6. Supporters and Representatives in Other Areas of Commonwealth Law

Contents

Summary

6.1 In Chapter 4, the ALRC recommends a new model for supported and fully supported decision-making in areas of Commonwealth legislative responsibility (the Commonwealth decision-making model). Chapter 5 discussed the application of the model to the National Disability Insurance Scheme (NDIS).

6.2 This chapter discusses how the Commonwealth decision-making model might be applied to other existing legislative schemes. These schemes already contain some decision-making mechanism or make some provision for supporters and representatives however they are described, and concern individual decision-making in relation to:

- social security, specifically under the *Social Security (Administration) Act 1999* (Cth);
- aged care, under the *Aged Care Act 1997* (Cth); and
- eHealth records, under the *Personally Controlled Electronic Health Records Act 2012* (PCEHR Act).

6.3 The chapter also discusses how the model might be applied to individual decision-making in relation to personal information under the *Privacy Act 1988* (Cth) and the provision of banking services.

6.4 In some of these areas, the ALRC considers that legislation should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model and suggests how this might be done. However, any reform needs to be proportionate to the situation, and the role of the supporter or representative. In relation to privacy and banking, the ALRC recommends new guidelines to encourage supported decision-making, rather than legislation.

6.5 One overarching issue is the interaction between Commonwealth decision-making schemes and state and territory appointed decision-makers. In each area, the interaction of Commonwealth supporters and representatives with state and territory appointed decision-makers will have to be considered.[1]

Social security

6.6 The legislative, policy and administrative framework for social security in Australia is set out in the *Social Security Act 1991* (Cth), the *Social Security (Administration) Act 1999* (Cth) and the *Social Security (International Agreements) Act 1999* (Cth).[2] This section discusses how the Commonwealth decision-making model may be applied in social security law.

Individual decision-making in social security

6.7 There are three key decision-making mechanisms in the context of social security law: autonomous decision-making by social security payment recipients; informal supported decision-making; and substitute decision-making by nominees.

6.8 In many circumstances, family members, friends and others may provide informal support to persons with disability to make social security-related decisions without any formal recognition or appointment. The significant role of 'informal and supportive decision-making arrangements' in the context of social security was emphasised by a number of stakeholders.[3]

6.9 It is important that providing mechanisms for the appointment of formal supporters and representatives under the *Social Security (Administration) Act* should not diminish the involvement of, or respect for, informal support.

6.10 The *Social Security (Administration) Act* contains a nominee scheme, and was the model for the nominee scheme under the *National Disability Insurance Scheme Act*

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1 See also Ch 10.

2 *Social Security (Administration) Act 1999* (Cth) s 3 defines social security law to include these three Acts. There are equivalent provisions for family assistance (including family tax benefit and child care) in *A New Tax System (Family Assistance) (Administration) Act 1999* (Cth) pt 8 ss 219TA—219TR.

3 See, eg, Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*.

2013 (Cth). Specifically, the Act makes provision for a 'principal'[4] to authorise another person or organisation to enquire or act on the person's behalf when dealing with the Department of Human Services (DHS).[5] There are two types of arrangements:

- correspondence nominees—a person or organisation authorised to act and make changes on the principal's behalf;[6] and
- payment nominees—a person or organisation authorised to receive a principal's payment into an account maintained by the nominee.[7]

6.11 Only one person can be appointed for each arrangement; however the same person can be appointed as both correspondence and payment nominee.[8]

6.12 A principal may appoint their own nominee. However, where a question arises in relation to a principal's capacity to consent to the appointment of a nominee, or any concerns arise in relation to an existing arrangement, DHS must 'investigate the situation'.[9] The *Guide to Social Security Law*[10] provides that, in circumstances where 'a principal is not capable, for example, due to an intellectual/physical constraint … of consenting to the appointment of a nominee', a delegate may appoint one.[11] The Guide also provides that 'where a principal has a psychiatric disability, a nominee can be appointed in these instances where there is a court-appointed arrangement such as a Guardianship Order'.[12]

6.13 Nominees have a range of functions and responsibilities.[13] The primary duty of nominees is to 'act at all times in the best interests of the principal'.[14]

6.14 With respect to issues of liability, a principal is protected against liability for the actions of their correspondence nominee. Correspondence nominees are not subject to any criminal liability under the social security law in respect of: any act or omission of the principal; or anything done, in good faith, by the nominee in his or her capacity as nominee.[15] However, if a correspondence nominee fails to satisfy a particular

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4 A 'principal' for the purposes of the nominee provisions is a social security payment recipient who has had a nominee appointed to receive either correspondence and/or payments on their behalf: *Social Security (Administration) Act 1999* (Cth) s 123A.

5 Social security law is administered by the Department of Human Services (DHS) through Centrelink.

6 *Social Security (Administration) Act 1999* (Cth) ss 123C, 123H; Department of Social Services, *Guide to Social Security Law* (2014) [8.52], [8.53].

7 *Social Security (Administration) Act 1999* (Cth) ss 123B, 123F; Department of Social Services, *Guide to Social Security Law* (2014) [8.5.1], [8.5.3].

8 *Social Security (Administration) Act 1999* (Cth) s 123D(1).

9 Department of Social Services, *Guide to Social Security Law* (2014) [8.5.1], [8.5.2].

10 The *Guide to Social Security Law*, produced by the Department of Social Services provides guidance to decision-makers in implementing this legislation: Department of Social Services, *Guide to Social Security Law* (2014).

11 'In these cases, a delegate may appoint a nominee on behalf of the principal, with attention to supporting evidence, and where the delegate is fully satisfied that the nominee is required and will act in the principal's best interests. The decision made by the delegate to appoint a nominee in these circumstances must be fully documented': Ibid [8.5.1]–[8.5.2].

12 Ibid.

13 *Social Security (Administration) Act 1999* (Cth) ss 123H–123L, 123O.

14 Ibid s 123O.

15 Ibid ss 123M, 123N.

requirement, the principal is taken to have failed to comply with that requirement. This may then have adverse consequences in terms of compliance and payments.[16]

The Commonwealth model and social security law

Recommendation 6–1 The *Social Security (Administration) Act 1999* (Cth) should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model.

6.15 To ensure better compliance with the *United Nations Convention on the Rights of Persons with Disabilities* (CRPD), the ALRC recommends that the *Social Security (Administration) Act* be amended in the light of the National Decision-Making Principles and the Commonwealth decision-making model.

6.16 The application of the Commonwealth decision-making model in social security law would contribute to the development of consistent decision-making structures across key Commonwealth areas of law. The desirability of such consistency was noted by stakeholders, such as the Law Council of Australia.[17]

6.17 Importantly, providing mechanisms for the appointment of formal supporters and representatives under the *Social Security (Administration) Act* should not diminish the involvement of, or respect for, informal support, including in relation to decision-making. However, as outlined in Chapter 4, the ALRC considers there are significant benefits to making provision for formal supported decision-making—a view shared by a range of stakeholders both generally and in the specific context of social security law.[18]

6.18 While the role played by correspondence nominees is broadly analogous to the role envisaged for supporters under the Commonwealth decision-making model, the existing nominee system does not make provision for formal supported decision-making. Accordingly, significant amendments would need to be made to the *Social Security (Administration) Act* to incorporate the Commonwealth decision-making model.

6.19 The ALRC does not prescribe a comprehensive new decision-making scheme for social security law. However, the ALRC outlines below some key ways in which the Commonwealth decision-making model might operate in the context of social security.[19]

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16 See, eg, Ibid s 123J.

17 Law Council of Australia, *Submission 83*.

18 See, eg, in relation to supported decision-making and social security law: Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*.

19 Some stakeholders expressed support for the proposals in the Discussion Paper: see, eg, National Association of Community Legal Centres, *Submission 127*; National Mental Health Consumer & Carer Forum, *Submission 100*.

6.20 In doing so, the ALRC recognises the importance of informal arrangements in the context of social security. NACLC observed that, in the experience of community legal centres, many clients with disability have a preference for informal arrangements:

> Often, people are apprehensive about invoking more formal, costly and potentially disempowering personal decision-making systems that involve state and territory guardians and administrators.

6.21 While supportive of the Commonwealth decision-making model, NACLC suggested that the ALRC consider ways in which to 'ensure that the application of the Commonwealth decision-making model will not have unintended consequences such as the over-formalisation of arrangements and could more fully articulate how the provision of statutory supported decision-making mechanisms can co-exist with informal support arrangements, including in relation to decision-making'.[20]

Objects and principles

6.22 Section 8 of the *Social Security (Administration) Act* contains general principles of administration. However, there are no principles relating to decision-making. The ALRC considers that s 8 could be amended to incorporate principles relating to decision-making and supported decision-making, or that principles could be inserted into the part of the Act which will contain provisions relating to supporters and representatives.

