

1

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')¹ 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* 420; 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 Bhailis 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 Bhailís 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 Cray, ‘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: Naturity 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' (2010) 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.