

Cambridge University Press & Assessment

978-0-521-76520-6 — Perfecting Pregnancy: Law, Disability, and the Future of Reproduction

Isabel Karpin , Kristin Savell

Frontmatter

[More Information](#)

PERFECTING PREGNANCY

Prenatal and preimplantation testing technologies have offered unprecedented access to information about the genetic and congenital makeup of our prospective progeny. Future developments such as preconception testing, noninvasive prenatal testing, and more extensive preimplantation testing promise to increase that access further still. The result may be greater reproductive choice, but it also increases the burden on women and men to avail themselves of these technologies in order to avoid having a child who has a disability. The overwhelming question for legislators has been whether and, if so, how to regulate the use of these technologies in the face of compelling but seemingly contradictory claims about the advancement of reproductive choice and the dangers of eugenic or discriminatory effects. This book examines the evolution of this legislative oversight across a number of jurisdictions and explores the tensions and ambiguities that inform these laws.

Isabel Karpin is a Professor in the Faculty of Law, University of Technology, Sydney.

Kristin Savell is an Associate Professor in the Faculty of Law, University of Sydney.

Cambridge Disability Law and Policy Series

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 toward 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

Eilionoir 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

Cambridge University Press & Assessment

978-0-521-76520-6 — Perfecting Pregnancy: Law, Disability, and the Future of Reproduction

Isabel Karpin , Kristin Savell

Frontmatter

[More Information](#)

PERFECTING PREGNANCY

Law, Disability, and the Future of Reproduction

Isabel Karpin

University of Technology, Sydney

Kristin Savell

University of Sydney



CAMBRIDGE
UNIVERSITY PRESS

Cambridge University Press & Assessment

978-0-521-76520-6 — Perfecting Pregnancy: Law, Disability, and the Future of Reproduction

Isabel Karpin, Kristin Savell

Frontmatter

[More Information](#)



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/9780521765206

© Isabel Karpin and Kristin Savell 2012

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 2012

First paperback edition 2013

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

Library of Congress Cataloging-in-Publication data

Karpin, Isabel.

Perfecting pregnancy : law, disability, and the future of reproduction / Isabel Karpin, Kristin Savell.

p. cm. – (Cambridge disability law and policy series)

Includes bibliographical references and index.

ISBN 978-0-521-76520-6 (hardback) – ISBN 978-0-521-75839-0 (paperback)

1. Human reproduction – Law and legislation 2. Pregnancy – Law and legislation.

3. Pregnant women – Legal status, laws, etc. I. Savell, Kristin, 1968– II. Title.

K3611.A77K37 2012

344.04'19–dc23 2011050126

ISBN 978-0-521-76520-6 Hardback

ISBN 978-0-521-75839-0 Paperback

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.

Contents

<i>Acknowledgments</i>	<i>page ix</i>
Introduction	1
1. Disability	13
2. Risk	59
3. Terminations	106
4. Deselections	157
5. Interpretations	239
6. Futures	296
Conclusion	340
<i>Bibliography</i>	349
<i>Index</i>	375

Acknowledgments

We share responsibility for this book as a whole as each chapter is the collaborative effort of both authors. However, Kristin took primary responsibility for writing Chapters 1, 3, and 5 while Isabel took primary responsibility for writing Chapters 2, 4, and 6.

Our very special thanks must go to Laura Crommelin, Andrew Dyer, Claire Deakin, Lauren Hustler, and Eloise Chandler, who worked as our research assistants during the development and writing of this book. We are immensely grateful for their patience and commitment. Thanks also to the clinicians and regulators who gave up their valuable time to speak with us so candidly about their experiences with the law and testing technologies. They gave us special insights that would not otherwise have been accessible.

The research for this book was supported by an Australian Research Council Discovery Grant (DP0988103), and we would especially like to thank Janice Mountford and Terry Carney for assisting us with the preparation of the grant application. It should also be noted that the views expressed herein are those of the authors and are not necessarily those of the Australian Research Council.

We would also like to thank a number of our colleagues past and present who have provided a nurturing intellectual environment and the space to undertake this task. Jointly we thank Belinda Bennett, Marie Fox, and Emily Jackson for their intellectual generosity and Karen O'Connell for being a great friend and sounding board.

Acknowledgments

Kristin would like to thank other friends and colleagues at Sydney University – especially Cameron Stewart, Roger Magnusson, and David Rolph, who have all shown great enthusiasm for the project – and Mark Findlay and Terry Carney for sharing their wisdom and experience at critical times. She would also like to express gratitude to her students in the Masters of Health Law program at Sydney University, who have debated and challenged her on many of the issues raised here, and past mentors Carl Elliott, Shauna Van Praagh, Rene Provost, and Jeremy Webber for getting her started on the intellectual journey that led to this point.

Isabel would like to thank overseas friends and colleagues; Martha Fineman, an untiring mentor and inspirational feminist legal scholar who set her on an academic path; Roxanne Mykitiuk, a longtime collaborator, who first drew her attention to many of the issues raised in this book; and Sarah Franklin, Rosemary Hunter, Jeff Nisker, and Sally Sheldon for their exchange of ideas and intellectual support. Closer to home she would especially like to thank Jenni Millbank, collaborator, colleague, and friend across two universities (Sydney and UTS), and other UTS colleagues Anita Stuhmcke, Jill McKeough, Lesley Hitchens, and Laurie Berg, who provide support and encouragement on a daily basis. She would also like to express her gratitude to former Sydney University colleagues Reg Graycar, Julie Stubbs (now UNSW), and Helen Irving.

These friends, colleagues, and mentors have all, in various ways, supported and fostered our academic careers, and, without their support, we would not have been able to write this book. Our thanks too must go to our editor, John Berger, and the team at Cambridge University Press for their expertise in shepherding the manuscript through the editorial process. Finally, the authors would like to thank each other for a stimulating, productive, and richly rewarding collaboration.

On a personal note we must, of course thank each of our loving friends and family who have supported us both through thick and thin:

Acknowledgments

For Isabel: special thanks to Alwyn, Phyllis, Max, Angela, Zoe, Alex, Matthew, and especially my beloved David Ellison (with whom I have had the great privilege to write) and our darling children, Zach and Ondine.

For Kristin: special thanks to Margaret, Terry, Katrina, and Gemma. My deepest gratitude is to my partner, David, and our beautiful girls, Tara and Remy, for their unqualified love and support.