Supporters

6.23 Under the Commonwealth decision-making model, a principal would be entitled to appoint one or more supporters to support them to make decisions related to social security. Ultimate decision-making power and responsibility would remain with the principal. Centrelink would need to recognise any decision made by a principal with the assistance of a supporter as being the decision of the principal.

6.24 A principal may appoint whomever they wish as their supporter including, for example, a family member, friend or carer. In the context of social security, the ability to appoint a supporter may also assist advocacy organisations to support persons with disability. For example, stakeholders such as the Multicultural Disability Advocacy Association of NSW emphasised the need for an 'authority form' to facilitate provision of support to clients from culturally and linguistically diverse or non-English speaking backgrounds to engage with Centrelink.[21] It may also address some of the privacy-related difficulties encountered by those who support persons with disability, given one of the potential roles of a supporter is to handle the relevant personal information of the principal.

6.25 In many respects, correspondence nominees under the current system reflect the role potentially played by a supporter, including making enquiries and obtaining information to assist the principal, completing forms, and receiving mail. The key difference under the model would be that the principal would formally retain ultimate

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20 National Association of Community Legal Centres, *Submission 127*.
21 MDAA, *Submission 43*.

decision-making responsibility. The role of a supporter, under the model, is to support the principal to make a decision, rather than the supporter themselves making a decision.

6.26 Rather than having a duty to act in the best interests of the principal, supporters would have duties to: support the principal to express their will and preferences; act in a manner promoting the personal, social, financial, and cultural wellbeing of the principal; act honestly, diligently and in good faith; support the principal to consult with other relevant people; and develop the capacity of the principal to make their own decisions. These duties may address concerns expressed by stakeholders that the current nominee provisions 'are generally disempowering of the person with the disability, as they place no obligation on a nominee to act in ways that genuinely involve the person or that assist them to exercise their legal capacity'.[22]

6.27 In addition, a principal would be entitled to terminate the appointment of a supporter at any time. This differs from the current system, under which there does not appear to be legislative provision for a principal to request cancellation of a nominee arrangement, an issue raised with concern by a number of stakeholders.[23]

Representatives

6.28 Consistent with the Commonwealth decision-making model, a principal would also be entitled to appoint a representative to support them to make social security related decisions.

6.29 There may also be other circumstances in which a representative might be appointed—for example, where a person may not be in a position to appoint their own representative, but requires full support in decision-making.

6.30 Chapter 4 discusses possible appointment mechanisms, including appointment by Commonwealth agency heads or delegates, in confined circumstances. Concerns expressed in relation to the powers of the Chief Executive Officer of the National Disability Insurance Agency to appoint a nominee, discussed in Chapter 4, may apply to the similar powers of Centrelink delegates.[24]

6.31 The key amendment applying the Commonwealth decision-making model with respect to representatives, would be to provide that representatives have a duty to consider the will, preferences and rights of the principal. This would replace the current duty of nominees to act in the best interests of the principal contained in the *Social Security (Administration) Act*.

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

23 Section 123E of the *Social Security (Administration) Act 1999* (Cth) outlines the specific power to revoke a nominee appointment, but does not appear to make provision for a request by a principal. See, eg, Law Council of Australia, *Submission 83*.

24 National Association of Community Legal Centres, *Submission 127*. For powers see Department of Social Services, *Guide to Social Security Law* (2014) [8.5.1]–[8.5.2].

6.32 Finally, this would require that the appointment and conduct of representatives be subject to appropriate and effective safeguards. In relation to social security law, these safeguards might include: mechanisms for review and appeal of the appointment of representatives; potential monitoring or auditing of representatives by Centrelink; and the retention of existing safeguards. For example, the power of DHS to require the provision of a statement from a payment nominee outlining expenditure of the principal's payments by the nominee, could be applied to representatives.[25]

Guidance and training

6.33 The ALRC considers guidance and training for all parties involved in decision-making under social security law is important in ensuring the effective operation of this model of decision-making. This is particularly so in the light of stakeholder concerns about existing difficulties in navigating the social security system, interacting with Centrelink, and obtaining information.

6.34 Accordingly, the ALRC considers it is necessary for Centrelink to develop and deliver guidance and training for:

- Centrelink payment recipients who require decision-making support;
- supporters and representatives; and
- Centrelink employees and others involved decision-making or engagement with customers.

6.35 The focus of guidance and training could include topics such as: the introduction of the supporter and representative model under social security law and differences between the new model and existing nominee provisions; interaction with state and territory decision-making systems; and supported decision-making in the context of social security.

Other issues

6.36 Stakeholders also raised a range of systemic issues concerning social security. Stakeholders consistently emphasised the complexity of the social security system and the difficulties persons with disability face in navigating the system; difficulties arising in relation to eligibility, participation requirements and the consequences of breach of certain requirements; and appeal and review processes. Stakeholders also highlighted the particular difficulties for persons with disability who are Aboriginal or Torres Strait Islanders, from a culturally and linguistically diverse community, or who live in a rural, regional or remote community.[26]

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25 *Social Security (Administration) Act 1999* (Cth) s 123L. It is a strict liability offence not to comply which attracts a penalty of 60 penalty units. See also Department of Social Services, *Guide to Social Security Law* (2014) [8.5.3].

26 See, eg, Legal Aid Qld, *Submission 64*; Vicdeaf, S*ubmission 56*; Central Australian Legal Aid Service, *Submission 48*; MDAA, *Submission 43*; Equal Opportunity Commission of South Australia, *Submission 28*; Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*. See also National People with Disabilities and Carers Council, *Shut Out: The Experience of People with Disabilities and Their Families in Australia* (2009).

6.37 While these are important issues in the lives of persons with disability, the issues do not relate directly to individual decision-making, and the ALRC therefore does not make recommendations in these areas.

Aged care

6.38 This section outlines how the National Decision-Making Principles and the Commonwealth decision-making model may apply to aged care to ensure equal recognition before the law and legal capacity for older persons with disability.

6.39 Older people receiving aged care services who have intellectual, cognitive, physical or mental disabilities may find it difficult, without support, to exercise their rights to health services and an adequate standard of living and social protection.[27] Caxton Legal Centre referred to 'Mrs L', an 83-year old woman who experienced multiple difficulties in asserting her rights at her nursing home and the Queensland Civil and Administrative Tribunal:

> Mrs L ... was a physically frail woman of European origin, who had a heavy accent. She was in a nursing home, but wished to be returned to the care of her husband. There was no medical evidence of dementia, but the nursing home had assumed she had dementia because she was difficult to understand following a surgical complication that affected her speech. Mrs L was also extremely depressed at the separation from her husband.
>
> At the guardianship hearing, questions were asked about her ability to cook and care for herself. Mrs L was a proud woman and acknowledged later that she felt too embarrassed to admit in front of strangers in an intimidating setting that she was too frail to cook. However, this was taken by the tribunal to mean she 'lacked insight' and therefore must have impaired capacity. There were also misunderstandings by a tribunal member about the type of food Mrs L was describing, as a result of her heavy accent. An interpreter had been requested for Mrs L but was not provided. The Adult Guardian and Public Trustee were appointed.[28]

6.40 Aged care is an increasingly important area of federal responsibility in the context of Australia's ageing population. The Australian Government regulates residential aged care and home care, under the *Aged Care Act*[29] and under the Home and Community Care program.[30]

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27 As required under *UN Convention on the Rights of Persons with Disabilities*, Opened for Signature 30 March 2007, 999 UNTS 3 (entered into Force 3 May 2008) arts 25(b), 28.

28 Caxton Legal Centre, *Submission 67*.

29 From 1 January 2014, the Australian Aged Care Quality Agency replaced the Aged Care Standards and Accreditation Agency to take on the accreditation of residential aged care homes. Accreditation is conducted in accordance with the *Quality of Care Principles 2014* (Cth), *Quality Agency Reporting Principles 2013* (Cth) and other legislative instruments issued pursuant to the *Aged Care Act 1997* (Cth).

30 On 1 July 2012, the Australian Government assumed full funding, policy and operational responsibility for the Home and Community Care (HACC) services for older people (over the age of 65 or 50 for Aboriginal and Torres Strait Islander people) in all states and territories except Victoria and Western Australia. Victoria agreed to transition responsibility for HACC for older people to the Commonwealth from 1 July 2015 and WA agreed to do the same from 2016–17. State and territory governments will continue to fund and administer HACC services for people under the age of 65 or under 50 for Aboriginal and Torres Strait Islander people.

