

Introduction and Background

In our daily lives as adults, we make many decisions that we consider determinative of our futures – where to live, what education to undertake and what health treatment to accept. Many of us may consider that we have a human right to make personal decisions and that such a right is key to our individual autonomy, essential to our dignity, and should be claimed equally by all. Article 12 of the United Nations *Convention on the Rights of Persons with Disabilities* ('CRPD') is said to enshrine such a human right for people with disability when it provides for the right to 'enjoy legal capacity on an equal basis with others'. However, historically and currently, challenges arise in recognising legal capacity or decision-making ability in the case of adults with cognitive disability – that is, disability associated with intellectual disability, acquired brain injury, aged dementia or mental illness.² Adults with cognitive disability have historically been denied (and for the most part, still are denied) the opportunity to make decisions that are recognised at law as their own and acted upon as such. They may have decisions made for them by substitutes, including guardians, attorneys or even clinicians,³ and such decisions may directly conflict with their own expressed desires or wishes.

This book interprets Article 12 of the CRPD – the 'right to enjoy legal capacity on an equal basis with others' – through the principle of the indivisibility, interdependence and interrelatedness of all human rights (the 'principle of indivisibility'). It concludes that the principle of indivisibility underpins an interpretation of Article 12 that requires adults with cognitive disability to be supported in making decisions but that also may require decision-making by substitutes in cases of last resort. Contrary to the view of the Committee on the Rights of Persons with Disabilities ('UN

¹ *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008) ('CRPD').

² See Section 2 – 'A Note on Terminology and Concepts'.

³ Ben White, Lindy Willmott and Shih-Ning Then, 'Chapter 7: Adults Who Lack Capacity: Substitute Decision Making' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Lawbook Co, 3rd ed., 2018) 207.

Disability Committee')⁴ and others,⁵ it argues that in 'hard cases', decision-making by substitutes may be required to uphold an adult's indivisible human rights. In interpreting Article 12, the book examines the role of the three human rights values of autonomy, dignity and equality and explains how these can be rearticulated in the language of indivisible human rights to support the above interpretation. It applies a concept of indivisibility that recognises the interdependencies between rights and the equal importance of economic, social and cultural ('socio-economic') rights with civil and political ('civil-political') rights.

This chapter provides context and background by explaining the ongoing contention around Article 12, the book's aims and scope, and why I have chosen to use certain key terms. It also introduces the CRPD, explains the book's structure and how it contributes in an original and significant way to the existing research and literature in this area.

1 ARTICLE 12 AND THE PROBLEM OF INTERPRETATION

The first three paragraphs of Article 12 provide that:

- (1) States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.

⁴ Committee on the Rights of Persons with Disabilities, *General Comment No 1 Article 12: Equal Recognition before the Law*, UN Doc CRPD/C/GC/1 (19 May 2014) ('General Comment No 1').

⁵ Tina Minkowitz, 'Legal Capacity: Fundamental to the Rights of Persons with Disabilities' (2007) 56(1) *International Rehabilitation Review* 25; International Disability Alliance, *Legal Opinion on Article 12 of the CRPD* <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/library/legal-opinion-LegalOpinion-Art12-FINAL.pdf> ('Legal Opinion'); Fiona Morrissey, 'The United Nations Convention on the Rights of Persons with Disabilities: A New Approach to Decision-Making in Mental Health Law' (2012) 19 *European Journal of Health Law* 423; Amita Dhanda, 'Legal Capacity in the Disability Rights Convention: Stranglehold of the Past or Lodestar of the Future' (2007) 34 *Syracuse Journal of International Law and Commerce* 429; Gerard Quinn and Anna Arstein-Kerslake, 'Restoring the "Human" in "Human Rights": Personhood and Doctrinal Innovation in the UN Disability Convention' in Costas Douzinas and CA Gearty (eds), *Cambridge Companion to Human Rights Law* (Cambridge University Press, 2012) 36; Theresia Degener, 'Editor's Foreword' (2017) 13(1) *International Journal of Law in Context* 1; Gerard Quinn and Abigail Rekas-Rosalbo, 'Civil Death: Rethinking the Foundations of Legal Personhood for Persons with a Disability' (2016) 56 *Irish Jurist* 286; Eilionóir Flynn and Anna Arstein-Kerslake, 'The Support Model of Legal Capacity: Fact, Fiction, or Fantasy?' (2014) 32(1) *Berkeley Journal of International Law* 124; Michael Bach and Lana Kerzner, *A New Paradigm for Protecting Autonomy and the Right to Legal Capacity: Advancing Substantive Equality for Persons with Disabilities through Law, Policy and Practice* (Law Commission of Ontario, October 2010); Nandini Devi, 'Supported Decision-Making and Personal Autonomy for Persons with Intellectual Disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities' (2013) 41(4) *The Journal of Law, Medicine & Ethics* 792; Cliona de Bhailís and Eilionóir Flynn, 'Recognising Legal Capacity: Commentary and Analysis of Article 12 CRPD' (2017) 13(1) *International Journal of Law in Context* 6; Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law* (Cambridge University Press, 2017); Kristin Booth Glen, 'Changing Paradigms: Mental Capacity, Legal Capacity, Guardianship and Beyond' (2012) 44 *Columbia Human Rights Law Review* 93.

- (2) States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
- (3) States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

There is wide if not universal agreement that paragraph 3 of Article 12 requires States to provide decision-making supports for adults with cognitive disability so that they can endeavour to exercise legal capacity in fulfilment of their human rights.⁶ These supports may be in the form of, for example, mentoring, communication assistance or advocacy, according to what have become known as systems of ‘supported decision-making’⁷ However, while promotion of supported decision-making is widely endorsed, there remains significant and entrenched disagreement about whether Article 12 allows for decision-making by substitutes in cases of last resort. These cases of last resort include those described in the literature as ‘hard cases’ (as discussed in the following section) but also potentially when a supporter chosen by the adult is exercising undue influence or abuse.⁸

1.1 Case Studies

The term ‘hard cases’ is used in the Article 12 literature to describe those situations where traditionally an adult would have a decision made for them by a guardian and where there are particular challenges for supported decision-making. This may be in cases of severe and profound cognitive disability;⁹ in situations where an adult

⁶ Rosemary Kayess and Therese Sands, *Convention on the Rights of Persons with Disabilities: Shining a Light on Social Transformation* (UNSW Social Policy Research Centre, 2020); Ron McCallum, *The United Nations Convention on the Rights of Persons with Disabilities: An Assessment of Australia’s Level of Compliance* (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020) 46–55.

⁷ See Section 2 of this chapter. Piers Gooding, ‘Supported Decision-Making: A Rights-Based Disability Concept and Its Implications for Mental Health Law’ (2013) 20(3) *Psychiatry, Psychology and Law* 431, 432–39.

⁸ Also, note the challenges of supported decision-making in these cases, in particular in ascertaining an adult’s autonomous will and preferences: see Section 5 of this chapter.

⁹ Anna Arstein-Kerslake and Eilionóir Flynn, ‘The General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities: A Roadmap for Equality before the Law’ (2016) 20(4) *The International Journal of Human Rights* 471, 482; Anna Arstein-Kerslake, ‘An Empowering Dependency: Exploring Support for the Exercise of Legal Capacity’ (2016) 18 *Scandinavian Journal of Disability Research* 77, 84; for the example of an adult in a persistent vegetative state, see Mary Donnelly, *Healthcare Decision-Making and the Law: Autonomy, Capacity and the Limits of Liberalism* (Cambridge University Press, 2010); Jillian Craigie et al, ‘Legal Capacity, Mental Capacity and Supported Decision-Making: Report from a Panel Event’ (2019) 62 *International Journal of Law and Psychiatry* 160, 162; Wayne Martin et al, *Three Jurisdictions Report: Towards Compliance with CRPD Article 12 in Capacity/Incapacity Legislation across the UK* (Essex Autonomy Project, 2016) 34; Australian Law Reform

wants to make a decision that will result in harm or serious harm to themselves or others;¹⁰ or where an adult is supported by someone who exercises undue influence over their decision-making.¹¹ The three case studies below are discussed in Chapters 4, 5 and 6, respectively, to illustrate the arguments made in this book. They have been chosen and shaped to illustrate where decision-making with support is challenging or complex and where decision-making by a substitute may be considered necessary as a last resort to uphold human rights.

ALEX

Alex is a 30-year-old man with an intellectual disability who refuses dental treatment because he is scared of, and doesn't trust, the dentist. Collateral information is that his fear is linked to post-traumatic stress disorder from childhood abuse. Counsellors have been unable to assuage his fears or convince him to have the treatment. They have warned him that he will lose all of his teeth if he does not have the treatment. His support workers and family all know that one of his real joys in life is to partake of gourmet food, and it is a significant social interest that he can share with others. If Alex loses all of his teeth, he will need to live chiefly on pureed food. It is not clear whether he understands this longer-term adverse impact (as opposed to the shorter-term impact of undergoing the treatment). It appears to Alex's supporters that he thinks that his teeth will get better on their own, and he will be able to eat steak again soon.

The case of Alex is a version of various hypothetical scenarios discussed in the Article 12 literature.¹² It illustrates challenges with supported decision-making when the

Commission, *Equality, Capacity and Disability in Commonwealth Laws: A Final Report* (2014) 33; Kristin Booth Glen, 'Introducing a New Human Right: Learning from Others, Bringing Legal Capacity Home' (2018) 49(3) *Columbia Human Rights Law Review* 1, 7, 15.

¹⁰ Arstein-Kerslake and Flynn (n 9); Lucy Series, 'Relationships, Autonomy and Legal Capacity: Mental Capacity and Support Paradigms' (2015) 40 *International Journal of Law and Psychiatry* 80, 87; Martin et al, *Three Jurisdictions Report* (n 9) 34.

¹¹ 'There is a risk that people in positions of power, such as medical professionals and supporters, may profess to be acting on the will and preference of the individual when they are really carrying out their own desires': Arstein-Kerslake and Flynn (n 9) 482; Arstein-Kerslake, 'An Empowering Dependency' (n 9) 88; 'Risk-taking behaviour presents a particular challenge in implementing the principle of support, as do the accompanying moral dilemmas, where the person rejects support and/or intimates a wish to place themselves in a situation of danger, exploitation, abuse or undue influence': Martin et al, *Three Jurisdictions Report* (n 9) 36.

¹² Arstein-Kerslake and Flynn (n 9) 483–84; de Bhaillís and Flynn (n 5), 16; Rosemary Kayess and Ben Fogarty, 'The Rights and Dignity of Persons with Disabilities' (2007) 32(1) *Alternative Law Journal* 22, 26; also for where dental treatment was ordered in the face of an adult's refusal: *In the matter of: Deon Wessels and Hayden William Kelly* [2012] NZFC 9487.

adult expresses desires or intentions that conflict; or when one or other of those desires or intentions might harm the adult.

