

1. Executive Summary

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Towards supported decision-making in Australia

1.1 This Inquiry is about ensuring people with disability have an equal right to make decisions for themselves. It is about respecting people's dignity, autonomy and independence, while supporting them to make their own decisions, where such support is needed. This reflects an important movement away from

viewing persons with disabilities as 'objects' of charity, medical treatment and social protection towards viewing persons with disabilities as 'subjects' with rights, who are capable of claiming those rights and making decisions for their lives based on their free and informed consent as well as being active members of society.¹

1.2 The Inquiry commenced in July 2013, the same month in which a pilot of the National Disability Insurance Scheme (NDIS) in Australia was initiated, representing 'a new way of providing community linking and individualised support for people with permanent and significant disability, their families and carers'.² The objective of the NDIS is to provide persons with disability with greater choice and control over the disability services and support they receive.

1 United Nations Enable-Secretariat for the CRPD, *Convention on the Rights of Persons with Disabilities* <www.un.org/disabilities>.

2 Department of Families, Housing, Community Services and Indigenous Affairs, *One Big Difference to Lots of Lives: An Introduction to DisabilityCare Australia* (2013) 3.

1.3 The Terms of Reference required the Australian Law Reform Commission (ALRC) to consider ‘how maximising individual autonomy and independence *could be modelled* in Commonwealth laws and legal frameworks’.³ The ALRC considers this can best be achieved by setting out principles and guidelines that can be used as a template for specific reforms. These principles and guidelines can be applied to Commonwealth and state and territory laws—in particular, guardianship and administration laws.

National Decision-Making Principles

1.4 The ALRC recommends that the reform of relevant Commonwealth, state and territory laws should be consistent with the following National Decision-Making Principles:

Principle 1: The equal right to make decisions

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

Principle 2: Support

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

Principle 3: Will, preferences and rights

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

Principle 4: Safeguards

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

1.5 These principles reflect the paradigm shift signalled in the United Nations *Convention on the Rights of Persons with Disabilities* (CRPD) to recognise people with disabilities as persons before the law and their right to make choices for themselves. The emphasis is on the autonomy and independence of persons with disability who may require support in making decisions—their will and preferences must drive decisions that they make, and that others make on their behalf.

1.6 These four general principles reflect the key ideas and values upon which the ALRC’s approach is based. 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.

1.7 The principles are supported by three sets of guidelines. The principles and guidelines are discussed in Chapter 3.

3 Terms of Reference (emphasis added).

A Commonwealth decision-making model

1.8 To encourage supported decision-making at a Commonwealth level, the ALRC recommends a new model (the Commonwealth decision-making model) based on the positions of ‘supporter’ and ‘representative’. These terms are also part of building a new lexicon for supported decision-making. The role of both supporters and representatives is to assist persons who need decision-making support to make decisions in relevant areas of Commonwealth law.

1.9 In Chapter 4, the ALRC makes recommendations about amending the objects or principles provisions in relevant Commonwealth legislation; the appointment, recognition, role and duties of supporters and representatives; and appropriate and effective safeguards.

The National Disability Insurance Scheme

1.10 The NDIS represents a significant new area of Commonwealth responsibility and expenditure with respect to persons with disability in Australia. In Chapter 5, the ALRC recommends that the Commonwealth decision-making model be applied to the NDIS, which already incorporates elements of supported decision-making. This will require some amendment of the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act) and Rules to provide for legal recognition of supporters and representatives, including provisions for their appointment, removal and associated safeguards.

1.11 The Chief Executive Officer of the National Disability Insurance Agency should retain the power to appoint a ‘representative’ for a participant as a measure of last resort. There are circumstances where the exercise of this power is necessary—in the absence of a Commonwealth guardianship tribunal or equivalent body—to ensure that persons with disability are properly supported in the relation to the NDIS.

1.12 There should be a presumption that an existing state or territory appointed decision-maker with comparable powers and responsibilities should be appointed as an NDIS representative, and amendments to the legislation governing state and territory decision-makers may be necessary to facilitate this.

1.13 In the light of the shift towards a supported decision-making model, the ALRC also recommends that the Australian Government provide guidance and training in relation to decision-making and the NDIS.

