

**MENTAL CAPACITY, DIGNITY AND THE POWER
OF INTERNATIONAL HUMAN RIGHTS**

Personhood, in liberal philosophical and legal traditions, has long been grounded in the idea of autonomy and the right to legal capacity. However, in this book, Julia Duffy questions these assumptions and shows how such beliefs exclude and undermine the rights of adults with cognitive disability. Instead, she reinterprets the right to legal capacity through the principle of the interdependence and indivisibility of human rights. In doing so, she compellingly argues that dignity and not autonomy ought to be the basis of personhood. Using illustrative case studies, Duffy demonstrates that the key human rights values of autonomy, dignity and equality can only be achieved by fulfilling a range of interdependent human rights. With this innovative book challenging common assumptions about human rights and personhood, Duffy leads the way in ensuring civil, economic, political, social and cultural inclusion for adults with cognitive disabilities.

JULIA DUFFY is Research Fellow at the Australian Centre for Health Law Research at the Queensland University of Technology. She writes and publishes in the areas of cognitive disability, decision-making and human rights law and theory and provides research and consultancy services to government and non-government agencies on supported decision-making and related areas. She has been a member of two health practitioner regulatory boards, a legal member of Queensland's Mental Health Review Tribunal and was for many years a member of the board of Family Planning Queensland. Julia has also had a substantial career as a government policy advisor, lawyer and senior executive, including roles as Chief Executive of a major Commission of Inquiry into Child Protection and as Deputy Public Guardian.

CAMBRIDGE BIOETHICS AND LAW

This series of books – formerly called Cambridge Law, Medicine and Ethics – was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. In the past twenty years, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law. It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy and bioethics debates in the UK, Europe and the international community over the past two decades have involved a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician-assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

Series Editors

Professor Graeme Laurie, *University of Edinburgh*
Professor Richard Ashcroft, *City, University of London*

Mental Capacity, Dignity and the Power of International Human Rights

JULIA DUFFY

Queensland University of Technology



CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)



Shaftesbury Road, Cambridge CB2 8EA, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi – 110025, India

103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

Cambridge University Press is part of Cambridge University Press & Assessment,
a department of the University of Cambridge.

We share the University's mission to contribute to society through the pursuit of
education, learning and research at the highest international levels of excellence.

www.cambridge.org

Information on this title: www.cambridge.org/9781009304528

DOI: 10.1017/9781009304481

© Julia Duffy 2023

This publication is in copyright. Subject to statutory exception and to the provisions
of relevant collective licensing agreements, no reproduction of any part may take
place without the written permission of Cambridge University Press & Assessment.

First published 2023

A catalogue record for this publication is available from the British Library

A Cataloging-in-Publication data record for this book is available from the Library of Congress

ISBN 978-1-009-30452-8 Hardback

Cambridge University Press & Assessment has no responsibility for the persistence
or accuracy of URLs for external or third-party internet websites referred to in this
publication and does not guarantee that any content on such websites is, or will
remain, accurate or appropriate.

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)

In memory of
Lloyd Davis

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)

Contents

<i>Acknowledgements</i>	page xiii
<i>Table of Cases</i>	xv
<i>Table of Treaties</i>	xvii
<i>List of Abbreviations</i>	xix
1 Introduction and Background	1
1 Article 12 and the Problem of Interpretation	2
1.1 Case Studies	3
1.2 The Problem the Book Is Addressing	6
1.3 An Overview of the Argument	8
2 A Note on Terminology and Concepts	10
2.1 ‘Cognitive Disability’	11
2.2 ‘Impairment’ and ‘Disability’	11
2.3 ‘Legal Capacity’	12
2.4 ‘Decision-Making by a Substitute’	12
2.5 ‘Supported Decision-Making’	13
3 The Convention on the Rights of Persons with Disabilities	14
3.1 Development of Human Rights Instruments for People with Disability	14
3.2 Inclusion of People with Disability in the Development of the CRPD	16
3.3 A Disability-Specific Convention	17
3.4 The Drafting of Article 12: A ‘Flashpoint’	18
4 Research Method and Scope	20
4.1 Doctrinal and Theoretical Analysis and Research	20
4.2 Scope	21
5 The Book’s Structure and Argument	23