SESHA

Philosopher Eva Feder Kittay describes her daughter Sesha as a girl and now woman, who ‘was diagnosed as having severe to profound retardation’. Kittay describes Sesha as ‘enormously responsive, forming deep personal relationships with her family and long-standing caregivers and friendly relations with her therapists and teachers.’¹³ Kittay has written quite a bit about her daughter’s love of music, especially but not exclusively classical symphonic music, Beethoven being on the top of her list. Sesha cannot read, and Kittay says she cannot ‘engage in moral practical reasoning’¹⁴ or participate in political life but that her life is full. It is hard to know what cognitive capacities Sesha possesses because she cannot speak. She also has physical functional limitations, with unsteady legs and no dexterity with a spoon or knife. Kittay is fortunate enough to have the material resources to provide her daughter with carers, therapists and teachers. As an adult, Sesha lives in supported accommodation – a group home with five other young people who are also described as having cognitive and multiple disabilities.

The case of Sesha is referred to by Kittay¹⁵ and others¹⁶ in the philosophical literature on personhood, autonomy and dignity. Sesha’s life and circumstances, and her

¹³ Eva Feder Kittay, ‘The Personal Is Philosophical Is Political: A Philosopher and Mother of a Cognitively Disabled Person Sends Notes from the Battlefield’ (2009) 40(3–4) *Metaphilosophy* 606, 616.

¹⁴ Eva Feder Kittay, ‘Equality, Dignity and Disability’ in Mary Ann Lyons and Fionnuala Waldron (eds), *Perspectives on Equality: The Second Seamus Heaney Lectures* (Liffey Press, 2005) 100.

¹⁵ Kittay, ‘Equality, Dignity and Disability’ (n 14); Eva Feder Kittay, ‘At the Margins of Moral Personhood’ (2005) 116(1) *Ethics* 100; Kittay, ‘The Personal Is Philosophical Is Political’ (n 13) 624.

¹⁶ Susan Dodds, ‘Depending on Care: Recognition of Vulnerability and the Social Contribution of Care Provision’ (2017) 21(9) *Bioethics* 500, 508; Alice Crary, ‘Cognitive Disability and Moral Status’ in David T Wasserman and Adam Cureton (eds), *The Oxford Handbook of Philosophy and Disability* (Oxford University Press, 2018) 2; Camillia Kong, *Mental Capacity in Relationship: Decision-Making, Dialogue and Autonomy* (Cambridge University Press, 2017) 205–7; Christie Hartley, ‘An Inclusive Contractualism: Obligations to the Mentally Disabled’ in Kimberley Brownlee and Adam Cureton (eds), *Disability and Disadvantage* (Oxford University Press, 2009) 138, 151; Lorraine Krall McCrary, ‘Hannah Arendt and Disability: Natality and the Right to Inhabit the World’ in Barbara Arneil and Nancy J Hirschmann (eds), *Disability and Political Theory* (Cambridge University Press, 2016) 198, 201, 215; Bach and Kerzner (n 5) 70; Martha C Nussbaum, *Frontiers of Justice Disability, Nationality, Species Membership* (Harvard University Press, 2009) 96.

inability to ‘engage in moral reasoning’, means that she presents as a hard case of severe and profound cognitive disability.

JESS

Jess, aged 76, has advanced dementia and lives on a rural property with her adult son. The property has been in the family for generations and Jess has always wanted it to stay in the family. She has also been very house-proud in the past.

To ‘manage’ her dementia, her son has placed Jess in the laundry under the house and locked the door to prevent her from wandering. Jess does not object to her living situation and appears acquiescent or compliant, always favouring her son over her other children.

Neighbours report the situation to the police, who find Jess under the house, malnourished and soiled.

The case of Jess illustrates the complexities surrounding severe cognitive disability in the case of aged dementia and where the adult has chosen a supporter whose neglectful and abusive actions result in harm to the adult.¹⁷

1.2 *The Problem the Book Is Addressing*

On the one hand, there is a prevailing view held by the UN Disability Committee and others that decision-making by a substitute will breach Article 12 legal capacity rights because it constitutes a denial of autonomy for adults with cognitive disability and constitutes unlawful discrimination.¹⁸ Under the tenets of liberal philosophy, autonomy is the foundation of personhood.¹⁹ According to this logic, denial of legal capacity and autonomy constitutes a violation of all human rights by situating adults with cognitive disability as ‘non-persons’. Their position as ostensible non-persons,

¹⁷ This is similar to a hypothetical scenario described in Elizabeth Anderson, ‘Animal Rights and the Values of Non-human Life’ in Cass R Sunstein and Martha C Nussbaum (eds), *Animal Rights: Current Debates and New Directions* (Oxford University Press, 2004) 277, 282.

¹⁸ *General Comment No 1*; Lucy Series and Anna Nilsson, ‘Article 12 CRPD: Equal Recognition before the Law’ in Ilias Bantekas, Michael Ashley Stein and Anastasiou Dimitris (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 339, 340.

¹⁹ John Christman, ‘Autonomy in Moral and Political Philosophy’, *The Stanford Encyclopedia of Philosophy* (Fall 2020 Edition), Edward N Zalta (ed) [1.2] <https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/>. See also Chapter 4.

in turn, amounts to unlawful discrimination because they are treated unequally in all aspects of their lives.²⁰

On the other hand, there is also a widely held view that decision-making by substitutes may be reasonable, necessary and inevitable in some cases, and that Article 12 allows for substitute decision-making ‘as a last resort’.²¹ I argue for this second interpretation – that in some cases where an adult has impaired capacity, Article 12 allows for and may even require a decision to be made by a substitute. There is no widely held agreement as to the basis for this interpretation. Some writers refer to the inevitability of substitute decision-making;²² some seek alternative bases for personhood to replace autonomy;²³ some view prevention of harm as a permissible exception to legal capacity rights;²⁴ and others consider how equality may be

²⁰ *General Comment No 1; Arstein-Kerslake, Restoring Voice to People with Cognitive Disabilities* (n 5) 38.

²¹ See Chapter 2, Section 4.2.

²² Scott Kim: ‘The debate should not be over whether we sometimes should decide for others. The fact is that we inevitably do, whether we acknowledge this or not’: Craigie et al (n 9) 165; ‘Our own approach incorporates the frank admission that the exercise of legal capacity may not always be possible, even when all possible supports are provided.’ Martin et al, *Three Jurisdictions Report* (n 9) 37; ‘A more common interpretation, supported by most States Parties, is that certain or all situations necessitate substitute rather than supportive decision-making.’ Kjersti Skarstad, ‘Ensuring Human Rights for Persons with Intellectual Disabilities?’ (2018) 22(6) *International Journal of Human Rights* 774, 777; ‘The position taken by the Committee on the issue of legal capacity is a challenge for common sense’ in Silvana Galderisi, ‘The UN Convention on the Rights of Persons with Disabilities: Great Opportunities and Dangerous Interpretations’ (2019) 18(1) *World Psychiatry* 47, 47.

²³ Skarstad suggests that autonomy in a descriptive sense is not necessary for personhood or for claiming human rights because ‘By focusing on the process or act of just treatment, human rights can include all persons on equal terms’ in Kjersti Skarstad, ‘Human Rights through the Lens of Disability’ (2018) 36(1) *Netherlands Quarterly of Human Rights* 24, 40; Nussbaum proposed dignity as the foundation for moral personhood in various writings including Martha Nussbaum, *Creating Capabilities: The Human Development Approach* (Harvard University Press, 2011); Kittay proposes an ethics of care as an inclusive foundation for moral personhood in, for example, Licia Carlson and Eva Feder Kittay, ‘Introduction: Rethinking Philosophical Presumptions in the Light of Cognitive Disability’ (2009) 40(3–4) *Metaphilosophy* 307; Bilchitz proposes dignity as either ‘the capacity of individuals to have a conscious experience of the world ...’ or ‘the ability of individuals to develop purposes and to seek to achieve them’: in David Bilchitz, ‘Dignity, Fundamental Rights and Legal Capacity: Moving beyond the Paradigm Set by the General Comment on Article 12 of the Convention on the Rights of Persons with Disabilities’ (2016) 32(3) *South African Journal on Human Rights* 410, 430–31; Hall proposes vulnerability as the foundation for moral personhood in Margaret Isabel Hall, ‘Mental Capacity in the (Civil) Law: Capacity, Autonomy, and Vulnerability’ (2012) 58(1) *McGill Law Journal – Revue de Droit de McGill* 61.

²⁴ ‘A representative may override the person’s will and preferences only where necessary to prevent harm’: ALRC (n 9) 13; Martin et al endorse a functional capacity test and decision-making by substitutes when the aim of fostering autonomy conflicts with protecting life or ensuring protection and safety, in Wayne Martin et al, *Achieving CRPD Compliance: Is the Mental Capacity Act of England and Wales Compatible with the UN Convention on the*

considered differently for adults with cognitive disability.²⁵ All of these arguments are considered at various points in the book.

I argue that autonomy is one very valuable good amongst others for those who are capable of autonomy. However, for adults who are not capable of decision-making autonomy (even with support), we can still respect their personhood through respecting their human dignity. If we respond to them through the lens of substantive ‘inclusive equality’, then decision-making by a substitute as a last resort will not violate human rights but may actually be required in order to uphold them.

1.3 *An Overview of the Argument*

The book makes the argument that Article 12 requires both supported decision-making *and* decision-making by substitutes as a last resort. It does this by using a human rights framework that recognises the principle of indivisibility to interpret Article 12 as:

- (1) refashioning liberal autonomy from non-interference to a process of achieving autonomy or developing autonomy competencies, and incorporating a demand for the provision of real options;
- (2) underpinned by a concept of personhood based on dignity as inclusive of people with a cognitive disability, rather than on autonomy as rationality, which is inevitably exclusive; and
- (3) acknowledging that the difference of cognitive disability allows for differential treatment in the form of supported decision-making and also decision-making by substitutes to achieve non-discrimination and what the UN Disability Committee has itself described as ‘inclusive equality’.²⁶

Rights of Persons with Disabilities? If Not, What Next? (Essex Autonomy Project, 2014) 19; Jeanne Snelling and Alison Douglass, ‘Legal Capacity and Supported Decision-Making’ in Iris Reuecamp and John Dawson (eds), *Mental Capacity Law in New Zealand* (Thomson Reuters, 2019) 163, 172.

