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.

Anna Arstein-Kerslake is an academic at Melbourne Law School and the Academic Convenor of the Disability Research Initiative (DRI) at the University of Melbourne. She is the founding Director of the Disability Human Rights Clinic (DHRC) at Melbourne Law School. Prior to coming to Melbourne, she held a Marie Curie Research Fellowship at the National University of Ireland, Galway. She has participated widely in consultation with governments and other bodies, including the United Nations, the World Health Organisation, the United Kingdom Ministry of Justice, the Irish Ministry of Justice, Amnesty Ireland, Interights, and the Mental Disability Advocacy Center, among others.

CAMBRIDGE DISABILITY LAW AND POLICY SERIES

Edited by Peter Blanck and Robin Paul Malloy

The Disability Law and Policy series examines these topics in interdisciplinary and comparative terms. The books in the series reflect the diversity of definitions, causes, and consequences of discrimination against persons with disabilities while illuminating fundamental themes that unite countries in their pursuit of human rights laws and policies to improve the social and economic status of persons with disabilities. The series contains historical, contemporary, and comparative scholarship crucial to identifying individual, organizational, cultural, attitudinal, and legal themes necessary for the advancement of disability law and policy.

The book topics covered in the series also are reflective of the new moral and political commitment by countries throughout the world towards equal opportunity for persons with disabilities in such areas as employment, housing, transportation, rehabilitation, and individual human rights. The series will thus play a significant role in informing policy makers, researchers, and citizens of issues central to disability rights and disability antidiscrimination policies. The series grounds the future of disability law and policy as a vehicle for ensuring that those living with disabilities participate as equal citizens of the world.

Books in the Series

Ruth Colker, *When Is Separate Unequal? A Disability Perspective*, 2009

Larry M. Logue and Peter Blanck, *Race, Ethnicity, and Disability: Veterans and Benefits in Post–Civil War America*, 2010

Lisa Vanhala, *Making Rights a Reality? Disability Rights Activists and Legal Mobilization*, 2010

Alicia Ouellette, *Bioethics and Disability: Toward a Disability-Conscious Bioethics*, 2011

Eilionóir Flynn, *From Rhetoric to Action: Implementing the UN Convention on the Rights of Persons with Disabilities*, 2011

Isabel Karpin and Kristin Savell, *Perfecting Pregnancy: Law, Disability, and the Future of Reproduction*, 2012

Arie Rimmerman, *Social Inclusion of People with Disabilities: National and International Perspectives*, 2012

Andrew Power, Janet E. Lord, and Allison S. deFranco, *Active Citizenship and Disability: Implementing the Personalisation of Support for Persons with Disabilities*, 2012

Lisa Schur, Douglas Kruse, and Peter Blanck, *People with Disabilities: Sidelined or Mainstreamed?*, 2013

Eliza Varney, *Disability and Information Technology: A Comparative Study in Media Regulation*, 2013

Jerome Bickenbach, Franziska Felder, and Barbara Schmitz, *Disability and the Good Human Life*, 2013

Robin Paul Malloy, *Land Use Law and Disability: Planning and Zoning for Accessible Communities*, 2014

Peter Blanck, *eQuality: The Struggle for Web Accessibility by Persons with Cognitive Disabilities*, 2014

Arie Rimmerman, *Family Policy and Disability*, 2015

Anna Arstein-Kerslake, *Restoring Voice to People with Cognitive Disabilities: Realizing the Right to Equal Recognition before the Law*, 2017

Arie Rimmerman, *Disability and Community Living Policies*, 2017

Paul Harpur, *Discrimination, Copyright and Equality: Opening the E-Book for the Print-Disabled*, 2017

Restoring Voice to People with Cognitive Disabilities

REALIZING THE RIGHT TO EQUAL RECOGNITION BEFORE THE LAW

ANNA ARSTEIN-KERSLAKE
Melbourne Law School

CAMBRIDGE
UNIVERSITY PRESS

CAMBRIDGE
UNIVERSITY PRESS

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/9781107141421

First published 2017

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

ISBN 978-1-107-14142-1 Hardback

Contents

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

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 transitionary 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, Eilionóir 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.