6.41 Under the *Australian Aged Care Quality Agency Act 2013* (Cth), the Australian Aged Care Quality Agency is responsible for the accreditation, monitoring and quality assurance of Commonwealth subsidised residential aged care providers, and for monitoring the quality of home and community aged care services.

6.42 The Australian Government responded to the Productivity Commission's recommendations in the 'Caring for Older Australians' report[31] with the 'Living Longer Living Better' reforms to aged care.[32]

6.43 Both Houses of Parliament have examined issues concerning dementia in recent years. The House of Representatives Standing Committee on Health and Ageing recommended uniform definitions, laws and guidelines relating to capacity, in state and territory legislation.[33] The Senate Committee on Community Affairs recommended the creation of a new Medicare item that encourages health practitioners to undertake longer consultations with a patient and at least one family member or carer where the patient has presented with indications of dementia.[34] The Committee also recommended the review of accreditation standards for residential aged care facilities in relation to managing symptoms of dementia.[35]

6.44 The Commonwealth decision-making model responds to calls for clear, national guidance for decision-making in aged care that is compliant with the CRPD.[36] The model would provide for the recognition of supporters who assist aged care consumers in their decision-making and representatives to make decisions directed by the will, preferences and rights of aged care consumers.

Individual decision-making in aged care

6.45 At present, decisions in aged care are made in three ways: by the aged care recipients themselves; informally by their families or carers; or by formally appointed substitute decision-makers such as guardians.

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31 'Caring for Older Australians' (Inquiry Report No 53, Productivity Commission, 2011). The Productivity Commission was requested to develop detailed options for redesigning the aged care system to meet the challenges facing it in coming decades, including the increasing incidence of dementia, severe arthritis and serious visual and hearing impairments, and the need for psycho-geriatric care.

32 See *Aged Care (Living Longer Living Better) Act 2013* (Cth) and associated legislation. Changes such as income testing for home care packages, new accommodation payment arrangements for residential aged care, and the removal of the distinction between high and low levels of care in residential care commenced on 1 July 2014: Department of Social Services, *Reform Overview* <www.dss.gov.au>.

33 House of Representatives Standing Committee on Health and Ageing, *Thinking Ahead: Report on the Inquiry into Dementia-Early Diagnosis and Intervention*, 2013 recs 4–5.

34 Senate Committee on Community Affairs, Parliament of Australia, *Care and Management of Younger and Older Australians Living with Dementia and Behavioural and Psychiatric Symptoms of Dementia* (2014) rec 1.

35 Ibid recs 8–10, 13–15.

36 John Chesterman, 'The Future of Adult Guardianship in Federal Australia' (2013) 66 *Australian Social Work* 26; 'Caring for Older Australians', above n 31, rec 15.10; Law Council of Australia, *Submission 83*; Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*; Office of the Public Advocate (Qld), *Submission 05*.

6.46 Informal decision-making for an aged care recipient seems routine and customary in aged care. The Victorian Law Reform Commission report on guardianship noted that many people with impaired decision-making capacity live in facilities like nursing homes with only the informal consent of a family member or carer.[37] On the other hand, government agencies and service providers seem to prefer the formality of legal arrangements for aged care decisions.

6.47 The Australian Guardianship and Administration Council (AGAC) submitted that 'informal decision making' or 'de facto arrangements' were initially approved as 'less restrictive alternatives' when compared to formal guardianship appointments. However, AGAC also expressed concern that informal decision-making lacks safeguards against abuse as required by art 12(4) of the CRPD.[38]

6.48 AGAC's experience has been that where Commonwealth agencies have assumed that most persons with disability have formally appointed guardians and designed forms on this basis, state and territory tribunals have been periodically 'inundated by applications for appointment of guardians or administrators' to give effect to decisions relating to aged care, for example, for asset assessment required for application for residential aged care.[39]

6.49 The current legal framework provides for some elements of supported and representative decision-making in aged care. Section 96–5 of the *Aged Care Act* provides for a person, other than an approved provider, to represent an aged care recipient who, because of any 'physical incapacity or mental impairment' is unable to enter into agreements relating to residential care, home care, extra services, accommodation bonds and accommodation charges. Section 96–6 states that in making an application or giving information under the Act, a 'person authorised to act on the care recipient's behalf' can do so.

6.50 There is a differentiation between 'representation' for binding contracts and 'authorisation' for obtaining and receiving information for the aged care recipient. However, there is inconsistency in the use of the term 'representative' throughout the Commonwealth laws and legal frameworks for aged care recipients. This is evident in the disparate references to a 'legal representative' to imply a guardianship arrangement;[40] 'representative' to refer to an advocate;[41] and an undefined 'appropriate person'.[42]

6.51 The new *Quality of Care Principles 2014* (Cth) set out the responsibilities of approved providers in providing residential and home care services. These principles also define the 'representative' of a care recipient more clearly than in the Act.

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37 Victorian Law Reform Commission, *Guardianship*, Final Report No 24 (2012) ch 15, 318.
38 AGAC, *Submission 51*.
39 Ibid.
40 *Aged Care Act 1997* (Cth) s 52F–2.
41 Ibid s 81.1(1)(c)(ii).
42 Ibid s 44.8A.

6.52 A representative under the *Quality of Care Principles* means either: a person nominated by the care recipient as a person to be told about matters affecting the care recipient; or a person who nominates themselves and who the relevant approved provider is satisfied has a connection with the care recipient and is concerned for the 'safety, health and well-being of the care recipient'.[43] Section 5(2) of the *Quality of Care Principles* states that a person who has a connection with a care recipient includes:

- a partner, close relation or other relative of the care recipient;
- a person who holds an enduring power of attorney given by the care recipient;
- a person who has been appointed by a state or territory guardianship board (however described) to deal with the care recipient's affairs; or
- a person who represents the care recipient in dealings with the approved provider.[44]

6.53 This definition of representative is similar to both supporters and representatives in the Commonwealth decision-making model. The intention behind the new definition in the *Quality of Care Principles* is to recognise the role of 'informal substitute decision-makers' as representatives of care recipients in their dealings with approved providers without conferring on them powers of a formal, state or territory appointed decision-maker such as a guardian or financial manager.[45]

6.54 This move to acknowledge the role of informal supporters of aged care consumers is consistent with the ALRC's overall approach. The requirement for a representative to have a connection and concern for the safety, health and wellbeing of an aged care consumer is also broadly consistent with the National Decision-Making Principles. However, in support of further reform in aged care, stakeholders emphasised the need to preserve aged care consumers' right to their autonomy, and the importance of supporting them in decision-making.

6.55 Caxton Legal Centre noted the 'omission of the CRPD' in the Living Longer Living Better reforms with respect to art 12.[46] The Centre for Rural and Regional Law and Justice, and the National Rural Law and Justice Alliance stressed the value of supported decision-making and co-decision-making arrangements, which are particularly relevant in the regional and rural context.[47]

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43 *Quality of Care Principles 2014* (Cth) s 5(1).

44 *Quality of Care Principles 2014* (Cth) notes nothing in this section intends to affect the powers of a substitute decision-maker appointed for a person under a state or territory law.

45 Explanatory Statement, *Quality of Care Principles 2014* (Cth) s 5.

46 Caxton Legal Centre, *Submission 67*.

47 Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance, *Submission 20*. The Centre also drew attention to the difficulties in accessing in-home support and respite services, which can greatly exacerbate the 'disabling effects of ageing' and, thereby, create greater difficulties for the person in the exercise of legal capacity.

6.56 Others reflected on addressing the 'balance between duty of care and the dignity of risk' in aged care decision-making.[48] The OPA (SA and Vic) submitted that the operation of the Commonwealth model needs to do this 'while protecting older people from exposure to abuse'.[49] The Illawarra Forum recommended change to the legislation so that 'risk management strategies' do not result in older people with dementia being 'locked up' in aged care.[50]

6.57 One issue which encapsulates these concerns is the use of restrictive practices on aged care recipients. The Mental Health Coordinating Council drew attention to the chemical restraint of some older people and people with mental illness who are deemed to be 'challenging' in care facilities. The Council argued:

> Supported decision-making is extremely important for this group of particularly vulnerable people, who the system characteristically 'medicates' and 'manages'. It is critical that the mental health and age care services work closely together so that a vulnerable and isolated person does not fall between service gaps and that older people are appropriately cared for in mental health and age care facilities using principles of recovery and enablement.[51]

6.58 The OPA (SA) suggested amendment of the *User Rights Principles*[52] to minimise and eliminate the use of restrictive practices in aged care.[53] The Office recommended that there should be a clear definition of each restrictive practice, a requirement that non-coercive measures be considered and clear authority before any restrictive practice is used.[54]

The Commonwealth model and aged care

Recommendation 6–2 The *Aged Care Act 1997* (Cth) should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model.