²⁵ Martin et al, *Achieving CRPD Compliance* (n 24) 14–26; ‘Moreover, these errors reveal the Committee’s flawed conception of discrimination.’ In John Dawson, ‘A Realistic Approach to Assessing Mental Health Laws’ Compliance with the UNCRPD’ (2015) 40 *International Journal of Law and Psychiatry* 70, 73; Katrine Del Villar, ‘Should Supported Decision-Making Replace Substituted Decision-Making? The Convention on the Rights of Persons with Disabilities and Coercive Treatment under Queensland’s Mental Health Act 2000’ (2015) 4(2) *Laws* 173, 183; Anita Smith, ‘Are Guardianship Laws and Practices Consistent with Human Rights Instruments?’ in A Kimberly Dayton (ed), *Comparative Perspectives on Adult Guardianship* (Carolina Academic Press, 2014) 247, 264.

²⁶ Committee on the Rights of Persons with Disabilities, *General Comment No 6: On Equality and Non-Discrimination*, UN Doc CRPD/C/GC/6 (26 April 2018) (‘General Comment No 6’).

1.3.1 The Principle of Indivisibility

The principle of indivisibility is investigated and described in Chapter 3 as requiring recognition of:

- (1) the interdependency of human rights, both between the two categories of civil-political rights and socio-economic human rights, and between individual rights within or across those categories; and
- (2) the equal importance of socio-economic with civil-political human rights.

Civil rights are traditionally associated with negative state action (or restraint), protecting personal life from state interference. They are presumed to be cost-free, capable of being implemented immediately and are justiciable. Socio-economic rights are, on the other hand, traditionally framed as requiring positive state actions, intervention in the personal sphere, intensive resources, progressive realisation and as non-justiciable.²⁷ The principle of indivisibility recognises that these ostensible differences between the two categories of rights are far from clear-cut and are frequently overstated.²⁸

The principle of indivisibility has been chosen as the central and coherent organising concept for the book's argument. This is because, as referenced in the literature, the CRPD, more than any other convention, embodies the indivisibility, interdependence and interrelatedness of human rights.²⁹ It is the only convention to have a statement of indivisibility in its Preamble,³⁰ and it includes civil-political and socio-economic rights not just within the one convention but within the same articles.³¹ It demands that Article 12 be interpreted in the context of the whole of the CRPD in a way that is consistent with the convention in its entirety.

1.3.2 Autonomy, Dignity and Equality

Both the right to legal capacity and the right to equality expressed in Article 12 (i.e. the right 'to enjoy legal capacity on an equal basis with others') are traditionally

²⁷ Kristin Henrard, 'Introduction: The Justiciability of ESC Rights and the Interdependence of all Fundamental Rights' (2009) 2(4) *Erasmus Law Review* 373, 373.

²⁸ *Ibid* 373–34.

²⁹ Janet E Lord, 'Preamble' in Ilias Bantekas, Michael Ashley Stein and Dēmētrēs Anastasiou (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 1, 11; Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities* (n 5) 19; Arlene S Kanter, *The Development of Disability Rights under International Law from Charity to Human Rights* (Routledge, 2015) 9; Ida Elizabeth Koch, 'From Invisibility to Indivisibility: The International Convention on the Rights of Persons with Disabilities' in Oddný Mjöll Arnadóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Nijhoff, 2009) 67, 77; Gauthier DeBeco, 'The Indivisibility of Human Rights and the Convention on the Rights of Persons with Disabilities' (2019) 68 (January) *International and Comparative Law Quarterly* 141; Michael Ashley Stein, 'Disability Human Rights' (2007) 95(1) *California Law Review* 75, 77–79.

³⁰ 'Reaffirming the universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms ...' CRPD Preamble para 3; DeBeco (n 29) 149.

³¹ Koch, 'From Invisibility to Indivisibility' (n 29) 77; DeBeco (n 29) 149–51.

categorised as civil–political rights.³² The principle of indivisibility demands both recognition of the interdependence of rights and acknowledgement that socio-economic rights are as important as civil–political rights. I argue, therefore, that indivisibility (as applied to Article 12) leads to the disruption of the hegemony of the right to legal capacity over other rights, autonomy (as the basis for personhood) over other values (including dignity), and formal over substantive equality.

First, this disruption allows for recognition that achievement of the civil–political rights of legal capacity (or autonomy) and equality may depend on fulfilling socio-economic rights. It further recognises that autonomy for adults with cognitive disability is more than the right to non-interference. Second, it recognises that equality is achieved not just by restraint from the state but sometimes by positive, differential treatment in the form of supported decision-making or decision-making by substitutes. Third, it recognises that personhood is not just located in the abstraction of rationality but is inter-relational and embodied. I draw on philosophical and legal literature and jurisprudence to argue for a concept of dignity (instead of autonomy) to underpin Article 12 personhood. I argue that this ‘five-dimensional’ concept of human dignity, infused as it is with the principle of indivisibility, underpins the CRPD and Article 12.

This book focuses on the values of, or rights to, autonomy, dignity and equality for reasons explained in Chapters 4, 5 and 6, respectively. Overarching these explanations is the fact that the text of the CRPD itself places particular emphasis on these three values as being fundamental to disability human rights. Specifically, Article 12 is explained widely in the literature as upholding autonomy and often as asserting a right to *equal* autonomy. Further, the right to legal capacity is frequently described as respecting human dignity as the ‘dignity of risk’.³³ This book examines how the case of cognitive disability denies a simplistic understanding of these central concepts as they have developed and been applied in the liberal tradition.

2 A NOTE ON TERMINOLOGY AND CONCEPTS

Morris observes how writing and speaking in disability studies is fraught with complexity ‘because non-disabled people have had ... “absolute power” over narrative when it comes to the representation of impairment ...’.³⁴ In this context, I have settled on using the following terms.

³² *General Comment No 1* [30].

³³ ALRC (n 9) 75; Suzanne Doyle and Eilionóir Flynn, ‘Ireland’s Ratification of the UN Convention on the Rights of Persons with Disabilities: Challenges and Opportunities’ (2013) 41(3) *British Journal of Learning Disabilities* 171, 174. For further discussion on the ‘dignity of risk’, see Chapter 2, Sections 3.2.2 and 3.3.2, and Chapter 5, Sections 3.2.1 and 4.1.

³⁴ Jenny Morris, ‘Impairment and Disability: Constructing an Ethics of Care that Promotes Human Rights’ (2001) 16(4) *Hypatia* 1, 6; note also that ‘disabled people’ is the language favoured by British theorists because according to the social model of disability ‘Disabled people are those people with impairments who are disabled by society’: *Ibid* 2.

2.1 'Cognitive Disability'

I use the umbrella term 'cognitive disability'³⁵ to describe impairments in adults associated with intellectual disability, acquired brain injury, age-related dementia³⁶ and mental illness. For the term 'intellectual disability', I rely on the definition provided by the American Association of Intellectual and Developmental Disabilities as: 'a disability characterised by significant limitations in both intellectual functioning and in adaptive behaviour, which covers many everyday social and practical skills [and which] originates before the age of 18'.³⁷ The term 'mental illness' is chosen because it reflects the language used predominantly in legislation relating to involuntary treatment.³⁸

Many adults will have cognitive disability associated with more than one of these conditions, but these categorisations are still used widely. While to an extent these labels or 'diagnoses' reflect a much-criticised 'medical' model of disability, of which I write further in Chapter 2,³⁹ they also indicate broadly different individual, social and legal circumstances embodied in and around the person.

2.2 'Impairment' and 'Disability'

The terms 'impairment' and 'disability' have attracted particular and distinct meanings in the commentary. As explained in Chapter 2, the social model of disability

³⁵ The terminology used takes account of the approach of the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission'): "This report uses the singular term "disability" rather than the plural "disabilities" to adhere to the human rights model of disability ... and uses the more common term "people" instead of the specific legal use of "persons" used in the CRPD" in Kayess and Sands (n 6) 49.

³⁶ Cahill notes that although the CRPD uses the terms 'mental' and 'intellectual' impairment in Article 1, she recommends a change of wording to include 'cognitive' to recognise dementia more squarely: Suzanne Cahill, *Dementia and Human Rights* (Policy Press at the University of Bristol, 2018) 49; Article 1 [2] provides that 'Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

³⁷ Website of the American Association on Intellectual and Developmental Disabilities <https://aaid.org/intellectual-disability/definition>, retrieved 17 September 2018. Used in Devi (n 5) 794. An alternative definition is used by Bach and Kerzner, that is, 'generally means having greater difficulty than most people with intellectual and adaptive functioning due to a long term condition that is present at birth or before the age of eighteen': Bach and Kerzner (n 5) 14.

³⁸ See, for example, *Mental Health Act 2016 (Qld)* s 10(1), *Mental Health Act (Vic)* s 4(1). Note that the CRPD refers to 'mental impairment': Article 1; the World Network of the Users and Survivors of Psychiatry uses 'psychosocial disability': World Network of Users and Survivors of Psychiatry, 'Implementation Manual for the United Nations Convention on the Rights of Persons with Disabilities' (February 2008) www.wnusp.net/documents/WNUSP_CRPD_Manual.pdf; but that this terminology is not universally adopted: Anne Plumb, 'UN Convention on the Rights of Persons with Disabilities: Out of the Frying Pan into the Fire? Mental Health Service Users and Survivors Aligning with the Disability Movement' in Helen Spandler et al (eds), *Madness, Distress and the Politics of Disablement* (Bristol University Press, 2015) 183, 184.

³⁹ See Chapter 2, Section 2.2.

makes a distinction between them. In short, the social model frames disability as being caused by the failure of society to accommodate an individual's impairment.⁴⁰ However, in Chapter 2, I also explain how the interpretation of Article 12 presented in this book is premised on acceptance of a critique of the social model of disability that questions the basis of the distinction between these two concepts.⁴¹ For these reasons, I use the words 'impairment' and 'disability' largely interchangeably, except where the context requires or implies otherwise – for example, when describing or critiquing the social model of disability and related commentary.

2.3 'Legal Capacity'

'Legal capacity' is not defined in the CRPD, thereby contributing to the interpretive contention around Article 12. But in *Equality, Capacity and Disability in Commonwealth Laws: A Final Report* ('the ALRC Report'), the Australian Law Reform Commission ('ALRC') provides usefully that:

Capacity in a general sense refers to decision-making ability ...; Legal capacity sets the threshold for individuals to take certain actions that have legal consequences ... [and] ... Legal capacity goes to the validity, in law, of choices and being accountable for the choices made.⁴²

The significance of the concept of legal capacity for adults with cognitive disability is that where an adult lacks capacity to make legally enforceable decisions (or has impaired capacity), a substitute may in some cases make a decision or decisions on the adult's behalf.⁴³

2.4 'Decision-Making by a Substitute'

Much of the debate around Article 12 has been complicated and confused by different understandings of the terminology used to describe decision-making by substitutes for an adult with impaired capacity.⁴⁴ In 2014, the UN Disability Committee published its General Comment No 1 Article 12: Equal Recognition before the Law ('General Comment No 1'), explaining its interpretation of Article 12. However, the definition it contained of 'substitute decision-making', was later made subject to a corrigendum, the status of which is unclear, adding yet more confusion.⁴⁵ The

⁴⁰ See Chapter 2, Section 2.3. See also Kayess and Sands (n 6) 33.