6	Why the Book Is Important	28
7	Conclusion: The Significance of the CRPD and Article 12	29
2	Article 12 – Context and Background	32
1	Introduction	32
2	Different ‘Models’ of Disability	34
2.1	Charity Model	34
2.2	Medical Model	36
2.3	Social Model	37
2.4	Beyond the Social Model of Disability	39
3	Decision-Making and People with Cognitive Disability	44
3.1	The Era of Mass Institutionalisation	44
3.2	Legal Capacity Tests	46
3.3	Decision-Making Principles	50
3.4	Supported Decision-Making	52
3.5	Summary and Conclusions	56
4	The CRPD and Article 12 as a ‘Paradigm Shift’ but also a Site of Contest	58
4.1	Arguments That Recognition of Legal Capacity Demands the Abolition of Substitute Decision-Making	59
4.2	Arguments That Recognition of Legal Capacity Allows for Retention of Decision-Making by Substitutes as a Last Resort	65
5	Summary, Commentary and Conclusions	72
3	The Principle of Indivisibility and Article 12	74
1	Introduction	74
2	The History of the Principle of Indivisibility	75
2.1	The Universal Declaration of Human Rights	76
2.2	Indivisibility Invoked on Division of Human Rights into Two Binding Covenants	77
2.3	Increasing References to Indivisibility by UN Institutions from 1970s	78
2.4	Conclusions on Status of Indivisibility as a Human Rights Principle	78
3	What Is Meant by ‘the Principle of Indivisibility’?	79
3.1	Indivisibility as Interdependence between Different Rights	80
3.2	Indivisibility as No Hierarchy between the Two Sets of Rights: Civil-political and Socio-economic	81
3.3	Traditional Demarcations Between the Two Categories of Rights and Challenges to the Hierarchy	83
3.4	Conclusion and Commentary on Definition of Indivisibility	88

Contents

ix

4	Indivisibility, Disability and the CRPD: The Importance of Socio-economic Rights	89
4.1	From Social Policy to Human Rights	89
4.2	The Importance of Indivisibility for Disability	92
4.3	Summary and Conclusions	95
5	Indivisibility in the Text of the CRPD	96
5.1	Rights from Both the ICCPR and the ICESCR and the Right of Communication	97
5.2	Civil–Political and Socio-economic Rights Mixed in the Same Articles	97
5.3	A Mix of State Restraint and State Protection/Support in the Personal Sphere	99
5.4	Indivisible, but Still Visible and <i>Not</i> Totally Entwined or Dissolved into One Another	99
5.5	Summary, Commentary and Conclusions	102
6	Interpreting and Applying Article 12 through the Principle of Indivisibility	102
6.1	Article 12 as a Civil-political Right	103
6.2	Article 12 as a Socio-economic Right	104
6.3	The ‘Chicken and Egg’ or ‘Initiation Problem’	108
6.4	Summary and Conclusions on Article 12 and Indivisibility	108
7	Summary and Conclusions	109
4	Article 12 and Autonomy	112
1	Introduction	112
2	The Traditional Liberal View of Autonomy: ‘To Live One’s Life according to Reasons and Motives That Are Taken as One’s Own’	114
2.1	Autonomy as Rationality	115
2.2	Autonomy as Independence	116
2.3	Autonomy as Non-interference in the Private Sphere	116
2.4	The Case of Alex	117
3	Autonomy as Personhood: But Refashioned by Divorcing Autonomy from Rationality	118
3.1	A Role for Emotions in Decision-Making and Autonomy	118
3.2	Rationality Not Needed for Exercising ‘Mere Choice’ or ‘Preference’	119
3.3	Rationality Not Needed for a Person to Have an ‘Authentic’ Self	121
3.4	Why Autonomy without Rationality Does Not Work as Universal Personhood	122