6.59 To ensure better compliance with art 12 of the CRPD, the ALRC recommends that the *Aged Care Act* be amended in the light of the National Decision-Making Principles and the Commonwealth decision-making model.

Objects

6.60 Division 2 of the *Aged Care Act* lists the objects of the legislation in regulating and funding aged care. They include: encouraging aged care services that 'facilitate the

48 Offices of the Public Advocate (SA and Vic), *Submission 95*.
49 Ibid.
50 The Illawarra Forum, *Submission 19*.
51 Mental Health Coordinating Council, *Submission 07*.
52 *User Rights Principles 2014* (Cth) replaced *User Rights Principles 1997* (Cth) on 1 July 2014. *User Rights Principles* are among principles made pursuant to *Aged Care Act 1997* (Cth) s 96–1.
53 Office of the Public Advocate (SA), *Submission 17*. See also Office of the Public Advocate (Vic), *Submission 06*.
54 Restrictive practices are discussed in Ch 8.

independence of, and choice available to' recipients[55] and helping recipients 'to enjoy the same rights as all other people in Australia'.[56] The extensive set of objects does not, however, directly apply them to decision-making arrangements.

6.61 The ALRC recommends that s 2–1 of the *Aged Care Act* be amended to incorporate principles relating to supported decision-making. The application of the Commonwealth decision-making model should help deliver the rights and responsibilities of aged care recipients contained in the *User Rights Principles 2014* (Cth).[57]

Supporters and representatives

6.62 The *User Rights Principles* mention representatives in the context of the right of a home care recipient to participate in their care decisions, if they do not have capacity to make those decisions themselves.[58]

6.63 The *User Rights Principles* also recognise some roles analogous to those of a supporter under the Commonwealth model. The *User Rights Principles* provide that a person whom a care recipient has asked to act for them and 'advocates and community visitors' who are acting for the care recipients, have the right to access aged care services to check the approved providers have met their responsibilities.[59] For example, approved providers must assist the care recipient to understand information about their rights and responsibilities.[60] Under the existing framework, a person acting for a care recipient can check whether or not this has occurred. However, the person must either be a paid advocate or a community visitor.[61]

6.64 The Commonwealth decision-making model could inform further reform of aged care legislation towards a rights-based and consumer-focused approach that acknowledges the role played by family, friends and carers. The model provides a structured approach for the involvement and regulation of representatives in decisions by aged care consumers. Supporters and representatives would be guided in their functions and be certain of their responsibilities.

6.65 Under this Commonwealth model, all aged care consumers have the right to make their own decisions.[62] Supported decision-making in the aged care context means that people who require decision-making support can make as many of their own decisions as possible, with the assistance of a 'supporter', whether it is about where they live or what personal or health care services they receive. For representative decision-making in aged care, the 'will, preferences and rights' standard would replace the existing 'best interests' test.

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55 *Aged Care Act 1997* (Cth) s 2–1(1)(g)(ii).
56 Ibid s 2–1(1)(h).
57 *User Rights Principles 2014* (Cth) schs 1–2. These provisions contain the charters of care recipients' rights and responsibilities for residential care and home care.
58 Ibid sch 2(1)(2)(d).
59 Ibid ss 8, 18.
60 Ibid ss 11(3), 20(3).
61 Ibid ss 8(3), 18.
62 See Ch 3.

6.66 The Commonwealth decision-making model would apply from the first trigger for decision-making by an aged care consumer, such as an assessment of care needs by the Aged Care Assessment Team.[63] The decision to undergo assessment of care needs is often made under pressure when a crisis has arisen for the potential aged care consumer. This is why there are likely to be benefits in terms of efficiency and effectiveness for both consumers and approved providers, where an aged care consumer who needs support has a supporter with them or if they do not have a supporter available to them, a representative who will make decisions for them according to their will, preferences and rights.

6.67 The next significant decision for the aged care consumer may be whether to enter a resident agreement or home care package agreement. These agreements are legally binding documents that outline the services to be provided, fees charged, and the rights and responsibilities of both parties. Under the Commonwealth decision-making model, depending on the aged care consumer's ability to make decisions and the availability of support, these decisions may be made by themselves, with the assistance of a supporter or by their representative.

6.68 There are myriad decisions made in aged care, on a daily, if not an hourly basis, which cannot practically be governed by a formalised supporter and representative model. The supporter and representative model might apply only to certain types of decisions, be trialled by new approved providers of home care services or otherwise tailored to suit the needs of the aged care consumers and approved providers.

6.69 The accreditation and quality monitoring system is an important safeguard of rights in the aged care sector. A suite of accreditation standards and guidelines made under the *Aged Care Act* regulates service providers.[64] There is recognition of representatives of aged care consumers in the assessor's guide to accrediting residential aged care services.[65]

6.70 If the Commonwealth decision-making model were to be adopted, these standards and guidelines would need to be revised to recognise the roles of supporters and representatives. For instance, the Resident Care Manual states that a representative may be a guardian or a person nominated by the care recipient as his or her representative.[66] The current requirement for a person to act as a representative is that the approved provider is satisfied that the nominated person has a connection with the resident, and is concerned for the 'safety, health and well-being' of the resident.[67] Under the Commonwealth decision-making model, this would change to the standard of the 'will, preferences and rights' and the representative would have a duty to act in a way that promotes the 'personal, social, financial and cultural wellbeing' of the person.[68]

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63 The Aged Care Assessment Service in Victoria.

64 The four accreditation standards for residential aged care facilities are set out in the *Quality of Care Principles 2014* (Cth). Approved providers must meet 44 outcomes which relate to these standards.

65 'Results and Processes Guide' (Australian Aged Care Quality Agency, June 2014).

66 Department of Social Services, 'The Residential Care Manual' (2014) 6.

67 Ibid.

68 See Chs 3–4.

6.71 The Home Care Packages Program Guidelines provide that shared decision-making between the consumer, an appointed representative and the home care provider should take place where the consumer has 'cognitive impairment'.[69] The Commonwealth decision-making model would give consistent guidance, so that an aged care consumer would be presumed to have the ability to make decisions and entitled to support in making those decisions. If a representative is appointed, the consumer would be entitled to have the representative make decisions that accord with the will, preferences and rights of the consumer.

Safeguards against elder abuse

6.72 Stakeholders raised significant concern over elder abuse and the need for safeguards in protecting the rights of aged care consumers.[70] Elder abuse is defined by the World Health Organization as 'a single, or repeated act, or lack of appropriate action, occurring within any relationship where there is an expectation of trust which causes harm or distress to an older person'.[71] It can be physical, psychological, emotional, sexual or financial abuse. It can also be the result of intentional or unintentional neglect.[72]

6.73 Advocacy and safeguarding of rights through having supporter and representative duties, as well as the guardianship systems around Australia are critical to preventing elder abuse. Under an effective, nationally coordinated model, the aged care consumer will receive the kind of assistance they need from supporters whose role and duties are specified. The aged care consumers will know that they are ultimately responsible for the decision made with the assistance of a supporter.

6.74 Where a representative makes a decision for the aged care consumer, the decision will be based on the will and preferences of the person requiring support and safeguards should apply, consistent with the Safeguards Guidelines. This would ensure that decisions and interventions are:

- least restrictive of the person's human rights;
- subject to appeal; and
- subject to regular, independent and impartial monitoring and review.[73]

6.75 The representative will have duties under the model and, when they are also the aged care consumer's guardian, they will be bound by duties under state and territory legislation.

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69 Department of Social Services, 'Home Care Packages Program Guidelines' (July 2014) [3.1.4].

70 Offices of the Public Advocate (SA and Vic), *Submission 95*; AGAC, *Submission 91*; Caxton Legal Centre, *Submission 67*; The Illawarra Forum, *Submission 19*; Office of the Public Advocate (SA), *Submission 17*; Office of the Public Advocate (Vic), *Submission 06*.

71 World Health Organization, *Elder Abuse* <www.who.int/ageing/projects/elder_abuse/en/>.

72 Ibid.

73 See Ch 3.

6.76 It is important for the Commonwealth decision-making model to augment existing state and territory systems with a clear, structured approach to decision-making that will mirror the rights and responsibilities of consumers and approved providers of aged care.[74]

Guidance and training

6.77 Guidance and training for all parties involved in decision-making under the Commonwealth legislative framework for aged care is critical to the effective operation of this model. The OPA (SA and Vic) submitted:

> Significant reform and concurrent sector and community education will be required to ensure that the operation of the Commonwealth decision-making model will balance duty of care and dignity of risk, while protecting older people from exposure to abuse.[75]

6.78 The Department of Social Services (DSS) should develop and deliver targeted guidance and training for:

- aged care consumers who require decision-making support;
- supporters and representative; and
- DSS and Australian Aged Care Quality Agency employees and others involved decision-making or engagement with aged care consumers.