⁴¹ See Chapter 2, Section 2.4.

⁴² ALRC (n 9) 44.

⁴³ See Chapter 2, Section 3.2, for a description of the different capacity tests.

⁴⁴ *Ibid* 52; Series and Nilsson (n 18) 347.

⁴⁵ Committee on the Rights of Persons with Disabilities, *General Comment No 1 (2014) Article 12: Equal Recognition before the Law, Corrigendum*, 11th sess, UN Doc CRPD/C/GC/1.Corr.1 (26 January 2018). See further Chapter 2, Section 4.1 including footnotes.

UN Disability Committee generally uses the terms ‘guardianship’ and ‘substitute decision-making’.⁴⁶ In other contexts, the terms ‘surrogates’⁴⁷ or ‘representatives’⁴⁸ may be used to include: guardians who make decisions for personal matters;⁴⁹ administrators⁵⁰ and managers⁵¹ who make financial decisions; and clinicians who may make decisions for adults relating to mental health treatment.⁵² The *Mental Capacity Act 2005* (England and Wales) (‘MCA’) uses the term ‘deputy’ to describe a substitute appointed to make decisions on financial or personal matters.⁵³

In an attempt to find some clarity, this book uses the term ‘decision-making by a substitute’ to refer to decisions made by a second person for an adult with impaired capacity, where the decision is legally recognised as having been made by the second person rather than the adult.⁵⁴ Unless the context demands otherwise, this would include decisions by all those types of decision-makers referred to above. The more specific terms are used in the context of particular situations, legislation or commentary.

2.5 ‘Supported Decision-Making’

Article 12(3) provides that States shall provide for people with disabilities, ‘the support they may require in exercising their legal capacity’. Chapter 2 surveys the historical and ongoing development of various practices of providing support for an adult to exercise legal capacity to make their own decisions.⁵⁵ It shows that there is no universal consensus on what the practice entails, or where the line should be drawn between supported decision-making and substitute decision-making. Different terms including ‘assisted decision-making’, ‘support for decision-making’

⁴⁶ *General Comment No 1*.

⁴⁷ Allen Buchanan and Dan W Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge University Press, 1989).

⁴⁸ ALRC (n 9).

⁴⁹ Legislation in Australian jurisdictions tends to make a distinction between a ‘guardian’ and ‘administrator’ as indicated; for example, *Guardianship and Administration Act 2000* (Qld) (‘GAA Qld’) sch 4, Dictionary.

⁵⁰ For example, *Guardianship and Administration Act 2019* (Vic) (‘GAA Vic’) pt 3 provides for guardianship orders for personal matters and administration orders for financial matters.

⁵¹ For example, *Guardianship Act 1987* (NSW) (‘GA NSW’) pt 3A provides for managers to be appointed under ‘Financial management orders’.

⁵² For involuntary mental health treatment, see White, McDonald and Willmott (n 3) 735, 743–50.

⁵³ Section 16.

⁵⁴ Note that although legislation recognises that the decision is made by the guardian, it also provides that the decision has an effect against third parties as if it were made by the adult. For example, s 38(3) GAA Vic (n 50) provides that: ‘(3) A decision made, action taken, consent given or thing done by a guardian under a guardianship order has effect as if it were made, taken, given or done by the represented person and the represented person had decision-making capacity for the matter in relation to which the order was made.’

⁵⁵ See Chapter 2, Sections 3.4, 4.1.3 and 4.1.4.

and ‘supported decision-making’ all have some currency.⁵⁶ The Law Commission of England and Wales usefully provides that ‘Supported decision-making refers to the process of providing support to a person whose decision-making ability is impaired, to enable them to make their own decisions wherever possible’.⁵⁷ The term ‘supported decision-making’ is used in this book to refer to this collection of informal and formal practices.

3 THE CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES

In using the principle of indivisibility to understand and interpret Article 12, this book examines the right to legal capacity in the context of the whole of the CRPD. The CRPD and the Article 12 literature are in turn situated in the broader context of the development of disability policy and human rights – a history that has shaped the text of the convention as well as the interpretations surrounding it. This section briefly describes this history of the CRPD’s development, which is further elaborated on in later chapters, especially Chapter 3, in its explanation of the principle of indivisibility.

3.1 *Development of Human Rights Instruments for People with Disability*

Historically, disability was not referred to as a human rights issue, reflecting the social, political and legal exclusion of people with disability.⁵⁸ Gradually, non-binding human rights instruments began to recognise people with disability as attracting specific claims to human rights, culminating in the 2006 adoption of the CRPD, which signalled formal inclusion of people with disability on the human rights agenda.

The two foundational UN human rights conventions – the International Covenant on Civil and Political Rights (‘ICCPR’)⁵⁹ and the International Covenant on Economic Social and Cultural Rights (‘ICESCR’)⁶⁰ – both expressly apply to ‘all

⁵⁶ Then refers to terminology including ‘assisted decision-making also known as supported, interdependent or co-decision-making’. In Shih-Ning Then, ‘Evolution and Innovation in Guardianship Laws: Assisted Decision-Making’ (2013) 35(1) *Sydney Law Review* 133, 134.

⁵⁷ Law Commission, *Mental Capacity and Deprivation of Liberty* (Report No 372, 2017) 167.

⁵⁸ Theresia Degener and Andrew Begg, ‘From Invisible Citizens to Agents of Change: A Short History of the Struggle for the Recognition of the Rights of Persons with Disabilities at the United Nations’ in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer International Publishing, 2017) 1, 2–15.

⁵⁹ ICCPR, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976).

⁶⁰ ICESCR, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976).

members of the human family',⁶¹ thereby including people with disability. However, the prohibited grounds of discrimination list (inclusively) '...race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status'.⁶² The omission of disability from this list meant that disability was implicitly or arguably included in the catch-all of 'other status'.⁶³

Beginning in the 1970s, the UN began to develop non-binding instruments that acknowledged the human rights of people with disability. In 1971, the UN adopted the 'Declaration on the Rights of Retarded Persons' ('1971 Declaration')⁶⁴ and in 1975 the 'Declaration on the Rights of Disabled Persons' ('1975 Declaration').⁶⁵ The 1971 Declaration specifically provides that it may be 'necessary to restrict or deny'⁶⁶ some human rights of persons with cognitive disability provided that legal safeguards are put in place to prevent abuse. Rather than view guardianship as a potential tool of human rights abuse, the 1971 Declaration included a 'right to a qualified guardian'.⁶⁷ The 1975 Declaration uses the language of paternalism rather than human rights when it defines a 'disabled person' as 'any person unable to ensure by himself or herself, wholly or partly, the necessities of a normal individual and/or social life, as a result of deficiency, either congenital or not, in his or her physical or mental capabilities'.⁶⁸

Increasing recognition of the human rights of people with disability led in 1981 to the UN declaring the International Year of Disabled Persons, which also launched the United Nations World Programme of Action Concerning Disabled Persons.⁶⁹ These were followed by the adoption in 1993 of the 'Standard Rules

⁶¹ ICCPR (n 59) Preamble para 2; ICESCR (n 60) Preamble para 2.

⁶² ICCPR (n 59) Article 2(1); ICESCR (n 60) Article 2(1).

⁶³ Moreover, the requirement contained in Article 2 (2) of the Covenant that the rights 'enunciated ... will be exercised without discrimination of any kind' based on certain specified grounds 'or other status' clearly applies to discrimination on the grounds of disability'. Committee on Economic Social and Cultural Rights, *General Comment 5: Persons with Disabilities*, 11th sess (9 December 1994) ('ESCR General Comment No 5'). It was not until the adoption of the UN Convention on the Rights of the Child in 1989 that discrimination based on disability was expressly articulated in a UN treaty as a violation of human rights. *Convention on the Rights of the Child*, opened for signature 29 November 1989, 1577 UNTS 11 (entered into force 2 September 1990) ('CRC'). Article 2(1).

⁶⁴ 1971 Declaration, proclaimed by General Assembly resolution 2856 (XXVI) (20 December 1971).

⁶⁵ 1975 Declaration, UN Doc GA, Res, 3447 (XXX), at 88, UN GAOR, Supp, No 34, UN Doc, A/10034 (9 December 1975).

⁶⁶ 1971 Declaration (n 64) [7].

⁶⁷ *Ibid* [5].

⁶⁸ 1975 Declaration (n 65) [1]; 'the 1971 Declaration on the Rights of Mentally Retarded Persons and the 1975 Declaration on the Rights of Disabled Persons – did state that persons with disability are subjects of international human rights law, but did this largely within the context of the medical model of disability': Kayess and Sands (n 6) 8. The language of 'deficiency' also embodies the much criticised 'medical model' of disability: see Chapter 2, Section 2.2.

⁶⁹ United Nations, General Assembly, *World Programme of Action Concerning Disabled Persons*, GA Res 37/52, UN Doc A/RES/37/52 (3 December 1982)

on the Equalisation of Opportunities for Persons with Disabilities’ (‘the Standard Rules’),⁷⁰ which are referred to in the CRPD’s Preamble⁷¹ and which have been described as having a ‘significant impact on the emergence of disability-based anti-discrimination legislation in many countries around the globe’.⁷²

3.2 *Inclusion of People with Disability in the Development of the CRPD*

On 12 March 2000, the ‘World NGO Summit on Disability’ meeting in Beijing made a declaration (‘the Beijing Declaration’), urging that:

people with diverse disabilities and their organizations, and other civic organizations, local and national governments, members of the United Nations system and other inter-governmental bodies, as well as the private sector, ... collaborate closely in an inclusive and wide consultative process aimed at the development and adoption of an international convention to promote and protect the rights of people with disabilities, and enhance equal opportunities for participation in mainstream society.⁷³

By resolution on 19 December 2001 the United Nations (‘UN’) General Assembly established an ‘Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities’ (‘the Ad Hoc Committee’).⁷⁴ As urged by the Beijing Declaration, collaboration and consultation were considered key to the development of what became the CRPD, and it has indeed been lauded as the first UN treaty to be negotiated directly with civil society organisations.⁷⁵ In the past, such organisations had made known their views through States parties. However, in the case of the CRPD, given the historical social and political exclusion of those with disability, it

⁷⁰ *Standard Rules*, 48th sess, UN Doc A/RES/48/96 (4 March 1994).