Supporters and representatives in other areas of Commonwealth law

1.14 The Commonwealth decision-making model may also be applied to other existing legislative schemes in Commonwealth laws that already contain a decision-making mechanism or make some provision for supporters and representatives—however described.

1.15 As discussed in Chapter 6, these schemes concern individual decision-making in relation to social security, 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* (Cth).

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

1.17 In some of these areas, legislation should be amended to include provisions dealing with supporters and representatives consistent with the Commonwealth decision-making model. However, any reform needs to be proportionate to the situation, and to 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.

1.18 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.

Access to justice

1.19 Chapter 7 deals with issues concerning decision-making and access to justice. There are a range of Commonwealth laws and legal frameworks affecting persons with disability involved in court proceedings, including as:

- defendants in criminal proceedings—the concept of unfitness to stand trial;
- parties to civil proceedings—the appointment and role of litigation representatives;
- witnesses in criminal or civil proceedings—giving evidence as a witness, and consenting to the taking of forensic samples; and
- potential jurors—qualification for jury service.

1.20 In each of these areas there are existing tests of a person's capacity to exercise legal rights or to participate in legal processes. The ALRC recommends that these tests be reformed consistently with the National Decision-Making Principles. By providing models in Commonwealth laws, the ALRC seeks to inform and provide a catalyst for reform of state and territory laws.

1.21 An important theme is the tension between laws that are intended to operate in a 'protective' manner—for example, in order to ensure a fair trial—and increasing demands for equal participation, in legal processes, of persons who require decision-making support.

Restrictive practices

1.22 The term 'restrictive practices' refers to the use of interventions that have the effect of restricting the rights or freedom of movement of a person in order to protect them. Serious concerns have been expressed about inappropriate and under-regulated use of restrictive practices in a range of settings in Australia.

1.23 Current regulation of restrictive practices occurs mainly at a state and territory level. However, the Commonwealth, state and territory disability ministers endorsed

the *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* (National Framework) in March 2014 to forge a consistent national approach.

1.24 As discussed in Chapter 8, the National Framework is intended to reduce the use of restrictive practices, including by informing the development of the NDIS quality assurance and safeguards system. The ALRC recommends that the Australian Government and the Council of Australian Governments (COAG) incorporate aspects of the National Decision-Making Principles in developing the NDIS system.

1.25 The ALRC also recommends that the Australian Government and COAG adopt a similar, national approach to the regulation of restrictive practices in other relevant sectors such as aged care and health care.

Electoral matters

1.26 Australia is obliged, under the CRPD, to guarantee that persons with disability can ‘effectively and fully participate in political and public life on an equal basis with others, directly or through freely chosen representatives’, including the right and opportunity to vote and be elected.⁴

1.27 In Chapter 9, the ALRC recommends that the ‘unsound mind’ provisions of the *Commonwealth Electoral Act 1918* (Cth) (the Electoral Act), which relate to disqualification for enrolment and voting, be repealed. A new exemption to compulsory voting based on a functional test consistent with the National Decision-Making Principles should be enacted, so that a person who lacks decision-making ability relating to voting is exempt from penalties arising from a failure to vote.

1.28 Where a person with disability requires assistance to vote, they should be supported by all available means. The ALRC recommends that current provisions of the Electoral Act concerning permissible support be broadened, and that the Australian Electoral Commission (AEC) provide its officers with guidance and training to improve support in enrolment and voting for persons with disability. As the right to a secret vote is fundamental to the right to vote, but may be compromised by some forms of support, the AEC should also investigate methods of maintaining the secrecy of voting.

Review of state and territory legislation

1.29 This new approach to individual decision-making at the Commonwealth level can also be used to guide law reform at the state and territory level. Reform at the state and territory level is critical to the implementation of the CRPD because many important areas of decision-making are governed by state and territory law—including in relation to guardianship and administration, consent to medical treatment, mental health and disability services.

⁴ *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 29.

1.30 The ALRC recommends that state and territory governments review their legislation that deals with decision-making to ensure laws are consistent with the National Decision-Making Principles and the Commonwealth decision-making model. In Chapter 10, the ALRC discusses how, in conducting such a review, regard should be given to:

- interaction with any supporter and representative schemes under Commonwealth legislation;
- consistency between jurisdictions, including in terminology;
- maximising cross-jurisdictional recognition of arrangements; and
- mechanisms for consistent and national data collection.