6.79 The focus of guidance and training could include topics such as: the introduction of the supporter and representative model under the law on aged care and differences between current practice and the new model; interaction with state and territory decision-making systems; and supported decision-making in the context of aged care.

eHealth records

6.80 The following section discusses the *Personally Controlled Electronic Health Records Act 2012* (PCEHR Act), which contains provisions dealing with decision-making concerning the collection, use and disclosure of personally controlled electronic health records—referred to as 'eHealth records'.

6.81 An eHealth record is an electronic summary of a person's health records, which the individual consumer and their healthcare providers can access online when needed. The eHealth record system was implemented nationally in July 2012, allowing people seeking healthcare in Australia to register for an eHealth record. Healthcare Provider Organisations can also register to participate in the eHealth record system, and authorise their employees to access the eHealth record system.

6.82 As the system develops over time, having an eHealth record will give healthcare providers access to a summary of key health information, as long as the person gives

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74 Australian Government Department of Social Security, *Charter of Residents Rights and Responsibilities*; Australian Government Department of Social Security, *Charter of Rights and Responsibilities for Home Care*. See further, Ch 10.

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

consent in confirming access settings for the eHealth record. This will include information such as medications, hospital discharge summaries, allergies and immunisations.[76]

Individual decision-making and eHealth records

6.83 Under the legislative framework for eHealth, there are protections against the mishandling of information.[77] Individuals can control their own eHealth record by choosing to restrict which healthcare provider organisations can access it and what information is included through exercising 'access controls'.[78] Unauthorised collection, use or disclosure of eHealth record information is both a contravention of the PECHR Act and an interference with privacy under the *Privacy Act 1988* (Cth).[79]

6.84 The Office of the Australian Information Commissioner (OAIC) is the privacy regulator for the PECHR Act. The OAIC regulates the handling of personal information in the eHealth system by individuals, Australian Government agencies, private sector organisations and some state and territory agencies (in particular circumstances).[80]

6.85 The PCEHR Act contains detailed schemes for 'nominated representatives' and 'authorised representatives'. In the terminology used by the ALRC, the former are analogous to 'supporters' and the latter to 'representatives'.

'Nominated representatives'

6.86 The nominated representative provisions are intended to support the involvement of people other than healthcare professionals in assisting consumers in managing their healthcare. Nominated representatives may be family members, carers, neighbours or any other person nominated by a consumer.[81]

6.87 For a person to be a nominated representative, there must be an agreement between the consumer and the proposed nominated representative. This agreement does not have to be in writing. The consumer must also notify the System Operator that the other person is her or his nominated representative.[82]

6.88 Consumers remain able to access and control their eHealth records themselves, and access by a nominated representative is subject to any access controls set by the consumer.

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76 Department of Health, *EHealth–General Individuals FAQs* <www.ehealth.gov.au>.
77 *Personally Controlled Electronic Health Records Act 2012* (Cth) pt 4.
78 See, eg, Ibid s 61.
79 Ibid s 73.
80 Office of the Australian Information Commissioner, *Submission 90*.
81 Explanatory Memorandum, Personally Controlled Electronic Health Records Bill 2011 (Cth) 10.
82 *Personally Controlled Electronic Health Records Act 2012* (Cth) s 7. In practice, notification is automatically generated by the system. The Secretary of the Department of Health is the System Operator.

6.89 For example, in some cases a nominated representative may have 'read-only' access to a consumer's eHealth record. In other cases, a consumer may allow a nominated representative to do anything the consumer can do, including setting access controls, and granting access to healthcare provider organisations.

> This flexibility in setting access controls is designed to take into account the many circumstances where a person may not be able to, or may not wish to, manage their own [eHealth record] but where they do not have a formal legally recognised representative to act on their behalf.[83]

6.90 A nominated representative must always act in the 'best interests' of the consumer, subject to the consumer's directions.[84] A consumer may have more than one nominated representative.[85]

'Authorised representatives'

6.91 People who may have impaired decision-making ability are able to have an eHealth record. To facilitate this, an authorised representative is able to register a consumer for an eHealth record and manage the access controls on behalf of the consumer.

6.92 A person may be an authorised representative of a person over 18 years old if the System Operator is satisfied that a consumer is not capable of making decisions for themselves, and that another person is authorised by an Australian law, or by a decision of an Australian court or tribunal, to act on behalf of the consumer.[86]

6.93 If there is no such person, the System Operator may appoint someone else if satisfied that the person is an appropriate person to be the authorised representative.[87] This provision is said to allow the System Operator, in making appointments, to 'take into account a range of other circumstances for people without capacity, or with only limited capacity'.[88]

6.94 For the purposes of the PCEHR Act and the eHealth system, an authorised representative is treated as if they were the consumer. That is, the authorised representative can do anything authorised or required of the consumer, and anything done by an authorised representative in relation to the system is taken as if it were done by the consumer.[89]

6.95 An authorised representative must always act in the best interests of the consumer, having regard to any directions from the consumer expressed when they had capacity to act on their own behalf.[90] A consumer may have more than one authorised representative.[91]

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83 Explanatory Memorandum, Personally Controlled Electronic Health Records Bill 2011 (Cth) 10.
84 *Personally Controlled Electronic Health Records Act 2012* (Cth) s 7(6).
85 Ibid s 7(5).
86 Ibid s 7(4).
87 Ibid s 6(4)(b).
88 Explanatory Memorandum, Personally Controlled Electronic Health Records Bill 2011 (Cth) 10.
89 *Personally Controlled Electronic Health Records Act 2012* (Cth) s 6(7).
90 Ibid s 6(9).
91 Ibid s 6(8).

The Commonwealth model and eHealth records

Recommendation 6–3 The *Personally Controlled Electronic Health Records Act 2012* (Cth) should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model.

6.96 The existing scheme for authorised and nominated representatives contained in the PCEHR Act is detailed and tailored to the operation of the voluntary national system for the provision of access to electronic health information.

6.97 The scheme is designed, among other things, to ensure that people who have impaired decision-making ability are able to have an eHealth record, and to enable people to share their health information with those who need it. For example, an older person may want their son or daughter to be able to view key health information, such as currently prescribed medications and test results, in order to provide care and assistance to them.

6.98 The ALRC does not prescribe any comprehensive new decision-making scheme for the PCEHR Act. Individual decision-making under the PCEHR Act is relatively limited—being confined to decisions about the collection, use and disclosure of health information. This is more confined than, for example, decision-making under the *Aged Care Act*, which often involves significant decisions about the provision of residential and home care services and the entering of contractual arrangements.

6.99 However, the existing PCEHR Act provisions concerning nominated and authorised representatives should be reviewed and amended in the light of the National Decision-Making Principles and the Commonwealth decision-making model.

6.100 Broadly, nominated representatives under the PCEHR Act are analogous to 'supporters' in the Commonwealth decision-making model. They are nominated by the person concerned, and are subject to directions by the consumer, who may also continue to make decisions under the PCEHR Act.

6.101 Apart from adopting consistent terminology, changes to these nominated representatives provisions should include providing that, in making decisions, supporters have obligations to:

- consider the will, preferences and rights of the person represented (rather than the current best interests test);
- consult with existing appointees, family members, carers and other significant people;
- perform the role diligently and in good faith.

6.102 Authorised representatives provide substitute decision-making concerning eHealth records and, therefore, perform a role analogous to that of 'representatives' in the Commonwealth decision-making model. Changes to these PCEHR Act provisions

should include incorporating the 'will, preferences and rights' approach to decision-making; the recommended guidelines for determining decision-making ability; and the recommended factors for determining whether a person or organisation is suitable for appointment.