⁷¹ Preamble para 6.

⁷² Degener and Begg (n 58) 9.

⁷³ *Beijing Declaration on Disabled Persons in the New Millennium*, World NGO Summit on Disability (12 March 2000); Anna Lawson, ‘The United Nations Convention on the Rights of Persons with Disabilities: New Era or False Dawn?’ (2007) 34(2) *Syracuse International Journal of Law and Commerce* 563, 586.

⁷⁴ Comprehensive and integral international convention to promote and protect the rights and dignity of persons with disabilities, UN Doc A/Res/56/168 (19 December 2001).

⁷⁵ See, for example, Barbara Carter, ‘Seeking the Essence of Guardianship: Beyond the United Nations Convention on the Rights of Persons with Disabilities’ (Conference Paper, World Guardianship Congress, 15–16 October 2012) 1 <https://agac.org.au/conference-papers/72-2012-oct-2nd-world-congress-melbourne>; Kayess and Fogarty (n 12) 22; World Network of Users and Survivors of Psychiatry (n 38) 4–5; Sarah Arduin, ‘Article 3: General Principles’ in Ilias Bantekas, Michael Ashley Stein and Anastasiou Dimitris (eds), *The UN Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford University Press, 2018) 85, 97; Rosemary Kayess and Philip French, ‘Out of Darkness into Light? Introducing the Convention on the Rights of Persons with Disabilities’ (2008) 8(1) *Human Rights Law Review* 1, 3–4.

was considered of paramount importance that their voices be heard directly in negotiations, reflecting what had become the slogan of the disability movement: ‘nothing about us, without us’.⁷⁶ The CRPD was to become a convention developed by people with disability *for* people with disability as subjects and claimants of human rights.⁷⁷ Their autonomy, personhood and equality were recognised in the drafting process itself.

3.3 A Disability-Specific Convention

In 2002, the year following the formation of the Ad Hoc Committee, the UN High Commissioner on Human Rights released a report titled *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instrument in the Context of Disability* (‘the 2002 Report’).⁷⁸ The 2002 Report conceives the then-proposed disability-specific treaty as underpinning the existing conventions by particularising human rights norms in the context of disability in a binding instrument.⁷⁹ Reflecting these beginnings, the UN Disability Committee has affirmed that the CRPD does not create new rights but is to be articulated as interpreting pre-existing rights. Nevertheless, several commentators have queried whether this is, in fact, the case, or whether the CRPD has actually created new rights, including those expressed in Article 12.⁸⁰

During the drafting of the CRPD, there had been some discussion as to whether a narrow, non-discrimination approach, such as that in the *International Convention on the Elimination of All Forms of Racial Discrimination* (‘CERD’)⁸¹ and the *Convention on the Elimination of All Forms of Discrimination against Women* (‘CEDAW’),⁸² should be adopted. The alternative proposal was for a broader,

⁷⁶ McCallum (n 6) 156.

⁷⁷ The ongoing participation of those with disability in the review and monitoring of the CRPD is also ensured by Articles 33 and 34. Article 33 provides that ‘Civil society, in particular persons with disabilities and their representative organisations, shall be involved and participate fully in the monitoring process’. Article 34 provides that when nominating members of the UN Disability Committee to oversee and monitor the CRPD, States Parties shall give consideration to ‘the participation of experts with disabilities’.

⁷⁸ Gerard Quinn and Theresia Degener, *Human Rights and Disability: The Current Use and Future Potential of United Nations Human Rights Instruments in the Context of Disability* (United Nations, 2002).

⁷⁹ *Ibid* 294–95.

⁸⁰ Kayess and French (n 75) 32; María Soledad Cisternas Reyes, ‘Foreword’ in Valentina Della Fina (ed), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017) v; Elif Celik, ‘The Role of CRPD in Rethinking the Subject of Human Rights’ (2017) 21(7) *The International Journal of Human Rights* 933, 935.

⁸¹ CERD, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969).

⁸² CEDAW, opened for signature 1 March 1980, 1249 UNTS 8 (entered into force 3 September 1981).

comprehensive rights approach modelled on the United Nations *Convention on the Rights of the Child* ('CRC').⁸³ The travaux préparatoires indicate that the Ad Hoc Committee ultimately decided on the CRC model and drafted a comprehensive convention expressing the full range of human rights. They further indicate that paragraph 3 of the CRPD's Preamble, which recognises the 'universality, indivisibility, interdependence and interrelatedness of all human rights and fundamental freedoms', was inserted in recognition of this approach.⁸⁴ This broader, comprehensive approach means that the principle of indivisibility is particularly prominent in the text of the convention,⁸⁵ and also (as explained in Chapter 6) that it embraces a broad concept of substantive equality.

In summary, the CRPD was the first stand-alone, binding human rights instrument that dealt wholly with disability rights. From their invisibility in the category of 'other status' in the ICCPR and ICESCR, people with disability came to be included as subjects of rights, and their autonomous personhood was respected in the drafting process itself. The CRPD was intended to achieve not just non-discrimination for people with disability but inclusion as people with substantive equality.

3.4 *The Drafting of Article 12: A 'Flashpoint'*

The CRPD – and Article 12, in particular – has been referred to as representing and effecting a 'paradigm shift' in disability human rights.⁸⁶ During the drafting process, Australia was one of many States acknowledging this paradigm shift to supported decision-making away from substitute decision-making. The Australian delegate described Article 12 as providing: '...the seeds for an important paradigm shift by giving primacy to supported decision making ... [and] continues that shift by providing for personal representation only as a last resort'.⁸⁷ However, many of the civil society organisations involved in drafting considered that the 'paradigm shift' of supported decision-making needed to be more radical. As drafting progressed, these organisations had formed a coalition – the International Disability Caucus ('IDC') – whose representative said that:

Substituted decision making is based on the premise of incompetence and must not be legitimized. Supported decision making is based on the premise of

⁸³ CRC (n 63).

⁸⁴ Degener and Begg (n 58) 13.

⁸⁵ See Chapter 3, Section 5.

⁸⁶ Quinn (n 20) 12; Quinn and Arstein-Kerslake (n 5) 44; ALRC (n 9) 24; 23; Amita Dhanda, 'Constructing a New Human Rights Lexicon: Convention on the Rights of Persons with Disabilities' (2008) 8 *Sur – Revista Internacional de Direitos Humanos* 43, 45; Bach and Kerzner (n 5).

⁸⁷ Ad Hoc Committee, *Daily Summary of the Seventh Session: Discussions Related to Article 12 Equal Recognition as a Person before the Law (continued)* (18 January 2006) www.un.org/esa/socdev/enable/rights/ahc7sum18jan.htm Ad Hoc Committee ('Daily Summary 18 January 2006').

competence. The two cannot exist together and successfully achieve the paradigm shift desired.... Addressing states' concerns for safeguards for guardianships and worrying about implementation does not promote the paradigm shift but reinforces the traditional abusive systems.⁸⁸

As stated above following ratification of the CRPD, the UN Disability Committee's *General Comment No 1* was published in 2014. It adopted an interpretation effectively supporting the IDC's view that adults with cognitive disability have their legal capacity recognised, their will and preferences given effect to, and their autonomy preserved.⁸⁹ Many commentators, both before and after *General Comment No 1*'s publication, have expressed strong endorsement of the interpretation it prescribes.⁹⁰ Others have continued to pursue some of the counter arguments raised during drafting. These include that decision-making by substitutes is required as a safeguard⁹¹ and that implementing supported decision-making for all adults with cognitive disability has unresolvable challenges in implementation.⁹²

While all parties agree that *General Comment No 1* is not technically binding, it is also widely agreed that it has significant normative force.⁹³ In particular, under the CRPD, the UN Disability Committee has responsibility for monitoring states' compliance with the convention. It does this by considering States' reports⁹⁴ as well as through hearing and considering 'communications' or complaints of human rights violations.⁹⁵ As a result of both of these processes, the UN Disability Committee can make suggestions or recommendations for compliance, and will be guided by its own General Comments in doing so.⁹⁶ States' parties compliance (or non-compliance) with *General Comment No 1* will continue to be monitored as a critical issue.

While this book agrees that a paradigm shift is needed, it argues that recognition of universal legal capacity may actually serve to perpetuate the old paradigms. The

⁸⁸ Ibid.

⁸⁹ *General Comment No 1*.

⁹⁰ Minkowitz, 'Legal Capacity' (n 5); International Disability Alliance (n 5); Morrissey (n 5); Dhanda, 'Legal Capacity in the Disability Rights Convention' (n 5); Quinn and Arstein-Kerslake (n 5); Flynn and Arstein-Kerslake, 'The Support Model of Legal Capacity' (n 5); Bach and Kerzner (n 5); Devi (n 5); de Bhailis and Flynn (n 5) Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities* (n 5); Glen, 'Changing Paradigms' (n 5).

⁹¹ Nicholas Caivano, 'Conceptualizing Capacity: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention' (2014) 4(1) *Western Journal of Legal Studies* 1, 23. See also Chapter 2, Section 4.2.4.

⁹² See criticisms of the 'best interpretation' principle in Chapter 2, Section 4.2.5.

⁹³ Martin et al, *Three Jurisdictions Report* (n 9) 56.

⁹⁴ See Articles 34 and 35.

⁹⁵ *Optional Protocol to the Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2518 UNTS 283 (entered into force 3 May 2008) Article 1.

⁹⁶ See for example where the UN Disability Committee has referred to several of its General Comments, including General Comment No 1 in: Committee on the Rights of Persons with Disabilities, *Concluding Observations on the Combined Second and Third Period Reports of Australia*, UN Doc CRPD/C/AUS/CO/2-3.

continued privileging of autonomy as the basis for personhood may only serve to further embed existing stigmatisation of adults who lack decision-making autonomy.⁹⁷ I further argue that a conception of equality that demands all adults with severe cognitive disability be treated the same ‘as others’ in the area of decision-making will fail to achieve substantive, inclusive equality.⁹⁸

4 RESEARCH METHOD AND SCOPE

4.1 *Doctrinal and Theoretical Analysis and Research*

The book uses legal doctrine and legal and philosophical theory to answer the central question of how Article 12 can be interpreted to require both supported decision-making and decision-making by substitutes as a last resort in order to uphold the human rights of adults with cognitive disability. Legal doctrine is drawn upon first to describe key legal concepts in guardianship, decision-making by substitutes and supported decision-making and to provide context for the interpretation and application of Article 12. The book refers to human rights law and doctrine, so as to describe and explain the principle of indivisibility. It further describes, analyses and applies the CRPD and Article 12 through reference to General Comments and other publications and decisions of UN committees. It also reviews cross-jurisdictional jurisprudence, which considers the role and meaning of dignity as a legal value or principle.