Other issues

1.31 Chapter 11 deals with a number of other issues raised that are relevant to Commonwealth laws and legal frameworks that concern the exercise of legal capacity, including in relation to:

- the common law relating to incapacity to contract;
- consumer protection laws;
- consent to marriage;
- the nomination of superannuation beneficiaries;
- acting in the role of a board member and in other corporate roles; and
- holding public office.

1.32 The ALRC recommends amendments to the *Marriage Act 1961* (Cth) and associated guidelines for marriage celebrants, and some provisions of the *Corporations Act 2001* (Cth) to better reflect the National Decision-Making Principles. It also recommends that the Australian Government should review and replace provisions in Commonwealth legislation that require the termination of statutory appointments by reason of a person's 'unsound mind' or 'mental incapacity'.

The law reform process

1.33 Law reform recommendations cannot be based upon assertion or assumption and need to be built on an appropriate conceptual framework and evidence base.

Framing principles

1.34 The ALRC identified five framing principles for guiding the recommendations for reform in this Inquiry: dignity; equality; autonomy; inclusion and participation; and accountability. There was wide support by stakeholders for these principles, which are reflected in the decision-making model that is developed in the Report.

1.35 **Dignity** is one of the guiding principles of the CRPD⁵ and is recognised in a number of other international human rights instruments.⁶ In Australia, the National Disability Strategy (NDS) prioritised the concept of dignity in its principles.⁷ Similarly, the Productivity Commission identified human dignity as ‘an inherent right’ of persons with disability and suggested that dignity as a human being is linked to self-determination, decision-making and choice.⁸

1.36 **Equality** is at the heart of the CRPD. The United Nations Committee on the Rights of Persons with Disabilities stated that: ‘Equality before the law is a basic and general principle of human rights protection and is indispensable for the exercise of other human rights’.⁹ Similarly, art 5 prohibits all discrimination on the basis of disability and requires States to promote equality, and arts 6 and 7 emphasise equality for women and children. The NDS principles emphasise equality of opportunity,¹⁰ and a range of Commonwealth laws also protect the equality of people and proscribe discrimination on the basis of disability—for example, the *Disability Discrimination Act 1992* (Cth).

1.37 **Autonomy** is a significant principle underlying the ability of persons with disability to exercise legal capacity. It is enshrined in the general principles of the CRPD and is a key principle of the NDS.¹¹ The objects and principles of the NDIS also reflect the notion of autonomy.¹² This Inquiry has been informed by autonomy in the sense of ‘empowerment’, not just ‘non-interference’.¹³ This involves seeing an individual in relation to others, in a ‘relational’ or ‘social’ sense,¹⁴ and understanding that connects with respect for the family as the ‘natural and fundamental group unit of society’ that is entitled to protection by States Parties.¹⁵ Such a view sits comfortably with a shift in emphasis towards supported decision-making, which ‘acknowledges that

5 *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 3(a).

6 See, eg, *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd Sess, 183rd Plen Mtg, UN Doc A/810 (10 December 1948); *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, UNTS171 (entered into force 23 March 1976); *International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976).

7 Australian Government, *National Disability Strategy 2010–2020*, 22.

8 Productivity Commission, ‘Review of the *Disability Discrimination Act 1992* (Cth)’ (30 Vol 1, 2004) 182.

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

10 Australian Government, *National Disability Strategy 2010–2020*, 22.

11 Australian Government, *National Disability Strategy 2010–2020*, 22.

12 *National Disability Insurance Scheme Act 2013* (Cth) ss 3, 4.

13 Mary Donnelly, *Healthcare Decision-Making and the Law—Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, 2010) 269–272. Donnelly draws, for example, on the work of Joseph Raz, eg Joseph Raz, *The Morality of Freedom* (Clarendon Press, 1986). See her discussion particularly in ch 1, ‘Autonomy: Variations on a Principle’.

14 John Christman, ‘Relational Autonomy, Liberal Individualism, and the Social Constitution of Selves’ (2004) 117 *Philosophical Studies* 143, 143.