6.103 There are arguments that no change to existing provisions of the PCEHR Act is necessary because the system already strikes a balance between safeguards for the privacy and related rights of the person and allows authorised representatives to be appointed without undue administrative complexity. The NSW Council for Intellectual Disability (NSWCID), for example, cautioned that if a decision-making system is not easy to understand and use,

> service agencies and health professionals will tend to either ignore the system or deny access to services to people with disability. For example, doctors are much less likely to embrace the system of eHealth records with their patients who have intellectual disability if the system for supported or representative decision making is complex. Similarly, complex decision making systems can unduly delay important exchange of information in relation to a person so that the person suffers detriment.[92]

6.104 There should be a balance between safeguards and avoiding undue administrative complexity so that mechanisms are

> proportionate to the situation. For example, there should be a straightforward process for a close family member to become the representative of a person for processes like Centrelink and eHealth records.[93]

6.105 The OAIC expressed concern that adopting the 'supporter' and 'representative' terminology in place of the current terminology could 'create confusion and additional complexities within the PCEHR system' because authorised and nominated representatives perform functions under the PCEHR Act that are not necessarily equivalent to the roles of supporters and representatives under the Commonwealth decision-making model.[94]

6.106 In the ALRC's view, it is important to encourage the implementation of supported decision-making in this area of Commonwealth responsibility but unnecessary formality should be avoided. Decisions under the PCEHR Act involve only the handling of personal information. Therefore, there may be a case for provisions that are more minimal than those recommended in the Commonwealth decision-making model.

6.107 The ALRC concludes that it would be better if the same terminology were used as in the NDIS scheme and social security, notwithstanding the more limited role of supporters and representatives under the PCEHR Act. The main objective is to ensure that consistent obligations are imposed, especially to consider the will, preferences and rights of the person being supported.

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92 NSW Council for Intellectual Disability, *Submission 131*.
93 Ibid.
94 Office of the Australian Information Commissioner, *Submission 132*.

6.108 The ALRC understands that at present, authorised representatives are generally the parents of persons under the age of 18, who wish their child to opt-in to the system. In this context, a review of the PCEHR has recommended transition to an 'opt-out' model for the PCEHR scheme.[95] Issues concerning the availability and obligations of representatives will take on a different character, if a representative is needed in order for someone to be able to opt-out of the scheme.

Information privacy

6.109 The *Privacy Act* is Australia's key information privacy law. The Act is concerned with the protection of personal information held by certain entities, rather than with privacy more generally. Personal information is defined in s 6(1) of the Act as information or opinion about an identified individual, or an individual who is reasonably identifiable, whether or not true and whether or not in material form.

6.110 The *Privacy Act* provides 13 'Australian Privacy Principles' (APPs) that set out the broad requirements on collection, use, disclosure and other handling of personal information.[96] The APPs bind only 'APP entities'—primarily Australian Government agencies and large private sector organisations with a turnover of more than $3 million. Certain small businesses are also bound, such as those that provide health services and those that disclose personal information to anyone else for a benefit, service or advantage.[97] Generally, individuals are not bound by the *Privacy Act*.[98]

6.111 Privacy of health information may be a special concern for persons with disability. Health and genetic information is 'sensitive information' that is subject to stronger protection under the APPs.[99] Separate Commonwealth legislation protects healthcare identifiers[100] and eHealth records.[101]

6.112 The major issue for stakeholders was to ensure that personal information is able to be shared appropriately in order to support persons with disability. National Disability Services, for example, stated:

> The key challenge is often to transfer sufficient personal information (such as medication requirements or worker safety issues) that will enable the provision of high quality, tailored and safe support, while also protecting the right to privacy.[102]

6.113 There is a public interest in families and friends being involved in the care and treatment of people with a mental illness, for example, and this clearly involves the

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95 Subject, among other things, to the establishment of clear standards for compliance for clinical users: see 'Review of the Personally Controlled Electronic Health Record' (Final Report, Panel on Review of the Personally Controlled Electronic Health Record, 2013) 29, rec 13.

96 *Privacy Act 1988* (Cth) sch 1.

97 'APP entity' is defined in Ibid s 6(1). Small businesses are not, in general, APP entities, with some exceptions as set out in s 6D.

98 There are some exceptions. For example, an individual who is a reporting entity under the *Anti-Money Laundering and Counter-Terrorism Financing Act 2006* (Cth), will be treated as an APP entity under the *Privacy Act 1988* (Cth).

99 *Privacy Act 1988* (Cth) s 6(1).

100 *Healthcare Identifiers Act 2010* (Cth).

101 *Personally Controlled Electronic Health Records Act 2012* (Cth).

102 National Disability Services, *Submission 49*.

sharing of information.[103] The NSWCID observed that, for a person with an intellectual disability, there may be 'numerous times in a month when an agency needs to obtain information about the person from a range of sources and provide information to a range of agencies or individuals'.[104] The ACT Disability, Aged and Carer Advocacy Service noted:

> If [supported decision-making] frameworks are to reduce or replace the use of guardianship, consideration needs to be given to how relevant information can be shared with decision supporters while balancing the right of people with disability to privacy.[105]

Individual decision-making and the *Privacy Act*

6.114 The *Privacy Act* makes no express provision for supporters or representatives to be recognised as acting on behalf of an individual in relation to decisions about the handling of personal information held by APP entities.

6.115 Some state privacy legislation does provide for representatives. The *Health Records and Information Privacy Act 2002* (NSW), for example, provides for the position of an 'authorised representative' to act on behalf of an individual who is 'incapable of doing an act authorised, permitted or required' by the Act.[106]

6.116 An authorised representative may not do an act on behalf of an individual who is capable of doing that act, unless the individual expressly authorises the authorised representative to do that act.[107]

6.117 An 'authorised representative' for these purposes means a person appointed under an enduring power of attorney, a guardian, a person having parental responsibility (if the individual is a child), or person who is 'otherwise empowered under law to exercise any functions as an agent of or in the best interests of the individual'.[108] Essentially, therefore, the NSW *Health Records and Information Privacy Act* provides recognition for representatives, but not for supporters, as those terms are used in this Report.

6.118 The ALRC has considered previously whether the *Privacy Act* should include provision for representatives. In its 2008 report, *For Your Information: Australian Privacy Law and Practice*, the ALRC recommended that the *Privacy Act* should be amended to include the concept of a 'nominee'. An agency or organisation would be able to establish nominee arrangements and then 'deal with an individual's nominee as

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103 Public Interest Advocacy Centre, *Submission 41*.
104 NSW Council for Intellectual Disability, *Submission 33*.
105 ADACAS, *Submission 29*.
106 *Health Records and Information Privacy Act 2002* (NSW) s 7. An individual is defined as incapable 'if the individual is incapable (despite the provision of reasonable assistance by another person) by reason of age, injury, illness, physical or mental impairment of: (a) understanding the general nature and effect of the act, or (b) communicating the individual's intentions with respect to the act'.
107 Ibid s 8(3).
108 Ibid s 8.

if the nominee were the individual'.[109] The ALRC recommended that nominee arrangements should include, at a minimum, the following elements:

> (a) a nomination can be made by an individual or a substitute decision maker authorised by a federal, state or territory law;
>
> (b) the nominee can be an individual or an entity;
>
> (c) the nominee has a duty to act at all times in the best interests of the individual; and
>
> (d) the nomination can be revoked by the individual, the nominee or the agency or organisation.[110]

6.119 The ALRC concluded that establishing nominee arrangements would 'provide flexibility for individuals to decide who can act as their "agent" for the purposes of the *Privacy Act*, and also operate as a useful mechanism in situations where an individual has limited, intermittent or declining capacity'.[111]

6.120 The rationale for the original ALRC recommendations was to address problems faced by individuals and their representatives in gaining access to benefits and services due to perceived or real conflicts with the *Privacy Act*. That is, organisations refusing to provide information or deal with supporters 'because of the *Privacy Act*'. Similar concerns were expressed in this Inquiry.[112]

6.121 The ALRC's 2008 recommendations would have provided recognition for both supporters and representatives. The ALRC envisaged that a nominee could be either nominated by the individual or a substitute decision-maker appointed under some other law. While it would not be necessary for an authorised substitute decision-maker to be registered as a nominee for the agency or organisation to recognise that person, the nominee arrangements were seen as a convenient way for the decision-maker to be recognised for ongoing dealings with the agency or organisation.[113]

The Commonwealth model and the *Privacy Act*

Recommendation 6–4 The Australian Information Commissioner should develop guidelines consistent with the Commonwealth decision-making model describing the role of supporters and explaining how 'APP entities' should recognise the role of supporters in assisting people to exercise their rights under the *Privacy Act 1988* (Cth).

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109 Australian Law Reform Commission, *For Your Information: Australian Privacy Law and Practice*, Report No 108 (2008) Rec 70–1.
110 Ibid Rec 70–2.
111 Ibid [70.96].
112 See, eg, NSW Council for Intellectual Disability, *Submission 33*; ADACAS, *Submission 29*.
113 Australian Law Reform Commission, *For Your Information: Australian Privacy Law and Practice*, Report No 108 (2008) [70.101].

6.122 Successive Australian Governments have not responded to the ALRC's recommendations concerning decision-making arrangements under the *Privacy Act*.[114] There seems good reason to revisit this issue in the context of the present Inquiry.

