

RESTORING VOICE TO PEOPLE WITH COGNITIVE DISABILITIES

The right to make decisions is important for every individual. It allows us to express ourselves, discover our likes and dislikes, and lead our lives in the way we desire. People with cognitive disability have historically been denied this right in many different ways – sometimes informally by family members or carers and other times formally by a courtroom or other legal authority. This book provides a discussion of the importance of decision-making and the ways in which it is currently denied to people with cognitive disability. It identifies the human right to equal recognition before the law as the key to ensuring the equal right to decision-making of people with cognitive disability. Looking to the future, it also provides a roadmap to achieve such equality.

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Restoring Voice to People with Cognitive Disabilities

REALIZING THE RIGHT TO EQUAL RECOGNITION
BEFORE THE LAW

ANNA ARSTEIN-KERSLAKE

Melbourne Law School



CAMBRIDGE
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Cambridge University Press & Assessment
978-1-107-14142-1 — Restoring Voice to People with Cognitive Disabilities
Anna Arstein-Kerslake
Frontmatter
[More Information](#)



Shaftesbury Road, Cambridge CB2 8EA, United Kingdom
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103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

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www.cambridge.org

Information on this title: www.cambridge.org/9781107141421

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First published 2017

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

ISBN 978-1-107-14142-1 Hardback

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Contents

<i>Foreword</i>	<i>page xi</i>
<i>Preface</i>	xiii
<i>Acknowledgements</i>	xv
<i>Table of Cases</i>	xvi
<i>Table of Statutes</i>	xviii
<i>Table of Treaties and UN Documents</i>	xx
1 Theoretical and Historical Foundations of the Right to Equal Recognition before the Law	1
1.1 Introduction	1
1.2 Liberal Political Theory in Human Rights Law: Prioritizing Individual Rights	2
1.3 Equal Recognition before the Law and the Social Contract	4
1.4 The Evolution of the Right to Equal Recognition before the Law	6
1.5 Equality and Non-discrimination: The Application to Cognitive Disability	8
1.6 Conclusion	14
2 The Meaning of the Right: Interpreting Article 12 of the CRPD	15
2.1 Framing Article 12 of the CRPD	15
2.2 Treaty Interpretation	16
2.3 The Object and Purpose of the CRPD	17
2.4 Interpreting the Text of Article 12 of the CRPD	21
2.5 The General Comment on Article 12	27
2.6 Summary of Article 12 Interpretation	28
2.7 Article 12 as a Civil and Political Right	30
2.8 Conclusion	37

3	The Significance of Article 12 of the CRPD: Legal Capacity as Legal Personhood and the Importance of Autonomy	38
3.1	Introduction	38
3.2	Legal Personhood and Liberty	39
3.3	Autonomy	49
3.4	Conclusion	53
4	Theoretical Tensions in Article 12 of the CRPD: Autonomy versus Paternalism and Liberty versus Social Support	55
4.1	Introduction	55
4.2	Opposites Attract: Marriage of Individual Liberty and State Protection in Article 12 of the CRPD	55
4.3	Autonomy versus Paternalism?: Balancing the Rights	57
4.4	Liberty and Social Support: Article 12 and Relational Autonomy	62
4.5	Conclusion	63
5	Denying Legal Capacity to People with Cognitive Disability	64
5.1	Introduction	64
5.2	Historical Development of Legal Capacity Law: Exploring The Dichotomy of Capacity and Incapacity	67
5.3	From Medical to Social Model: ‘Capacity’ as a Social Construct	70
5.4	Legal Capacity Regulatory Regimes	73
5.5	Conclusion	96
6	Case Law and the Right to Legal Capacity	98
6.1	Introduction	98
6.2	Using Human Rights Courts to Achieve Change: Examples from the European Court of Human Rights	98
6.3	Using Domestic Courts to Achieve Change: Examples from around the World	134
6.4	Conclusion	144
7	Right to Legal Capacity in all Aspects of Life	145
7.1	Introduction	145
7.2	Decision-Making and Legal Capacity: Defining the Denial of the Right to Legal Agency	145
7.3	Right to Choose Where to Live: Institutional Living, Service Provision, and Decision-Making	152
7.4	Right to Political Participation: Voting Rights, Forming Associations, and Running for Office	155