4	Autonomy as Personhood: But Refashioned as ‘ <i>Interdependence</i> ’ or Relational Autonomy, Relationships of Trust or as Positive and Negative Liberty	123
4.1	Autonomy as Shared Personhood or <i>Interdependence</i>	124
4.2	Relational Autonomy	125
4.3	Autonomy Characterised by Trust, Cooperation and the ‘Cognitive Prosthesis’	126
4.4	Supports as Enabling Positive Liberty/Autonomy	128
4.5	Regulation as ‘Positive Liberty’?	129
4.6	Why Refashioning Autonomy as Interdependence, Relational Autonomy or Relationships of Trust Does Not Work as Universal Personhood	130
4.7	Returning to the Case of Alex	136
4.8	Summary and Conclusions on Refashioning Autonomy to Underpin Universal Legal Capacity and Inclusive Personhood	137
5	Divorcing Autonomy from Personhood: But Still Refashioning Autonomy to Be More Inclusive	139
5.1	Autonomy as Achievement	140
5.2	Autonomy as the Development of Autonomy Competencies	141
5.3	Autonomy Necessitates the Provision of Real Choices and Options	142
5.4	Returning to the Case of Alex	142
5.5	Commentary and Conclusions	143
6	Autonomy and the Indivisibility of Human Rights	143
6.1	Autonomy as the Foundation of Civil-political Rights	144
6.2	Autonomy Competencies and Socio-economic Rights	145
6.3	A Range of Options Requires Fulfilment of a Range of Rights	145
6.4	Disrupting the Boundaries between the Individual and the State: Private and Public Spheres	146
6.5	Indivisibility and the Case of Alex	147
7	Summary and Conclusion	148
5	Article 12 and Dignity	151
1	Introduction	151
2	Dignity in the Text of Human Rights Instruments: An Overview	152
2.1	United Nations and Regional Human Rights Instruments	153
2.2	Dignity in the Text of the CRPD	154
3	Five Proposed Dimensions of Dignity	160
3.1	Dignity as Equal Worth or Value	160

Contents

xi

3.2	Dignity as Recognising the Autonomy of Those Who Are Capable of Autonomy	162
3.3	Dignity as Recognising the Interdependent, Interpersonal and Social Nature of Being Human	166
3.4	Dignity as Recognising the Embodied Nature of Personhood	174
3.5	Dignity as Underpinning and Affirming the Indivisibility of Human Rights	176
4	Dignity and the Article 12 Literature	183
4.1	Article 12 and Autonomy	183
4.2	Article 12 and Equality	185
4.3	Article 12: Beyond Autonomy and Equality	185
5	Supported Decision-Making, Decision-Making by Substitutes and Dignity	189
6	Overview and Conclusion	193
6	Article 12 and Equality	196
1	Introduction	196
2	Equality and Non-discrimination in Human Rights Law	198
2.1	Introduction to <i>General Comment No 6</i>	199
2.2	Key Equality Provisions in the CRPD	200
2.3	Formal Equality	202
2.4	Substantive Equality	204
2.5	Direct and Indirect Discrimination	205
2.6	Differential Treatment for Substantive Equality	207
2.7	Analysis and Conclusions	210
3	Inclusive Equality: An Adaptation of Transformative Equality	211
3.1	Foundations in ‘Transformative’ Equality: A Four-Dimensional Approach	212
3.2	Equal to What or with Whom? Equality as an Approximation for Inclusion	213
3.3	Equality and Indivisibility	214
3.4	Inclusive Equality, Difference and Models of Disability	217
3.5	Analysis and Conclusions	219
4	Discrimination, Equality and Article 12	220
4.1	The Search for ‘Disability-Neutral’ Criteria	221
4.2	‘Disability-Neutrality’ Is Not Essential for Equality	224
5	‘Inclusive Equality’ and the Right to Legal Capacity	227
5.1	Supported Decision-Making and Inclusive Equality	227
5.2	Equality, Substitute Decision-Making and Indivisibility	230
5.3	Case Study: Jess, Decision-Making and Inclusive Equality	232
6	Conclusion	233