Some reliance is placed on the *Vienna Convention on the Law of Treaties* (‘VCLT’).⁹⁹ Article 31 provides a general rule that a treaty is to be interpreted ‘within the ordinary meaning to be given the terms of the treaty in their context and in the light of its object and purpose’¹⁰⁰ including its Preamble.¹⁰¹ Article 32 VCLT further provides that when the meaning of a provision is ‘ambiguous or obscure’, recourse can be made to the ‘preparatory work of the treaty and the circumstances of its conclusion’ to aid interpretation.¹⁰²

The book also includes a substantial theoretical research component, in describing, reviewing, analysing and critiquing the literature in law and philosophy relating to the central concepts of disability, human rights, autonomy, dignity and equality.

⁹⁷ See Chapter 4, Sections 4.1 and 4.6.

⁹⁸ See Chapter 6.

⁹⁹ Opened for signature 18 December 1979, 1155 UNTS 331 (entered into force 27 January 1980).

¹⁰⁰ *Ibid* Article 31(1).

¹⁰¹ *Ibid* Article 31(2).

¹⁰² ‘Recourse may be had to supplementary means of interpretation, including the preparatory work of the treaty and the circumstances of its conclusion, to confirm the meaning resulting from the application of Article 31, or to determine the meaning when the interpretation according to Article 31 (a) leaves the meaning ambiguous or obscure; or (b) leads to a result which is manifestly absurd or unreasonable.’

The research is cross-disciplinary, referring to the work of lawyers, philosophers, psychologists and sociologists, many of whom have written on Article 12 directly, as well as on the human rights values and concepts on which it is founded.

4.2 Scope

The focus of this book is on how Article 12 can be interpreted as allowing for decision-making by substitutes, arguing that such decision-making can actually uphold human rights. Its focus is not on the latest developments in supported decision-making. Rather, it examines the principles and values underpinning supported decision-making to the extent required to explain how autonomy, dignity and equality are theorised and applied across decision-making by, with and for adults with cognitive disability.

I wish to clarify that there are several other extremely important areas of investigation that are nevertheless beyond this book's scope. Chapter 2 describes the different decision-making principles used by substitutes – that is, 'best interests'¹⁰³ or adopting the adult's 'will and preferences'.¹⁰⁴ The argument in this book for the retention of decision-making by substitutes as a last resort assumes that such decisions will take account of an adult's will and preferences and that there will be time and domain limits on the appointments of substitutes.¹⁰⁵ The book contributes to the development of those principles by anticipating that the adult's full range of indivisible human rights will be considered when a substitute makes a decision. However, it does not investigate the challenging and important question of how rights are to be balanced, whether through the principle of proportionality¹⁰⁶ or otherwise, in any particular case.

Also beyond scope of this book is how decisions by substitutes are implemented. The book's argument assumes that once decisions are made (whether supported or by a substitute), goods and services must be provided to adults in ways that respect their personhood, ensure their social inclusion and uphold their rights. Important considerations of modes and methods of service delivery are beyond scope.

Decision-making by a substitute may occur when an adult's capacity is impaired, whether such impairment is associated with intellectual disability, acquired brain injury, dementia or mental illness. The literature referenced in the book includes consideration of how Article 12 applies in decision-making practices in all of the

¹⁰³ See Chapter 2, Section 3.3.1.

¹⁰⁴ Also referred to as 'substituted judgement'. See Chapter 2, Section 3.3.2.

¹⁰⁵ Chapter 2, Section 4.2.3.

¹⁰⁶ 'The principle of proportionality is the means by which a court or tribunal applying international human rights law determines whether a particular restriction on a human right is a justified restriction ...': Justice Virginia Bell, 'Equality, Proportionality and Dignity: The Guiding Principles for a Just Legal System' (2017) 42(1) *Alternative Law Journal* 4, 5.

above cases. However, the case studies chosen are related to guardianship and don't include cases of involuntary treatment for mental illness. This is because of the significant amount of controversy and disagreement over which mental health treatments are effective and justified, quite apart from whether they are provided voluntarily or at the direction of a substitute decision-maker.¹⁰⁷ The effectiveness of any particular type of treatment is beyond the scope of this book. To avoid using case studies that deflect attention from the method of decision-making to the nature of the treatment itself, case studies in the area of mental health treatment have not been used. Case studies used in this book describe adults with physical health and support needs, where the premise is clear that the health or support service in question would be beneficial in some way to the adult.

Partly for the same reason, that it would lead to a diversion into another major field of study, the impact of Article 12 on the criminal law is beyond scope. While there has been some important commentary around how Article 12 affects the criminal defence of unsound mind and pleas of unfitness for trial,¹⁰⁸ consideration of the interpretation and application of Article 12 in the criminal context is not considered. Others have commented and proposed that interpreting Article 12 as recognising universal legal capacity in the criminal context would require a much-needed wholesale review of criminal law and procedure internationally.¹⁰⁹ Hall, on the other hand, has expressed the view that Article 12 and the right to legal capacity have no relevance to interpretation and application of the criminal law.¹¹⁰

¹⁰⁷ 'A growing research base has produced evidence indicating that the status quo, preoccupied with biomedical interventions, including psychotropic medications and non-consensual measures, is no longer defensible in the context of improving mental health': Pūras, Dainius, Special Rapporteur, *Report of the Special Rapporteur on the Right of Everyone to the Enjoyment of the Highest Attainable Standard of Physical And Mental Health*, UN Doc A/HRC/35/21 (28 March 2017) [5].

¹⁰⁸ Melvyn Colin Freeman et al, 'Reversing Hard Won Victories in the Name of Human Rights: A Critique of the General Comment on Article 12 of the UN Convention on the Rights of Persons with Disabilities' (2015) 2(9) *The Lancet Psychiatry* 844, 844; Piers Gooding et al, 'Unfitness to Stand Trial and the Indefinite Detention of Persons with Cognitive Disabilities in Australia: Human Rights Challenges and Proposals for Change' (2017) 40 *Melbourne University Law Review* 816; Peter Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75(5) *The Modern Law Review* 752, 753–54; Tina Minkowitz et al, 'Advancing the Rights of Users and Survivors of Psychiatry using the UN Convention on the Rights of Persons with Disabilities: An Interview with Tina Minkowitz' in Helen Spandler, Jill Anderson and Bob Sapery (eds), *Madness, Distress and the Politics of Disablement* (Bristol University Press; Policy Press, 2015) 171, 178; Meron Wondemaghen, 'Testing Equality: Insanity, Treatment Refusal and the CRPD' (2018) 25(2) *Psychiatry, Psychology and the Law* 174.

¹⁰⁹ Amita Dhanda and Gabor Combos, 'Questions of Criminal Culpability and Persons with Disabilities' in Eilionoir Flynn, Anna Arstein-Kerslake, Clóna De Bhaillís and Maria Laura Serra (eds), *Global Perspectives on Legal Capacity Reform: Our Voices, Our Stories* (Routledge, 2018) 32, 40

¹¹⁰ Margaret Isabel Hall, 'Putting the Pieces Together: Article 12, 'Safeguarding' and the Right to Legal Capacity' in Mary Donnelly, Rosie Harding and Ezgi Tascioglu (eds), *Supporting Legal Capacity in Socio-Legal Context* (Hart Publishing 2022) 273, 278.

Finally, as described in Chapter 3, the indivisibility of human rights as doctrine or principle is contested by some scholars and theorists.¹¹¹ Chapter 3 reviews the dominant writings on this topic and draws on these to formulate the concept of indivisibility relied on by this book. Further consideration as to whether indivisibility is officially recognised as a doctrine or principle or otherwise is beyond scope. Chapter 3 refers to and reviews a body of literature that affirms the incorporation of the principle of indivisibility into the CRPD.

5 THE BOOK'S STRUCTURE AND ARGUMENT

This chapter has introduced the research problem, explained key terms, provided background to the development of the CRPD and Article 12, described the research methodology, and defined the book's scope. This section provides an overview of the book's interpretive argument, as it is developed chapter by chapter – in particular, how it relates to the principle of indivisibility and the key values of autonomy, dignity and equality.

Chapter 2 explains the historical and contemporary policy, legal and human rights contexts for decision-making by, with and for adults with cognitive disability.¹¹² It describes the dominant narrative in the literature as depicting a journey from paternalism to autonomy, from exclusion to inclusion, and from discrimination to equality. This journey is reflected in the development of three widely recognised models of disability: the charity, medical and social models.¹¹³ The development of these models, in turn, parallels and charts the development of decision-making frameworks from mass institutionalisation, through guardianship to supported decision-making. Chapter 2 also reviews widespread critiques of the social model of disability and argues that a social model that recognises the residual impacts of impairment¹¹⁴ serves as a more useful reference point for the development of law and policy than what some have referred to as a 'strict' social model.

Chapter 2 also summarises the major arguments grounding different interpretations of Article 12. Arguments for abolition of decision-making by substitutes are: legal capacity includes the ability to act on rights and not just hold them;¹¹⁵

¹¹¹ See Chapter 3, Section 2.4.

¹¹² See Chapter 2, sections 2 and 3.

¹¹³ Theresa Degener, 'A New Human Rights Model of Disability' in Valentina Della Fina, Rachele Cera and Giuseppe Palmisano (eds), *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* (Springer, 2017) 41; Shane Clifton, *Hierarchies of Power: Disability Theories and Models and Their Implications for Violence against, and Abuse, Neglect, and Exploitation of, People with Disability* (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2020).

¹¹⁴ 'But to properly grasp the normative obligations entailed in the provision of decisional support, differences that are residual from impairment must be taken into account.' Kong, *Mental Capacity in Relationship* (n 16) 152.

¹¹⁵ *General Comment No 1* [12]–[13]; International Disability Alliance (n 5).

decision-making by substitutes can never be a safeguard;¹¹⁶ and (3) it is always discriminatory against people with cognitive disability.¹¹⁷ Related to these arguments is the proposal that it is always possible to recognise an adult's decision-making autonomy by making a 'best interpretation' of his or her will and preferences.¹¹⁸ The chapter explains the limitations of these arguments as privileging autonomy at the expense of other values; and in privileging the civil-political right to legal capacity over other civil, economic, political, social and cultural human rights.