6.123 The *Privacy Act* does not prevent a supporter from providing assistance to the individual where this is done with the consent of the individual. Where the assistance requires the supporter to have access to the personal information of the individual, the individual can provide consent for the agency or organisation to disclose the information to the supporter. Sometimes it should be quite clear, for example, that a requested disclosure of personal information would be permitted by APP 6.[115]

6.124 There are concerns, however, that such arrangements are not implemented consistently, or recognised by agencies and organisations.[116] The NSWCID submitted:

> So far as possible, people with intellectual disability should be given the support that they need to make their own privacy decisions. If this is not adequate, there needs to be a legislative system of substitute consent and/or administrative safeguards that provides reasonable safeguards on the privacy of the individual whilst also recognising that other rights of the individual may be imperilled if personal information cannot be gathered and promptly used as occasions arise.[117]

6.125 If the privacy rules covering this sort of information exchange are 'cumbersome or complex', then optimal support of people with intellectual disabilities will not occur.[118] Other stakeholders referred to the desirability of uniform Commonwealth, state and territory privacy regulation.[119]

6.126 The advantages of recognising supporters in Commonwealth laws are discussed in Chapter 4. In particular, formalisation of support is likely to create greater certainty for third parties about the role of supporters, and facilitate the provision of support to people who need it. In the context of information privacy, this is likely to allow third parties to interact with supporters with greater confidence, allowing for timely collection, use and disclosure of information.

6.127 There is a downside to this approach, however, in that legislative arrangements may work against flexible practices by encouraging the perception that a supporter must be formally appointed in order to be recognised. On the other hand, more informal arrangements may not be implemented consistently or recognised by APP

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114 Many other recommendations made in the 2008 privacy report were implemented following the enactment of the *Privacy Amendment (Enhancing Privacy Protection) Act 2012* (Cth).

115 That is, the disclosure is for the purpose the information was collected, or the individual has consented to the disclosure of the information: *Privacy Act 1988* (Cth) sch 1, cl 6.

116 Australian Law Reform Commission, *For Your Information: Australian Privacy Law and Practice*, Report No 108 (2008) [70.104].

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

118 The NSWCID referred to the *Health Records and Information Privacy Act 2002* (NSW) as a good model for dealing with 'incapacity issues': Ibid.

119 See, eg, Mental Health Coordinating Council, *Submission 07*. The ALRC has previously recommended an intergovernmental cooperative scheme that provides that the states and territories should enact legislation regulating the handling of personal information in the state and territory public sectors that is consistent with the *Privacy Act*: ALRC, *For Your Information: Australian Privacy Law and Practice*, Report No 108 (2008) Recs 3–4, 3–5.

entities. Some form of legislative underpinning may be more effective in establishing recognition of supporters.

6.128 Incorporating the Commonwealth decision-making model within the *Privacy Act* may facilitate assistance for people in making and communicating decisions concerning control of their personal information by recognising supporters, including family and carers, as being able to act on their behalf. At the least, supporters should be recognised and be made subject to a duty to support an individual's will and preferences in relation to the handling of their personal information.

6.129 However, some circumstances will require a more rigorous process for appointment and verification than others, due to the potential consequences of the disclosure of personal information or the transaction involved. For example, a bank or other financial institution might establish an arrangement that has effect for the purposes of disclosing account balances and banking transactions, but does not extend to a supporter withdrawing funds from an account on behalf of the individual, without putting further integrity measures in place.

6.130 While there was some support for the Discussion Paper proposals,[120] the OAIC did not consider amendments to the *Privacy Act* are needed. In this context, the OAIC advised that it does not generally support amendments to the *Privacy Act* unless there is evidence that the difficulty encountered is as a result of the current legislative framework. It was suggested that 'non-legislative measures, such as improved guidance, should be favoured' and, if this approach were found to be insufficient,

> careful consideration would need to be given to the regulatory impact of any amendments to ensure that they do not introduce additional complexities for individuals and APP entities, and meet the objectives of the *Privacy Act* set out in s 2A.[121]

6.131 The *Privacy Act* does not prevent supported decision-making where the individual has provided consent to the arrangement. Where the assistance requires the supporter to have access to the personal information of the individual, the individual can provide consent for the APP entity to disclose the information to the supporter.[122] The OAIC considered that a consistent application of the Commonwealth supported decision-making model can be achieved through the development of specific and targeted guidance for APP entities.[123]

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120 National Mental Health Consumer & Carer Forum, *Submission 100*.

121 Office of the Australian Information Commissioner, *Submission 132*.

122 There are a number of other exceptions in the APPs, which permit the use and disclosure of an individual's personal information to a representative, including where the use or disclosure is required or authorised by law; where a permitted health situation exists and information is disclosed to a responsible person for an individual; and in certain situations where there is a serious threat to the life, health or safety of any individual, or to public health or safety: See *Privacy Act 1988* (Cth) ss 16A, 16B(5).

123 Office of the Australian Information Commissioner, *Submission 132*.

6.132 In the Discussion Paper, the ALRC proposed that the *Privacy Act* should permit APP entities to establish a supporters and representatives scheme, but stated that this should not be mandatory.[124]

6.133 APP entities need to retain the flexibility to develop practices and procedures consistent with their broader operations. Agencies and organisations are subject to other obligations—such as the bankers' duty of confidentiality or particular legislative provisions—which place limits on decision-making by supporters. Each agency and organisation needs to consider the extent to which it is able to recognise and act upon decisions made by a supporter.

6.134 Applying the Commonwealth decision-making model in the *Privacy Act* would differ from other contexts, in that provisions would apply potentially to an individual's relationships with the full range of APP entities—Commonwealth government agencies and private sector organisations—and have to be administered by them, rather than by a single agency, such as the NDIA or Centrelink.

6.135 The ALRC concludes that it is not necessary to amend the *Privacy Act* itself to encourage the recognition of supported decision-making in privacy regulation. To begin with, there is no case for allowing all APP entities to create mechanisms for appointing representatives, although they should have processes for recognising substitute decision-makers appointed under state or territory law.

6.136 As suggested by the OAIC, the preferable approach may be to encourage supported decision-making through guidelines describing the role of supporters and explaining how APP entities should recognise the role of supporters in assisting people to exercise their rights under the *Privacy Act*.

Banking services

6.137 Banking is another area of Commonwealth legislative responsibility,[125] in relation to which the application of the decision-making model might be considered. Article 12(5) of the CRPD requires States Parties to take all appropriate and effective measures to ensure the equal right of persons with disabilities to control their own financial affairs and to have equal access to bank loans, mortgages and other forms of financial credit.[126]

6.138 In practice, a tension emerges between these rights and the need to protect people from financial abuse and exploitation in conducting their banking and financial activities. There is also a need to ensure the legal validity of financial transactions.

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124 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Discussion Paper No 81 (2014) Proposal 6–4, [6.109].

125 See, eg, *Banking Act 1959* (Cth); *Australian Prudential Regulation Authority Act 1998* (Cth); *Australian Securities and Investments Commission Act 2001* (Cth).

126 *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(5).

6.139 An issue in relation to banking is the refusal of some banks to allow persons with disability to access or operate a bank account independently, and hesitancy in recognising informal supporters. Such refusals may reflect bank concerns about capacity or financial exploitation.[127] In this context, the Australian Bankers' Association (ABA) has commented that

> Financial exploitation of a vulnerable person is a deeply challenging area for banks. Every customer's situation is unique and banks have an obligation to protect their customers' privacy, maintain the bank's duty of confidentiality, and to not unnecessarily intrude into their customers' lives.[128]

6.140 The ABA's Code of Banking Practice recognises the needs of older persons and customers with a disability to have access to transaction services and commits banks to taking reasonable measures to enhance their access to those services.[129] In addition, there are a number of industry standards and guidelines to assist banking accessibility. Individual banks have various customer service commitments, including Disability Action Plans and other service charters as well as policies, practices, business rules and product and service solutions to assist certain customers.[130]

6.141 The ABA issues other non-binding industry guidelines that are relevant to the ability of persons with disability to engage with the banking industry and to make decisions in that context.[131] In particular, the ABA has issued guidelines on responding to requests from a power of attorney or court-appointed administrator. These explain how powers of attorney and court-appointed administrator arrangements apply to banks' relationships with their customers; and outline a framework that banks can use to consistently deal with requests from attorneys and administrators.[132]

6.142 The ABA guidelines note that it 'is not the role of bank staff (or a bank) to determine a customer's capacity'.[133] They outline the roles of administrators and guardians, how to recognise their authority, and highlight differences in the role, authority and responsibilities of guardians and administrators between jurisdictions.[134]

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127 See, eg, Disability Rights Now, *Civil Society Report to the United Nations on the Rights of Persons with Disabilities* (2012) 190.