7	Conclusion	236
1	Introduction	236
2	Article 12: A Site of Contention	236
3	A Summary of the Argument	237
3.1	Privileging Autonomy, Civil-political Rights and Article 12	238
3.2	The CRPD and the Principle of Indivisibility	238
3.3	Article 12 and Autonomy	239
3.4	Article 12 and Dignity	241
3.5	Article 12 and Equality	242
4	Implications for Advocacy and Law Reform	244
4.1	‘Choice and Control’ in the Real World	245
4.2	The Right to Legal Capacity as a Right above All Others: Legitimising the Role of the ‘Lazy State’	246
5	Concluding Remarks	248
	<i>References</i>	249
	<i>Index</i>	268

Acknowledgements

There are many people without whose support this book would never have been written. My PhD supervisors Professors Ben White and Lindy Willmott and Associate Professor Andy McGee shared with me their extensive knowledge in health law and bioethics and pushed me in new and challenging directions, while providing a safety net of kindness and encouragement. They also provided a wonderfully collegial environment for what may otherwise have been a solitary pursuit, introducing me to their team of brilliant and dedicated researchers and other colleagues. I'd especially like to thank Professor Shih-Ning Then and members of her writing group, as well as Dr Katrine Del Villar and Dr Sam Boyle for reading and critiquing drafts of various chapters. Monica Chaplain and Kristina Chelberg provided invaluable support with copy-editing and indexing and Annabelle Duffy with proofreading.

Many friends and family members encouraged me, supported me and showed interest along the way (as they still do). Thanks to Annabelle, and especially to Charlotte and Joey Davis who inspire me every day.

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)

Table of Cases

- Airedale NHS Trust v Bland* [1993] AC 789, 161
Airey v Ireland (1979) 2 EHRR 305, 81
D v United Kingdom (1997) 24 EHRR 423, 172, 181, 241
Government of the Republic of South Africa and Others v Grootboom and Others (2000) (1) SA 46 (Constitutional Court), 179, 241
In the matter of: Deon Wessels and Hayden William Kelly [2012] NZFC 9487, 4
Keenan v United Kingdom (2001) 33 EHRR 913, 172
Khosa and Others v Minister for Social Development and Others 2004 (6) SA 505 (Constitutional Court), 180
Planned Parenthood of Southeastern Pa. v Casey, 505 U.S. 833 (1992), 163
Pretty v United Kingdom (2002) 35 EHRR 1, 154
Price v United Kingdom (2002) 34 EHRR 53, 156
R v Secretary of State for Social Security, ex parte Joint Council for the Welfare of Immigrants [1996] 4 All ER 385, 180
R (A, B, X and Y) v East Sussex County Council (No 2) (2003) 6 CCLR 194, 172
R (Adam and Limbuela) v Secretary of State for the Home Department [2005] UKHL 66, 181
R (Burke) v General Medical Council (Official Solicitor intervening) [2005] QB 424, 171, 172, 241
SW v United Kingdom ECHR 22 Nov 1995, 154

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)

Table of Treaties

- Charter of Fundamental Rights of the European Union*, 26 October 2012, 2012/C 326/02, 81
- Convention on the Elimination of All Forms of Discrimination against Women*, opened for signature 1 March 1980, 1249 UNTS 8 (entered into force 3 September 1981), 17, 153, 209
- Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 15 (entered into force 3 May 2008), 1
- Convention on the Rights of the Child*, opened for signature 29 November 1989, 1577 UNTS 11 (entered into force 2 September 1990), 15, 156, 220
- European Convention on Human Rights, as amended by Protocols Nos 11 and 14*, Council of Europe, ETS 5 (entered into force 3 September 1953), 154
- International Convention on the Elimination of All Forms of Racial Discrimination*, opened for signature 21 December 1965, 660 UNTS 195 (entered into force 4 January 1969), 17
- International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families*, signed 18 December 1990, 2220 UNTS 3 (entered into force 1 July 2003), 177
- International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976), 14
- International Covenant on Economic, Social and Cultural Rights*, opened for signature 16 December 1966, 993 UNTS 3 (entered into force 3 January 1976), 14, 75, 153, 201
- 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), 19, 97
- Optional Protocol to the International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976), 86
- Optional Protocol to the International Covenant on Economic, Social and Cultural Rights*, opened for signature 24 September 2009, UN Doc A/RES/63/117 (entered into force 5 May 2013), 81, 190
- Vienna Convention on the Law of Treaties*, opened for signature 18 December 1979, 1155 UNTS 331, opened for signature 23 May 1969 (entered into force 27 January 1980), 20, 158