Arguments for interpreting Article 12 as allowing for retention of decision-making by substitutes include that legal capacity means only the ability to hold rights and not the ability to act on them.¹¹⁹ Alternatively, or in addition, there are arguments that substitute decision-making is allowable as 100% support¹²⁰ or as a safeguard¹²¹ and that the hard reality is that some adults with cognitive disability are not capable of decision-making autonomy.¹²² There are associated arguments that making a 'best interpretation' of an adult's will and preferences lacks transparency,¹²³ is vulnerable to manipulation,¹²⁴ and amounts to substitute decision-making under a different guise.¹²⁵ The chapter explains how recognition of hard reality is consistent with the interpretive argument in this book, based as it is on a social model of disability, which recognises the residual impacts of impairment.

Chapter 3 introduces and explains the principle of the indivisibility of human rights. It explains how the principle of indivisibility is embodied in and developed by the CRPD, and how the commentary around the CRPD engages with the principle of indivisibility.¹²⁶ It establishes that the principle of indivisibility relied upon in this

¹¹⁶ 'The "best interests" principle is not a safeguard which complies with article 12 in relation to adults': *General Comment No 1* [21].

¹¹⁷ *Ibid* [32]–[34].

¹¹⁸ *Ibid* [21].

¹¹⁹ Ad Hoc Committee, *Daily Summary of the Fifth Session* (25 January 2005) www.un.org/esa/socdev/enable/rights/ahc5sum25jan.htm ('Daily Summary 25 January 2005').

¹²⁰ Ad Hoc Committee, *Daily Summary 18 January 2006* (n 87); ALRC (n 9) 94.

¹²¹ Caivano (n 91) 23.

¹²² Martin et al, *Achieving CRPD Compliance* (n 24) 23.

¹²³ Matthew Burch, 'Autonomy, Respect, and the Rights of Persons with Disabilities in Crisis' (2017) 34(3) *Journal of Applied Philosophy* 389, 390, 397; Malcolm Parker, 'Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making' (2016) 13(3) *Journal of Bioethical Inquiry* 381, 389.

¹²⁴ Anita Smith (n 25) 266–67.

¹²⁵ Terry Carney, 'Supported Decision-Making for People with Cognitive Impairments: An Australian Perspective?' (2015) 4 *Laws* 37, 45; Parker, 'Getting the Balance Right: Conceptual Considerations Concerning Legal Capacity and Supported Decision-Making' (2016) 13(3) *Journal of Bioethical Inquiry* 381, 387.

¹²⁶ Dhanda, 'Constructing a New Human Rights Lexicon' (n 86) 48–50; Marianne Schulte, 'Chapter 16: The Human Rights of Persons with Disabilities' in Anja Mihir and Mark Gibney (eds), *The SAGE Handbook of Human Rights* (SAGE Publications Ltd, 2014) 267, 277; Andrea Broderick, 'Harmonisation and Cross-fertilisation of Socio-Economic Rights in the Human Rights Treaty Bodies: Disability and the Reasonableness Review Case Study' (2016) 5 *Laws* 38, 42; DeBeco (n 29) 154; Koch, 'From Invisibility to Indivisibility' (n 29).

book recognises: (a) the interdependencies between rights within and across categories, and (b) the equal importance of socio-economic rights with civil-political rights. It further reviews and agrees with the literature that proposes the particular importance of socio-economic rights to people with disability, given their disproportionate levels of poverty and disadvantage.

Chapter 3 also describes and analyses how existing interpretations of Article 12 have accounted for the principle of indivisibility. It explains how disability issues had historically been sidelined by being included only on socio-economic rights agendas at a time when civil-political rights were regarded as the only 'true' human rights.¹²⁷ It argues that the framing of the civil-political right to legal capacity as fundamental to all other rights is an over-correction to this historical subordination of disability rights and thus fails to account for the principle of indivisibility.¹²⁸ It explains how civil-political rights are underpinned by the value of autonomy and how their privileging frames negative state actions and non-interference as always rights-affirming. Such framing, in turn, demands abolition of guardianship and involuntary treatment in pursuit of fulfilling civil-political human rights over socio-economic rights and the value of autonomy over other human rights values.

It describes how Carney¹²⁹ (and some other writers more tentatively)¹³⁰ has described Article 12 as embodying the principle of the indivisibility of human rights. While the right to legal capacity is more appropriately categorised as civil-political, Article 12(3) as a right to support is more convincingly categorised as a socio-economic right. It begins the analysis of Article 12 according to the principle of indivisibility, by explaining the interdependency of the two rights within Article 12 itself – that is, the right to legal capacity and the right to support.

Chapter 4 considers how the concept of autonomy relates to Article 12, and looks at endeavours in the literature to reconceptualise autonomy so as to include adults with cognitive disability. It explains how, in traditional liberalism, autonomy as the ability to reason has been recognised as the foundation for personhood, thereby excluding adults with cognitive disability.¹³¹ Interpretations of Article 12 that require the abolition of decision-making by substitutes refashion autonomy from being marked by rationality and independence to being marked by shared personhood¹³²

¹²⁷ Degener and Begg (n 58) 10; Gerard Quinn, 'The International Covenant on Civil and Political Rights and Disability: A Conceptual Framework' in Theresia Degener and Yolana Koster-Dreese (eds), *Human Rights and Disabled Persons* (Martinus Nijhoff, 1995) 69, 70.

¹²⁸ Chapter 3, Section 4.1.

¹²⁹ Terry Carney, 'Prioritising Supported Decision-Making: Running on Empty or a Basis for Glacial-to-Steady Progress?' (2017) 6(4) *Laws* 18, 18–23.

¹³⁰ Quinn and Rekas-Rosalbo (n 5) 303; Degener, 'A New Human Rights Model of Disability' (n 113) 45–46.

¹³¹ Christman, 'Autonomy in Moral and Political Philosophy' (n 19) [1].

¹³² Gerard Quinn, 'From Civil Death to Civil Life: The Decay and Re-Birth of Legal Capacity Law around the World' (Conference Paper, Australian Guardianship and Administration Council National Conference: Reflecting Will and Preference in Decision-Making, 17–18 October 2016) 10 www.agac.org.au/images/stories/2016nsw/quinn-decay-rebirth-legal-cap-law.pdf.

and interdependence or ‘positive liberty’¹³³ so as to include adults with cognitive disability.

I argue that these refashionings of autonomy ultimately fail because despite avowals to the contrary, they perpetuate the privileging of rationality and of the bounded, independent individual. The only difference is that the boundary now extends to include the supporter to the extent only that they are instrumental to the personhood of the adult. I further argue that such an interpretation also ignores the indivisibility of human rights by failing to recognise the interdependency of Article 12 with other rights in the CRPD, especially socio-economic rights.

Chapter 4 does acknowledge autonomy as a fundamental human rights value that underpins the CRPD and Article 12 but argues that the type of autonomy envisaged by Article 12 embodies the indivisibility of human rights. It draws on the relevant literature to affirm a conception of autonomy as only one good amongst others but decries its privileged position as the basis for universal personhood. It argues that a concept of autonomy as achievement, as the development of autonomy competencies, as demanding the availability of a range of options, and as demanding recognition of the indivisibility of human rights is the autonomy underpinning Article 12 and the CRPD.

Chapter 5 proposes an interpretation of Article 12 that allows for the abolition of decision-making by substitutes as a last resort through relocating personhood from recognition of an adult’s autonomy to recognition of their dignity. It describes and analyses the literature that considers the role that dignity plays in interpreting Article 12. It finds that the literature almost always equates dignity with autonomy, with autonomy described as respecting the ‘dignity of risk’.¹³⁴ It further describes the very limited forays in the Article 12 literature into proposing dignity as a value distinct from autonomy in order to justify decision-making by substitutes.¹³⁵

Drawing on the text of the CRPD and other human rights instruments, philosophy, legal commentary and jurisprudence, it settles on a concept of dignity as inherent in all humans,¹³⁶ as a legal principle (not a right) that underpins human rights and the

¹³³ Bach and Kerzner (n 5) 40–42.

¹³⁴ de Bhailís and Flynn (n 5) 17; Bach and Kerzner (n 5) 54, 86, 89, 134, 153, 163, 178, 184; Bruce Alston, ‘Towards Supported Decision-Making: Article 12 of the Convention on the Rights of Persons with Disabilities and Guardianship Law Reform’ (2017) 35(2) *Law in Context* 21, 24; ALRC (n 9) 53, 75, 85, 102, 153, 170.

¹³⁵ Mary Donnelly, ‘From Autonomy to Dignity: Treatment for Mental Disorders and the Focus for Patient Rights’ (2008) 26(2) *Law in Context* 37, 431; Marcus Düwell, ‘Setting the Agenda for Ethical Debates about the Rights of Persons with Disabilities’ in Joel Andersen and Jos Philips (eds), *Disability and Universal Human Rights: Legal, Ethical, and Conceptual Implications of the Convention on the Rights of Persons with Disabilities* (Netherlands Institute of Human Rights, 2012) 185, 190–94; Bilchitz (n 23) 431.

¹³⁶ CRPD Preamble para 1 ‘Recalling the principles proclaimed in the Charter of the United Nations which recognize the inherent dignity and worth and the equal and inalienable rights of all members of the human family as the foundation of freedom, justice and peace in the world ...’

CRPD, and as having five dimensions. The first dimension of human dignity is that it means equal worth or value of all humans and demands that they be treated as ends in themselves and not merely means. The second dimension recognises autonomy as an important component of dignity for people who have autonomy but seeks to position autonomy as only one very valuable good amongst others. The third dimension recognises that human dignity is reflexive and acknowledges the interdependent, interpersonal and social nature of being human. The fourth dimension of human dignity is that it underpins a concept of personhood that is embodied and particular, thereby recognising the residual impacts of impairment and the materiality of our lives. The fifth dimension of human dignity is that it embodies and demands an understanding of rights as interdependent and indivisible.

Chapter 6 considers the meaning of equality in Article 12, describing and explaining how equality is a fundamental human rights value foregrounded in the CRPD.¹³⁷ It describes the development of concepts of discrimination and equality in human rights law and theory, from direct to indirect discrimination, from formal to substantive equality, to transformative equality and ultimately ‘inclusive equality’. Inclusive equality has been developed and described by the UN Disability Committee in its *General Comment No 6 (2018) on equality and discrimination* (‘General Comment No 6’) as having four dimensions and as being the type of substantive equality that underpins the CRPD.¹³⁸

Chapter 6 goes on to describe how the phrase ‘on an equal basis with others’ in Article 12 has been interpreted to mean that Article 12 requires either the abolition of decision-making by substitutes¹³⁹ or its retention as a last resort.¹⁴⁰ It identifies unresolved contradictions in the arguments that decision-making by substitutes always or necessarily results in failure to achieve substantive equality. It describes those interpretations of Article 12 that explain how decision-making by substitutes can achieve equality,¹⁴¹ but develops and builds on these by applying the four dimensions of inclusive equality to interpret Article 12.

