approach favoured by the CRPD.<sup>49</sup>

3.72 The starting point in paragraph (c)(i) of the Will, Preferences and Rights Guidelines is necessarily the ability to ascertain the will and preferences of the person being supported. Ascertaining the will and preferences of a person is central to the paradigm shift signalled in the CRPD. It involves an emphasis on participation and communication. In practice, however, there will be a limit: cases where it is not possible to determine a person's will and preferences. In practice there may also be situations where the will and preferences of a person are known but are likely to cause harm to the person or others. Cases of possible harm are considered under the Safeguards Guidelines, Proposal 3–9.

3.73 Paragraph (c)(ii) of the Will, Preferences and Rights Guidelines provides the standard for how a representative should act, in circumstances where the supported person's will and preferences are not known. The representative must seek to ascertain what the person would likely have wanted in the particular circumstances. This requires a consideration of past information about decision-making choices. A key source of such information is likely to be the person's supporters. For example, the *Mental Capacity Act 2005* (UK) includes a list of those who could provide such information.<sup>50</sup> Similar lists have been included in, for example, the *Mental Health Act 2014* (Vic),<sup>51</sup> and the *Mental Health Bill 2013* (WA).<sup>52</sup>

3.74 Paragraph (c)(iii) of the Will, Preferences and Rights Guidelines is intended to embody a 'human rights' approach, where the will and preferences cannot be determined by any means:

- (iii) if it is not possible to determine what the person would likely want, the representative must act to promote and safeguard the person's human rights and act in the way least restrictive of those rights.

3.75 The underlying idea in this guideline is that the default position should not be expressed in terms of a 'best interests' standard.<sup>53</sup> There are different ways that this could be expressed. The VLRC, for example, recommended the 'promotion of the personal and social wellbeing of the person' to replace 'best interests'.<sup>54</sup> The QLRC recommended that powers in the amended legislation should be used in a way that

49 Ibid 193. Donnelly notes that the *Mental Capacity Act 2005* (UK) allows for both of these ways. She then analyses 'some of the practical and normative issues to which these legal mechanisms give rise'.

50 *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 SA 2008 cA4.2* s 2(d).

51 For example, s 71(4).

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

53 Some have suggested the retention of the 'best interests' approach as a fallback. For example, the NSW Council for Intellectual Disability 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*.

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

‘promotes and safeguards’ and is ‘least restrictive’ of the adult’s ‘rights, interests and opportunities’.<sup>55</sup>

3.76 The kinds of human rights embraced by this 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.

3.77 Hence where a representative decision-maker is appointed, the standard to be applied in decision-making is to give priority to the will and preferences of the person—these must direct the decision or types of decision to be made—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 that is also included specifically in the Safeguards Principle.<sup>56</sup>

3.78 While autonomy is a key principle of the CRPD, 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.<sup>57</sup>

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55 Queensland Law Reform Commission, Queensland Law Reform Commission, *Review of Old Guardianship Laws*, Final Report (2010) [5].

56 See, eg, *Mental Capacity Act 2005* (UK) s 1(6); *Adult Guardianship and Trusteeship Act SA 2008* 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*.

57 Donnelly, above n 22, 277.

## Safeguards

### **Proposal 3–8 National Decision-Making Principle 4**

Decisions, arrangements and interventions for persons who may require decision-making support must respect their human rights.

3.79 The Terms of Reference require the ALRC to consider safeguards in asking: ‘are the powers and duties of decision-making supporters and substituted decision-makers 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’.<sup>58</sup> Both these matters are included within the Safeguards Guidelines.

3.80 The Safeguards Guidelines build upon the requirements of art 12(4) of the CRPD and reflects the Inquiry’s framing principle of ‘accountability’. As the Caxton Legal Centre submitted,

Key factors in considering models should include monitoring of arrangements, provisions for accountability and regular and unscheduled review as safeguards against exploitation and abuse.<sup>59</sup>

## Safeguards Guidelines

### **Proposal 3–9 Safeguards Guidelines**

Laws and legal frameworks must contain appropriate safeguards in relation to decisions and interventions in relation to persons who may require decision-making support to ensure that such decisions and interventions are:

- (a) the least restrictive of the person’s human rights;
- (b) subject to appeal; and
- (c) subject to regular, independent and impartial monitoring and review.

3.81 These Guidelines are expressed in very general terms. They capture the essential elements of safeguards that should be incorporated in Commonwealth laws and legal frameworks about decision-making support.

3.82 Paragraph (a) reflects the fact that some decisions and interventions may be made contrary to what a person wants—particularly if the wishes and preferences of a person may cause harm to themselves or to others. A limitation based on harm puts a ‘hard edge’ on giving effect to a person’s wishes and preferences. It also tests the limits of autonomy, where the limitation concerns harm to oneself. Examples of limitations of

<sup>58</sup> The full Terms of Reference are set out on the ALRC website: <[www.alrc.gov.au](http://www.alrc.gov.au)>.

<sup>59</sup> Caxton Legal Centre, *Submission 67*.

this kind 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.<sup>60</sup> Safeguards may be included in terms of ensuring that the course of action proposed is the 'least restrictive' option.<sup>61</sup>

3.83 Whenever a limit is included, considerable care will be needed in translating it into practice. A provision that a person's will and preferences may be overridden, based on the outcome of that decision—in this case, harm—runs contrary to a focus on ability that is not outcomes-based.<sup>62</sup> But it is not necessarily inconsistent with a principle of autonomy.

3.84 Autonomy is not an absolute. The classical conceptualisation of autonomy, by John Stuart Mill, recognised some limit—that it may be limited in order 'to prevent harm to others'.<sup>63</sup> 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.<sup>64</sup>

3.85 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.<sup>65</sup>

3.86 One of the challenging areas in practice, for applying a limitation based on harm, is in the context of restrictive practices, particularly for people with mental

60 See, eg. Mental Health Bill 2013 cl 199(2)(a) regarding the administration of electroconvulsive therapy on an involuntary patient.

61 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.

62 See above.

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

64 Donnelly, above n 22, 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.

65 B Arnold and Dr W Bonython, *Submission 38*.

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disorders. Restrictive practices are discussed in Chapter 8. At a principle-based level, some limitation is appropriate, and is broadly consistent with the framing principles for this Inquiry. The challenge in practice, however, is the development of appropriate assessment and monitoring tools that are also consistent with the principles on an ongoing basis.<sup>66</sup>

3.87 The ALRC is interested in hearing how best to express the ‘least restrictive’ Safeguard Guideline, consistent with a human rights approach and the supported decision-making model proposed in this Discussion Paper.

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66 See, eg, the discussion in Donnelly, above n 22, esp ch 6.