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)

Abbreviations

1971 Declaration	<i>Declaration on the Rights of Mentally Retarded Persons</i>
1975 Declaration	<i>Declaration on the Rights of Disabled Persons</i>
Ad Hoc Committee	Ad Hoc Committee on a Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities
ALRC	Australian Law Reform Commission
ALRC Report	<i>Equality, Capacity and Disability in Commonwealth Laws: A Final Report</i>
Article 12	Article 12 of the United Nations <i>Convention on the Rights of Persons with Disabilities</i> – the ‘right to enjoy legal capacity on an equal basis with others’
CEDAW	<i>Convention on the Elimination of All Forms of Discrimination against Women</i>
CERD	<i>International Convention on the Elimination of All Forms of Racial Discrimination</i>
civil-political rights	civil and political rights
CRC	<i>Convention on the Rights of the Child</i>
CRPD	<i>Convention on the Rights of Persons with Disabilities</i>
Disability Royal Commission	Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability [Australia]
ECHR	<i>European Convention on Human Rights</i>

ESCR Committee	Committee on Economic, Social and Cultural Rights
<i>ESCR General Comment No 3</i>	Committee on Economic, Social and Cultural Rights, <i>General Comment No 3: The Nature of State Parties' Obligations</i>
<i>ESCR General Comment No 5</i>	Committee on Economic, Social and Cultural Rights, <i>General Comment No 5: Persons with Disabilities</i>
GAOR	General Assembly Official Records [United Nations]
<i>General Comment No 1</i>	Committee on the Rights of Persons with Disabilities <i>General Comment No 1 (2014) – Article 12: Equal Recognition before the Law</i>
<i>General Comment No 4</i>	Committee on the Rights of Persons with Disabilities, <i>General Comment No 4 (2016) – Article 24: Right to Inclusive Education</i>
<i>General Comment No 5</i>	Committee on the Rights of Persons with Disabilities, <i>General Comment No 5 (2017) on Living Independently and Being Included in the Community</i>
<i>General Comment No 6</i>	Committee on the Rights of Persons with Disabilities, <i>General Comment No 6 (2018) on Equality and Non-Discrimination</i>
<i>General Comment No 7</i>	Committee on the Rights of Persons with Disabilities, <i>General Comment No 7 (2018) on the Participation of Persons with Disabilities, Including Children with Disabilities, through Their Representative Organizations, in the Implementation and Monitoring of the Convention</i>
ICCPR	<i>International Covenant on Civil and Political Rights</i>
ICESCR	<i>International Covenant on Economic Social Cultural Rights</i>
IDC	International Disability and Caucus
MCA	<i>Mental Capacity Act 2005</i> (England and Wales)
NDIS	National Disability Insurance Scheme [Australia]
Optional Protocol to the ICESCR	<i>Optional Protocol to the International Covenant on Economic, Social and Cultural Rights (2013)</i>

List of Abbreviations

xxi

principle of indivisibility	the principle of the indivisibility, interdependence and interrelatedness of human rights
Proclamation of Teheran	<i>Proclamation of Teheran</i> in the <i>Final Act of the International Conference on Human Rights</i>
PVS	persistent vegetative state
QLRC	Queensland Law Reform Commission
socio-economic rights	economic, social and cultural rights
Standard Rules	<i>Standard Rules on the Equalisation of Opportunities for Persons with Disabilities</i>
UN	United Nations
UN Charter	<i>Charter of the United Nations</i>
UN Declaration	<i>Universal Declaration of Human Rights</i>
UN Disability Committee	United Nations Committee on the Rights of Persons with Disabilities
VCLT	<i>Vienna Convention on the Law of Treaties</i>
Vienna Declaration	<i>Vienna Declaration and Programme of Action</i> (1993)

Cambridge University Press & Assessment

978-1-009-30452-8 – Mental Capacity, Dignity and the Power of International Human Rights

Julia Duffy

Frontmatter

[More Information](#)