Contents

ix

7.5	Right to Health Care: Informed Consent, Mental Health, and Forced Treatment	156
7.6	Commercial Transactions: Contract Law and Decision-Making	160
7.7	Criminal Law: Unfitness to Plead and the Insanity Defence	162
7.8	Big Questions: Limited Communication and Other Hard Cases	165
7.9	Case Studies of Reform	168
7.10	Conclusion	175
8	The Nature of the Support Paradigm for People with Cognitive Disability	176
8.1	Introduction	176
8.2	Support to Exercise Legal Capacity	177
8.3	The Role of Supported Decision-Making in Moral Philosophy and Recognition of Personhood of People with Cognitive Disability	179
8.4	Exploring Supported Decision-Making: Prosthesis Model and Dependency Relationships	181
8.5	State Role in Regulating Supported Decision-Making	186
8.6	A Case Study on Supports	187
8.7	Principles for Safeguarding Supported Decision-Making	190
8.8	Avoiding Overregulation	192
8.9	Importance of Organic Formulation: Segregation of People with Cognitive Disability as a Barrier	194
8.10	Ensuring Support Systems Do Not Segregate	197
8.11	Dangers and Safeguards	199
8.12	Conclusion	202
9	Good Practice in Supports for the Exercise of Legal Capacity	203
9.1	Introduction	203
9.2	British Columbia, Canada: The Representation Agreement Act	204
9.3	South Australia: Supported Decision-Making Pilot	206
9.4	Sweden: The Abolition of 'Legal Incompetence' and the Establishment of Support	210
9.5	Bulgaria: Campaign for Supported Decision-Making	213
9.6	Conclusion	214

10	Future Directions in Research and the Pragmatics of Change	216
10.1	Introduction	216
10.2	Rights-Based Research: Co-production and Engaging People with Cognitive Disability in Research	216
10.3	Legal Research: Areas of Law to Examine in Light of Article 12	218
10.4	Empirical Research: Rights-Based Research on Supported Decision-Making	219
10.5	Social Change: Implementing Article 12	219
10.6	Recommendations and Conclusion	223
10.7	Conclusion	229
	<i>Bibliography</i>	232
	<i>Index</i>	248

Foreword

This book comes at an opportune moment. In the first decade of the twenty-first century, the drafters of the UN Convention on the Rights of Persons with Disabilities stumbled upon something long known by many across various disciplines. It turns out that the standard account of what it means to be human – pivoting on the essential defining characteristic of reason – is no longer standard. Indeed, it is questionable if it ever was. The Enlightenment – not known as the ‘age of reason’ for nothing – was of course one of the defining moments in world history. But it probably had the largely accidental effect of narrowing down our understanding of the ‘essence’ of personhood – an essence that telescoped narrowly into cognitive ability.

We now know that understanding the essence of personhood as cognitive ability is not true – indeed we all intuit it not to be true in our own lives. The diversity of world cultures and even religions pays scant attention to reason. Hard science is demonstrating daily the importance of emotion and intersubjectivity. Even economics is warming to the idea of irrationality as the prime basis for human action. So, depending on your view, the standard account of what it means to be human is either under constant scrutiny from a diversity of disciplinary insights, or, the extent to which it was never standard is being steadily revealed.

Why is this book opportune? Dean Roscoe Pound long preached that all law inevitably decays – that its original animating ideas fade. The pillars to doctrine shift. Yet it typically takes the law a long time to catch up. Ideas tend to ossify in law and become relatively immune to scrutiny. The law, it seems, as the encrustation of our communal values, is the last to change. What we are witnessing now is a transitional moment – we know the base has shifted but the law cannot let go of reason and cognition as the essence of what

it means to be human. It's hard to change the underlying base completely and quickly. So it is in a sense highly predictable that the law has the greatest of difficulties in letting go of an outdated paradigm.

This book points to the underlying shift of understanding that is slowly taking place in law (taking the emphasis off cognition), tracks processes of law reform so far (which contain many compromises) and adduces a future research agenda that can help sustain and drive the reform process forward and into territory that is not as beholden to reason as it was in the past. Along the way it explains notions of equality and human agency. But in essence it is about human personhood. It will be of inestimable value to those interested not just in the arcane debates over human agency and legal capacity (not to mention the future of a narrower and non-paternalistic protection agenda) but also in different renderings of what it means to be human.

Gerard Quinn

Preface

In 2008, I entered a hotel lobby in midtown Manhattan. I was a second-year law student. I knew what I wanted – to be a part of the struggle for social justice and the human rights of people with disability. I was meeting a disability activist, Tina Minkowitz. I saw a short figure coming towards me. I recognized Tina from the pictures and YouTube videos I had researched before the meeting. She is a leader in the international psycho-social disability rights movement. We sat down in the busy lobby on a purple sofa in the corner of the room.