15 *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, UNTS171 (entered into force 23 March 1976) art 23(1); *Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, GA Res 48, UN GAOR, 3rd Comm, 48th Sess, Agenda Item 109, UN Doc A/RES/48/96 (20 December 1993) r 9.

individuals rely to a greater or lesser extent on others to help them make and give effect to decisions'.¹⁶

1.38 Closely related to the principles of dignity and equality, the principles of **inclusion and participation** are central to many contemporary perspectives on disability, particularly a social model of disability. The social model emphasises that, while 'a person might have an impairment, their disability comes from the way society treats them, or fails to support them'.¹⁷ Inclusion and participation are active values, consistent with an approach to autonomy as empowerment. An emphasis on inclusion has important consequences for education, workforce participation and economic security, as people with disability are seen as 'citizens with rights, not objects of charity'.¹⁸ Further, one of the objects of the NDIS Act is to facilitate greater community inclusion of people with a disability.¹⁹ The focus on supported decision-making developed throughout the Report reflects the principle of inclusion and participation.

1.39 The principle of **accountability** has a number of key components. The first is the need for systemic and specific accountability mechanisms and safeguards. 'Supporters' who fulfil a supportive role in decision-making must be properly accountable, as well as those who are appointed to make decisions on a person's behalf. Another important component is the accountability and responsibility of persons with disability for their decisions, recognising that active participation involves both responsibilities and risks.²⁰

Building an evidence base

1.40 A major aspect of building the evidence base to support the formulation of ALRC recommendations for reform is consultation, acknowledging that widespread community consultation is a hallmark of best practice law reform.²¹ Under the provisions of the *Australian Law Reform Commission Act 1996* (Cth), the ALRC 'may inform itself in any way it thinks fit' for the purposes of reviewing or considering anything that is the subject of an inquiry.²²

1.41 The process for each law reform project may differ according to the scope of the inquiry, the range of stakeholders, the complexity of the laws under review, and the period of time allotted for the inquiry. For each inquiry the ALRC determines a consultation strategy in response to its particular subject matter and likely stakeholder interest groups. The nature and extent of this engagement is normally determined by the subject matter of the reference and the timeframe in which the inquiry must be

16 Piers Gooding, 'Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law' (2013) 20 *Psychiatry, Psychology and Law* 431, 435.

17 Productivity Commission, 'Disability Care and Support' (July 2011) 54 Vol 1, 98.

18 Australian Government, *National Disability Strategy 2010–2020*, 16.

19 *National Disability Insurance Scheme Act 2013* (Cth) s 3.

20 Children with Disability Australia, *Submission 68*.

21 B Opeskin, 'Measuring Success' in B Opeskin and D Weisbrot (eds), *The Promise of Law Reform* (2005), 202.

22 *Australian Law Reform Commission Act 1996* (Cth) s 38.

completed under the Terms of Reference. While the exact procedure is tailored to suit each inquiry, the ALRC usually works within an established framework, outlined on the ALRC's website.²³

Community consultation

1.42 A multi-pronged strategy of seeking community comments was used. Two consultation documents were released to facilitate focused consultations in stages through the Inquiry. An Issues Paper was released on 15 November 2013 and a Discussion paper on 22 May 2014.²⁴

1.43 The Discussion Paper put forward 56 proposals and 16 questions to assist the ALRC to develop its recommendations for reform. Both consultation papers and this final Report were also released in an Easy English format.²⁵

1.44 Two national rounds of stakeholder consultation teleconferences, meetings, forums and roundtables were also conducted following the release of each of the consultation documents.

1.45 The Terms of Reference for this Inquiry directed the ALRC to consult with relevant stakeholders, particularly persons with disability and their representative, advocacy and legal organisations, but also families and carers of people with disability, relevant Commonwealth, states and territory departments and agencies, the Australian Human Rights Commission, and other key non-government stakeholders. The many individuals, departments, agencies and organisations consulted in the Inquiry are listed at the end of the Report.

1.46 The ALRC received 156 submissions, a full list of which appears at the end of the Report. Submissions were received from a wide range of people and agencies, including: bodies representing persons with disability; courts; public guardians and advocates; individuals; academics; lawyers; community legal centres; law societies and representative groups; and Commonwealth and state government agencies.

1.47 The ALRC acknowledges the contribution of all those who participated in the Inquiry consultation rounds and the considerable amount of work involved in preparing submissions. This can have a significant impact in organisations with limited resources. It is the invaluable work of participants that enriches the whole consultative process and the ALRC records its deep appreciation for this contribution.