It argues that inclusive equality recognises that difference requires differential treatment in the form of supported decision-making or decision-making by substitutes to achieve equality. The chapter draws on existing commentary explaining the ‘hybrid’ nature of the right to equality in bridging both socio-economic and

¹³⁷ Ibid Preamble paras 1, 5, 6, 11, 18 and 24, and Articles 1, 3 and 5.

¹³⁸ *General Comment No 6*.

¹³⁹ *General Comment No 1; General Comment No 6* [3], [47]–[51].

¹⁴⁰ Martin et al, *Three Jurisdictions Report: Towards Compliance with CRPD Article 12 in Capacity/Incapacity Legislation across the UK* (n 9); Del Villar (n 25); George Szmukler, Rowena Daw and Felicity Callard, ‘Mental Health Law and the UN Convention on the Rights of Persons with Disabilities’ (2014) 37(3) *International Journal of Law and Psychiatry* 245.

¹⁴¹ Martin et al, *Achieving CRPD Compliance* (n 24); Del Villar (n 25) 183; Szmukler, Daw and Callard (n 140).

civil-political rights.¹⁴² It affirms that inclusive equality, which underpins the CRPD and Article 12, is driven by the indivisibility of human rights.

The final chapter summarises the book's argument and conclusions, and explains their implications for advocacy and law reform.

6 WHY THE BOOK IS IMPORTANT

This book addresses a key and prominent area of dispute over the interpretation and application of the CRPD, a convention that marks an important step forward in recognising the human rights of people with disability. It endeavours to make a significant and original contribution to the debate in several areas.

First, it situates the development and interpretation of the civil-political right in Article 12¹⁴³ against the background of the historical marginalisation of socio-economic rights. It then goes on to argue that an interpretation of the right to legal capacity as a right foundational to all other rights over-corrects the historical marginalisation of disability as relevant to socio-economic rights only.¹⁴⁴ Second, it critiques existing analysis of how the principle of indivisibility of human rights infuses the CRPD by dissolving distinctions between the two categories of rights, to propose instead a concept of indivisibility that retains those distinctions (albeit porous).¹⁴⁵

Third, it demonstrates through the case study of Alex how attempts to attribute autonomy to all adults with cognitive disability risk perpetuating the exclusion of adults with cognitive disability from personhood,¹⁴⁶ and argues that Article 12 autonomy demands fulfilment of both civil-political and socio-economic rights, according to the principle of indivisibility.¹⁴⁷ Fourth, with autonomy failing to include all adults with cognitive disability in personhood, the book proposes dignity as an alternative, inclusive basis for personhood in the CRPD (and in human rights law and theory more widely), and develops a novel concept of five-dimensional dignity, which incorporates the principle of indivisibility.¹⁴⁸ Fifth, the book reviews the

¹⁴² Anna Lawson, 'The UN Convention on the Rights of Persons with Disabilities and European Disability Law: A Catalyst for Cohesion?' in Oddný Mjöll Arnadóttir and Gerard Quinn (eds), *The UN Convention on the Rights of Persons with Disabilities: European and Scandinavian Perspectives* (Nijhoff, 2009) 81, 104–7; Rebecca Brown and Janet Lord, 'The Role of Reasonable Accommodation in Securing Substantive Equality for Persons with Disabilities' in Marcia H Rioux, Lee Ann Basser Marks and Melinda Jones (eds), *Critical Perspectives on Human Rights and Disability Law* (Martinus Nijhoff, 2011) 273, 281; Broderick, 'Harmonisation and Cross-Fertilisation of Socio-Economic Rights in the Human Rights Treaty Bodies' (n 126) 38.

¹⁴³ See *General Comment No 1* [30].

¹⁴⁴ See Chapter 3, Section 4.1.

¹⁴⁵ See Chapter 3, Section 5.4.

¹⁴⁶ See Chapter 4, Sections 3 and 4.

¹⁴⁷ See Chapter 4, Section 6.

¹⁴⁸ See Chapter 5, especially Section 3.

literature on equality and *General Comment No 6* in the context of Article 12.¹⁴⁹ In doing so it interprets recognition of legal capacity ‘on an equal basis with others’, according to the principle of indivisibility, as demanding decision-making by substitutes as a last resort.¹⁵⁰

In its argument for interpreting Article 12 according to the principle of indivisibility, the book weaves together a range of otherwise disparate analyses and complex ideas found in the Article 12 and CRPD literature, human rights law and theory, philosophy, legal commentary and jurisprudence. As a whole, it analyses, draws connections between, critiques and builds on existing bodies of knowledge and ideas in new ways. It presents an argument for interpreting Article 12 as requiring both supported decision-making and decision-making by substitutes in order to uphold the human rights of all adults with cognitive disability and recognise their human dignity and personhood.

7 CONCLUSION: THE SIGNIFICANCE OF THE CRPD AND ARTICLE 12

The CRPD is universally recognised as a major step forward for disability human rights, including for adults with cognitive disability. However, as a relatively recent UN convention, it is still subject to ongoing interpretation, and this book contributes to that significant project. Despite the authoritative status of the UN Disability Committee, a wide range of commentators have opposed its interpretation of Article 12 – in particular, it has not been supported by any law reform commission in the English-speaking world to date.¹⁵¹ More significantly, many States parties including Australia, Canada, France, Ireland, the Netherlands, Norway and Poland have made interpretive declarations or reservations stating that Article 12 still allows for decision-making by substitutes as a last resort.¹⁵² This exposes governments to condemnation from the UN, but even more problematically, such wide ‘non-compliance’ potentially undermines the moral and legal authority of Article 12, and

¹⁴⁹ See Chapter 6, especially Sections 2 and 3.

¹⁵⁰ See Chapter 6, Section 5.

¹⁵¹ Shih-Ning Then et al, ‘Supporting Decision-Making of Adults with Cognitive Disabilities: The Role of Law Reform Agencies – Recommendations, Rationales and Influence’ (2018) 61 *International Journal of Law and Psychiatry* 64.

¹⁵² Also, Canada, France, Ireland, the Netherlands, Norway, and Poland have lodged interpretive declarations or reservations in relation to Article 12. Interpretive declarations by Egypt, Estonia and Kuwait assert their understanding that legal capacity does not necessarily include the capacity to act or exercise rights. The implication is that decision-making by representatives is still permitted (see discussion in Chapter 2, Section 4.1.1). The declarations and reservations were made upon ratification. For a full list of reservations and declarations and their full text, see https://treaties.un.org/Pages/ViewDetails.aspx?src=TREATY&mtdsg_no=IV-15&chapter=4&clang=_en#EndDcc

the CRPD more broadly,¹⁵³ a result that would be widely decried by all of those seeking equality and inclusion for people with disability.

In Australia, at the time of writing, the ongoing neglect and stigmatisation of people with disability was being investigated and exposed by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('the Disability Royal Commission').¹⁵⁴ The Disability Royal Commission has emphasised the role of the CRPD as a framework for upholding the rights of people with disability, including their decision-making rights.¹⁵⁵ In 2013, Australia began its rollout of the National Disability Insurance Scheme ('NDIS'), which is premised on the right of people with disability to have choice and control in service provision.¹⁵⁶ In this project it follows other western nations including the UK, Europe, North America, Norway, Iceland, Israel and New Zealand, in introducing a system of individualised funding and budgeting for accommodation and services for people with disability. Such systems based on individualised budgets have been referred to variously as '... person-centred support, self-directed care, cash for care, personalised allocations, personal budgets, case and counselling, and individualised funding...'.¹⁵⁷ At their core they emphasise the value of autonomy over the old paternalisms, '...the key idea being that individuals should be empowered to have choice, control and flexibility in making their own decisions to spend money on the services that best suit their needs.'¹⁵⁸ In Australia, the NDIS is a significant and impressive venture that

¹⁵³ George Szmukler, "Capacity", "Best Interests", "Will and Preferences" and the UN Convention on the Rights of Persons with Disabilities' (2019) 18(1) *World Psychiatry: Official Journal of the World Psychiatric Association (WPA)* 34, 40; 'Structurally, an interpretation by a UN body that is not feasible risks undermining the authority of the wider UN human rights machinery': Craigie et al (n 9), 165.

¹⁵⁴ <https://disability.royalcommission.gov.au/>

¹⁵⁵ Kayess and Sands (n 6); McCallum (n 6).

¹⁵⁶ www.ndis.gov.au/ *National Disability Insurance Scheme Act 2013* (Cth). s 4 'General principles guiding actions under this Act ... (8) People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. (9) People with disability should be supported in all their dealings and communications with the Agency and the Commission so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs'; s 17A '(2) People with disability will be supported in their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised. (3) The National Disability Insurance Scheme is to: (a) respect the interests of people with disability in exercising choice and control about matters that affect them; and (b) enable people with disability to make decisions that will affect their lives, to the extent of their capacity; and (c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.'

¹⁵⁷ Laura Davy and Celia Green, 'The Right to Autonomy and the Conditions that Secure it: The Relationship Between the UNCRPD and Market-Based Policy Reform' in Franziska Felder, Laura Davy and Rosemary Kayess (eds), *Disability Law and Human Rights: Theory and Policy* (Palgrave, 2022) 127–45, 135–36.

¹⁵⁸ *Ibid.*

promises improved living conditions and social inclusion for many people with disability. However, it is vital – in all of these systems premised on the right to make decisions freely – that the specific challenges of cognitive disability are acknowledged, recognised and responded to in a way that upholds human rights.

Some commentators reject a human rights framework as being inadequate to ensure that adults with cognitive disability are treated in a way that social justice and ethical demands require.¹⁵⁹ However, the prevalence of human rights talk in our community, together with the high status that human rights are widely accorded,¹⁶⁰ demand that social justice solutions be articulated within a human rights framework to attract the moral and practical urgency that they deserve. This book aims to contribute to that significant project.

¹⁵⁹ Barbara Carter, 'The Case for Dignity as the Governing Principle in Adult Guardianship' (2010) 19(1) *Res Publica* 1.

¹⁶⁰ 'Human rights traditionally have been thought of as moral right of the highest order ...': Jack Donnelly, *Universal Human Rights in Theory and Practice* (Cornell University Press, 3rd ed, 2013) 11; 'But human rights are also a powerful discourse and practice in domestic and international law': Costas Douzinas, *The End of Human Rights: Critical Legal Thought at the Turn of the Century* (Hart, 2000) 4.