Table of Cases

CASE

Table of Statutes

STATUTE

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

Table of Treaties and UN Documents

TREATY

Charter of the United Nations, 26 June 1945, in force 24 October 1945, 1 UNTS xvi 31, 46

Committee on Economic, Social and Cultural Rights, General Comment No. 5 (1994) – Persons with disabilities, 9 December 1994, UN Doc E/1995/22 32

Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Brazil, 29 September 2015, UN Doc CRPD/C/BRA/CO/1 28

Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Kenya, 30 September 2015, UN Doc CRPD/C/KEN/CO/1 28

Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities (Peru), 16 May 2012, UN Doc CRPD/C/PER/CO/1 29, 74, 169

Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities (Spain), 19 October 2011, UN Doc CRPD/C/ESP/CO/1 25, 73, 183

Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by States parties under article 35 of the Convention: Concluding observations of the Committee on the Rights of Persons with Disabilities (Tunisia), 13 May 2011, UN Doc CRPD/C/TUN/CO/1 73, 183

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

Committee on the Rights of Persons with Disabilities, 'Draft General Comment on Article 12 of the Convention – Equal Recognition before the Law' (Advance Unedited Version), 2–13 September 2013 16, 74, 75, 78
Committee on the Rights of Persons with Disabilities, General Comment No. 1 (2014) – Article 12: Equal recognition before the law, 19 May 2014, UN Doc CRPD/C/GC/1 27, 146
Congress of the Republic of Peru, Transcript of the meeting of the Committee on Health and Population, 4 April 2012 169
Convention for the Protection of Human Rights and Fundamental Freedoms, 4 November 1950, in force 3 September 1953, 213 UNTS 222 99
Convention on the Elimination of All Forms of Discrimination against Women, 18 December 1979, in force 3 September 1981, 1249 UNTS 13 23
Convention on the Rights of the Child, 20 November 1989, in force 2 September 1990, 1577 UNTS 3 40
Convention on the Rights of Persons with Disabilities, 13 December 2006, in force 3 May 2008, 2515 UNTS 3 10, 15, 38, 55, 64, 73, 101, 154, 178, 207
Human Rights Committee, General Comment No. 13 (1984) – Article 14 (Administration of justice): Equality before the courts and the right to a fair and public hearing by an independent court established by law, 13 April 1984 36
Human Rights Committee, General Comment No. 31 (2004) – The nature of the general legal obligation imposed on States Parties to the Covenant, 26 May 2004, UN Doc CCPR/C/21/Rev.1/Add. 13 34
International Covenant on Civil and Political Rights, 16 December 1966, in force 23 March 1976, 999 UNTS 171 22, 46, 90, 163, 178, 203
International Covenant on Economic, Social and Cultural Rights, 16 December 1966, in force 3 January 1976, 993 UNTS 3 2, 4, 24, 30, 31, 35
Office of the United Nations High Commissioner for Human Rights (OHCHR), 'Background conference document prepared by the Office of the United Nations High Commissioner for Human Rights: Legal capacity', 1–12 August 2005, UN Doc A/AC.265/2005/CRP.5 4, 23
Optional Protocol to the Convention on the Rights of Persons with Disabilities, 30 March 2007, in force 3 May 2008, 2518 UNTS 283 65
Optional Protocol to the International Covenant on Civil and Political Rights, 19 December 1966, in force 23 March 1976, 999 UNTS 171 3
Optional Protocol to the International Covenant on Economic, Social and Cultural Rights, 5 March 2009, UN Doc A/RES/63/117 3
Protocol to the Convention for the Protection of Human Rights and Fundamental Freedoms, 20 March 1952, in force 18 May 1954, 213 UNTS 262 99

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

United Nations Conference on the Law of Treaties, First session, 26 March–24 May 1968, UN Doc A/CONF.39/11 16
United Nations Conference on the Law of Treaties, First and second sessions, 26 March–24 May 1968 and 9 April–22 May 1969, UN Doc A/CONF.39/11/Add.2 16
United Nations Conference on the Law of Treaties, Second session, 9 April–22 May 1969, UN Doc A/CONF.39/11/Add.l 16
United Nations Economic and Social Council, Commission on Human Rights, Draft of a Resolution for the General Assembly Submitted by the Representative of India, 31 January 1947, UN Doc E/CN.4/11 6
United Nations Economic and Social Council, Commission on Human Rights, Drafting Committee on an International Bill of Human Rights, First Session Report, 1 July 1947, UN Doc E/CN.4/21 6
United Nations Economic and Social Council, Commission on Human Rights, Report of the Drafting Committee to the Commission on Human Rights, 21 May 1948, UN Doc E/CN.4/95 6
United Nations Economic and Social Council, Report of the Commission on Human Rights, 17 December 1947, UN Doc E/600 6
United Nations General Assembly, Draft International Covenants on Human Rights, 10 December 1963, UN Doc A/5655 33
United Nations General Assembly, Draft International Covenant on Human Rights and measures of implementation: Future work of the Commission on Human Rights, 4 December 1950, UNGA res 421(V) 32
United Nations General Assembly, Preparation of two Draft International Covenants on Human Rights, 5 February 1952, UNGA res A/RES/543(VI) Universal Declaration of Human Rights, 10 December 1948, GA Res 217A (III), UN Doc A/810 32
Vienna Convention on the Law of Treaties, 23 May 1969, in force 27 January 1980, 1155 UNTS 331 16–7, 21, 156–7
Vienna Declaration and Programme of Action, 12 July 1993, UN Doc A/CONF.157/23 3, 35