Appointed experts

1.48 In addition to the contribution of expertise by way of consultations and submissions, specific expertise is also obtained in ALRC inquiries through the establishment of Advisory Committees, panels, roundtables and the appointment by the

23 <www.alrc.gov.au/law-reform-process>.

24 Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Issues Paper No 44 (2013) 41; Australian Law Reform Commission, *Equality, Capacity and Disability in Commonwealth Laws*, Discussion Paper No 81 (2014).

25 Easy English is an accessible format that uses simple, everyday language and illustrations for people with low English literacy.

Attorney-General of part-time Commissioners. The Advisory Committee for this Inquiry had 11 members, listed at the beginning of the Report. Two meetings were held in Sydney on 3 October 2013 and 8 April 2014.

1.49 In this Inquiry the ALRC was able to call upon the expertise and experience of Graeme Innes AM, Disability Discrimination Commissioner, who was appointed as a part-time Commissioner specifically to assist the ALRC in this Inquiry. The Hon Justice Berna Collier of the Federal Court of Australia contributed her experience as a part-time Commissioner until October 2013 and thereafter on the Advisory Committee for the Inquiry.

1.50 While the ultimate responsibility in each inquiry remains with the Commissioners of the ALRC, the establishment of a group of experts as an Advisory Committee, panel or roundtable and the enlisting of expert readers are invaluable aspects of ALRC inquiries. These experts assist in the identification of key issues, providing quality assurance in the research and consultation effort, and assisting with the development of reform proposals. The ALRC acknowledges the significant contribution made by the Advisory Committee in this Inquiry and expresses its gratitude to them for voluntarily providing their time and expertise.

Implementation

1.51 Once tabled in the Australian Parliament, the Report becomes a public document.²⁶ ALRC reports are not self-executing documents. The ALRC is an advisory body and provides recommendations about the best way to proceed—but implementation is a matter for others. However, the ALRC has a strong track record of having its advice followed. The Annual Report 2012–2013 records that 61% of ALRC reports are substantially implemented and 28% are partially implemented, representing an overall implementation rate of 89%.²⁷

1.52 Quite apart from such statistics, an assessment of the contribution that law reform work makes must have a long view. Law reform inquiries have a far bigger impact than just the implementation of recommendations, some of which may occur shortly after a report is released, some many years later. But whether or not recommendations are implemented, ALRC reports provide enormous value. Each ALRC report provides not only a mapping of law as at a particular moment in time, but in reviewing the submissions and consultations the reports also provide a snapshot of opinion on the issues being considered—providing a considerable contribution to legal history, and increasingly locating that within its particular social context at a given time. In making a submission to the Senate Standing Committee on Legal and Constitutional Affairs, when the Committee conducted an inquiry into the ALRC over

26 The Attorney-General is required to table the report within 15 sitting days of receiving it: *Australian Law Reform Commission Act 1996* (Cth) s 23.

27 Australian Law Reform Commission, *Annual Report 2011–2012* (ALRC Report 121), 24 and see Appendix F.

the summer of 2010–2011,²⁸ the Federal Court of Australia said that the Court benefits greatly from ALRC reports:

More often than not, an ALRC report contains the best statement or source of the current law on a complex and contentious topic that can remain the case for decades thereafter, whether or not the ALRC's recommendations are subsequently implemented.²⁹

Outcomes

1.53 Australia was an active participant and leader in the development of the CRPD, contributing greatly to the negotiations of the text of the Convention. Australia was also one of the original signatories when it opened for signature on 30 March 2007.

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

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

1.56 Recent reviews and amendment of state and territory guardianship and administration laws provide important directions for reform. In the Report, the ALRC puts forward a model to encourage supported decision-making under Commonwealth laws and to provide the catalyst towards further initiatives at the state and territory level.

1.57 In adopting the model and leading its implementation federally, the Australian Government can maintain its leadership in championing and implementing reforms for persons with disability, ensuring their equal recognition before the law in accordance with art 12 of the CRPD.

28 See the inquiry report: Australian Parliament, Senate Legal and Constitutional Affairs References Committee, *Inquiry into the Australian Law Reform Commission* (8 April 2011), <www.aph.gov.au/Parliamentary_Business/Committees/Senate/Legal_and_Constitutional_Affairs/Completed%inquiries/2010-13/lawreformcommission>.

29 Ibid, Submission 22.