128 Australian Bankers' Association, *Financial Abuse Prevention* (12 November 2013).

129 Australian Bankers' Association, *Code of Banking Practice* (2013) [7].

130 Australian Bankers' Association, *Submission 128*.

131 ABA industry guidelines provide assistance to banks in recognising financial abuse, advocate raising awareness among bank employees about this risk, and outline strategies for dealing with a situation of potential financial abuse: Australian Bankers' Association Industry Guideline, *Protecting Vulnerable Customers from Potential Financial Abuse*, June 2013.

132 Australian Bankers' Association Industry Guideline, *Responding to Requests from a Power of Attorney or Court-Appointed Administrator*, June 2013, 1.

133 Ibid 2.

134 Ibid 4–5, 7.

Encouraging supported decision making

Recommendation 6–5 The Australian Bankers' Association should encourage banks to recognise supported decision-making. To this end, the ABA should issue guidelines, reflecting the National Decision-Making Principles and recognising that:

(a) customers should be presumed to have the ability to make decisions about access to banking services;

(b) customers may be capable of making and communicating decisions concerning banking services, where they have access to necessary support;

(c) customers are entitled to support in making and communicating decisions; and

(d) banks should recognise supporters and respond to their requests, consistent with other legal duties.

6.143 There may be some reluctance on the part of banks to allow people who need decision-making support to access banking services independently and to recognise the role of supporters. Banks may prefer to recognise only formal, substitute decision-making appointments. The ABA guidelines state, for example:

> Banks have a contractual obligation to act in accordance with the customer's mandate. If a customer has set up a power of attorney, or a court has appointed an administrator to represent a customer's interests, then these authorities are considered to be in line with the customer's mandate. It is important to recognise and respond to requests from these authorities as if they were made from the customer themselves.[135]

6.144 In the ALRC's view, people who need decision-making support should not necessarily have to access banking services only through an administrator or the holder of a power of attorney.

6.145 Submissions referred to difficulties faced by persons with disability in obtaining access to banking services, including because supporters are not recognised. Pave the Way, for example, stated that banks often refuse to allow persons with disability to have their own bank account:

> This is a problem that is regularly experienced by families who are trying to open an ordinary bank account for their family member who has a disability. We are aware of numerous examples of banks being willing to open an account for a child without disability but refusing to open an account for a child with disability. Similarly banks regularly refuse to open accounts for adults with disability. While it appears that there is no actual legal impediment to banks offering this service, some banks express

135 Ibid 6.

> concern about capacity and others cite an obligation to protect vulnerable people. When facing this problem some families decide to seek an administration order.[136]

6.146 The Equal Opportunity Commission of South Australia referred to a decision of the Equality Opportunity Tribunal (SA), which found that a finance company had discriminated against a loan applicant on the basis of disability. The Commission stated that the decision is 'a reminder of the risk that service providers may take in making assumptions about a person based on a disability, without adequately assessing a person's capacity'.[137]

6.147 The Centre for Rural Regional Law and Justice and the National Rural Law and Justice Alliance submitted that recognition of supported decision-making arrangements could better enable people with disabilities to 'exercise equal legal capacity in their use of financial services'. While the reluctance of banks to recognise informal arrangements was said to be understandable, provision for supported decision-making could help provide certainty for banks, while still ensuring that 'support for people with disabilities in the exercise of legal capacity is tailored to their needs, as required by Article 12 of the [CRPD]'.[138]

6.148 Banking may not be an area in which the full Commonwealth decision-making model can easily be applied. It may not be practical, for example, to impose any legislative requirement on banks to set up their own systems for recognising supporters and responding to requests from these supporters.

6.149 The nomination of a supporter does not involve the limitations and protective formalities of, for example, a power of attorney.[139] As discussed in Chapter 2, the 'paradigm shift' towards encouraging supported, rather than substitute, decision-making, is a relatively new development. Fully recognising supported decision-making arrangements would constitute a break with existing banking practices, which are based on contract and agency law, with potentially unforeseen legal consequences.[140]

6.150 Nevertheless, there may be room to encourage a more flexible approach on the part of banks, without being prescriptive, and recognising that banks bear risks in relation to voidable transactions.

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136 Pave the Way, *Submission 09*.

137 Equal Opportunity Commission of South Australia, *Submission 28*. (Referring to *Jackson v Homestart Finance* [2013] SAEOT 13).

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

139 Eg, in relation to an appointment by written instrument, independent witnesses and so on.

140 Relevant legal obligations of banks include privacy laws, responsible lending obligations, duties of confidentiality towards customers, contractual obligations to act on the instructions of their customers or others formally appointed to act on behalf of the customer (attorneys or court-appointed administrators). Other legal obligations which restrict banks from dealing with others not formally appointed include identification requirements associated with anti-money laundering and counter-terrorist financing and obligations to protect customers from fraud, identity theft, financial abuse, and other potential security risks: Australian Bankers' Association, *Submission 128*.

6.151 The ALRC recommends that the ABA provide additional guidance on how banks may meet the needs of people who require decision-making support to access banking services. This would be consistent with the ABA's Code of Banking Practice.[141]

6.152 The new guidance should reflect the National Decision-Making Principles, including the Support Guidelines. In particular, banks should be encouraged to recognise that customers:

- should be presumed to have the ability to make decisions about access to banking services;
- may remain capable of making and communicating decisions concerning banking services, where they have access to necessary support; and
- are entitled to support in making and communicating decisions and banks should, where possible and consistent with other duties, recognise supporters and respond to their requests.

6.153 The proposal in the Discussion Paper attracted some support from stakeholders.[142] The OPA (SA and Vic) supported the proposal and highlighted the importance of legally recognised supported decision-making arrangements in helping people 'to better and more easily deal with financial institutions, and other third parties'. This was said to be particularly important to 'obtaining and communicating often complex information which may be an otherwise difficult undertaking for a person with a cognitive impairment'.[143]

6.154 However, AGAC noted the 'very practical' risk of undue influence in banking transactions, if banks recognise supporters who do not have some formal status. AGAC considered that 'banks are highly unlikely to expose themselves to a contingent liability that would at least prima facie be so evident'.[144]

6.155 The ABA submitted that industry guidelines are not necessary to encourage banks to recognise supported decision making because banks have already 'implemented policies, practices, and business rules as well as provided products, services and tools as solutions to assist customers with special needs'.[145] Banks may, for example, provide facilities for co-signing, allowing designated others to conduct banking along with the account holder.

6.156 The ABA expressed concern about 'supported decision making or co-decision making arrangements that do not establish clear boundaries for all parties' and about customers entering arrangements with others, especially where customers breach their contract with the bank (for example, by disclosing PINs) or give up their consumer rights and protections.

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141 Australian Bankers' Association, *Code of Banking Practice* (2013) [7].
142 Advocacy for Inclusion, *Submission 126*; Offices of the Public Advocate (SA and Vic), *Submission 95*.
143 Offices of the Public Advocate (SA and Vic), *Submission 95*.
144 AGAC, *Submission 91*.
145 Australian Bankers' Association, *Submission 128*.

> The ABA believes that supported decision making or co-decision making may expose individuals to liability and legal risks, rather than provide them with greater financial independence and autonomy, decision making freedom and flexibility. Additionally, it is inappropriate for banks and other service providers to be expected to identify or determine the capacity of their customers. Banks are not in a position (or qualified) to establish (or question) whether a customer has capacity or not.[146]

6.157 On the other hand, the ABA confirmed that some banks have introduced 'product and service solutions to assist customers have supported decision making without exposing these customers, or their banks, to liability and legal risks'.[147] While some 'alternative and third party arrangements may present certain liability and legal risks' banks have taken these risks in order to assist their customers.[148]

6.158 These arrangements are consistent with the outcomes envisaged by the ALRC's recommendation for ABA guidelines encouraging supported decision-making. These state that banks should recognise supporters and respond to their requests, 'where possible and consistent with other legal duties'.[149]

6.159 In the ALRC's view, an ABA guideline and associated commentary could encourage banks to explore options for further developing forms of supported decision-making in a flexible way—for example, through contractual means. This should not be a disjuncture with current approaches, given banks are said to have 'already embedded the values of the National Decision-Making Principles into the way in which they deal with their customers'.[150]

146 Ibid.
147 The ABA referred to these as 'instituted supported decision making arrangements': Ibid.
148 Ibid.
149 Ibid.
150 Ibid.