Tina is a survivor of forced psychiatric treatment, and during our meeting she shared with me her experiences. It was a window into a desperately flawed legal structure that discriminatorily denies people the legal right to make decisions in their own lives. I shared with her the mantra of my family home: “*I make good decisions.*” My sister has Prader-Willi Syndrome, which makes it difficult for her to make decisions around food. Her unique hormonal mix makes her feel hungry all the time, and she also has low muscle tone and low metabolism that make her only able to have a very limited number of calories every day. People with her disability have eaten themselves to death from stomach rupture. Her biology is working against her from multiple angles. Every meal, every day, is an exercise in supporting her without imposing decisions on her. My whole family now is attuned to this – supporting each other through life and decisions without paternalistically intervening. Tina was telling me that our daily struggle was an international struggle, a rights struggle, and a movement that needed more people who understood its core: people with cognitive disability must have the same right to make decisions and have those decisions legally recognized as others.

At the time, that international struggle had, very recently, achieved the victory of the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD), a binding international human rights

treaty. The CRPD includes, for the first time, an enumeration of the right to equal recognition before the law that requires respect for the right to legal capacity on an equal basis for people with disability. Human rights law finally enshrined a legal right for people with disability to have their decisions respected in law on an equal basis to people without disability. I left the hotel lobby feeling nervous and excited. My family's struggle and my sister's struggle were suddenly connected to something bigger than us.

Six years later, on 8 April 2014, I sat in my office in Galway, Ireland, as the United Nations Committee on the Rights of Persons with Disabilities adopted the General Comment on the Right to Equal Recognition Before the Law and thanked myself and my colleague, Eilíonóir Flynn, for assistance and support in drafting the comment. It enumerates the right of people with disabilities to have legal recognition of their decision-making on an equal basis with others and describes the obligations of States Parties to secure that right.

This book is based on my personal experiences of disability as well as extensive research and interaction in the field. My aim was to provide a description of the right to equal recognition before the law, an explanation of how that right is denied to people with cognitive disability, and possible solutions. The hope is that it is useful to other academics as it provides an original examination of the right as well as the effect of the right on the lives of people with cognitive disability. It also aims to provide practical definitions and explanations that could serve as a resource for government, policy makers, and other potential agents of change in the area of legal capacity law and policy.

Acknowledgements

I would like to thank my partner, Matthias Schmid, for his love, understanding and support.

When I submitted the manuscript for this book, I was five months pregnant with my daughter, Noa. My joyous anticipation of her arrival motivated me through the writing process. Her little kicks were beautiful reminders of the energy and strength that was soon to come. She was born prematurely one month later, she was bigger than the doctors expected, and she was breathing well. When she was four days old, she fought a valiant struggle against an antibiotic resistant ‘superbug’ in the hospital. The bacteria were too much for her little body. She died the morning of her fifth day in this world. My partner and I cherish every moment we had with our beautiful Noa – including the strength that she gave me throughout the writing of this book.

The funding for my PhD research, which was the basis of the research for this book, came from the Disability Rights Expanding Accessible Markets Initial Training Network funded under a European Union, FP7, Marie Curie Grant (Project ID: 265057).

I would also like to acknowledge the assistance and hard work of the Law Research Service of Melbourne Law School and the support of my fellow academics at the University of Melbourne; in particular, Professor Bernadette McSherry for her mentorship. In addition, I would like to thank Dr Eilionóir Flynn for her comments on an early draft of this book and Professors Gerard Quinn and Amita Dhanda for their guidance on the early research that went into this book.

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- Hirst v. United Kingdom* (No. 2) (74025/01) (2006) 42 EHRR 41 105
- H.L. v. United Kingdom* (45508/99) (2005) 40 EHRR 32 99, 103, 120
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Table of Cases

xvii

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Table of Statutes

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- Civil Code of Peru (1984) 171
- Commonwealth Electoral Act 1918 (Cth) (Australia) 155–6
- Criminal Law (Sexual Offences) Act 1993 (Ireland) 61, 67
- Family Act 2014 (Croatia) 174
- Fundamental Law of Hungary 2011 64, 105
- General Health Act No. 26842 (Peru) 168–71
- Guardianship and Administration Act 1986 (Victoria, Australia) 74, 87
- Lunacy Regulation (Ireland) Act 1871 65, 69, 172
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- New York Mental Hygiene Law 65, 78, 81, 88
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- The Mental Capacity Act 2005 (Commencement No.1) (England and Wales) Order 2007 90
- The Rights of Persons with Disabilities Bill 2011 (India) 65, 223

Table of Statutes xix

The Rights of Persons with Disabilities Bill 2012 (India) 65
The Rights of Persons with Disabilities Bill 2014 (India) 65
Trial of Lunatics Act 1883 (United Kingdom) 69

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 xvi 31, 46
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