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978-0-521-11030-3 - Bioethics and Disability: Toward a Disability-Conscious Bioethics

Alicia Ouellette

Frontmatter

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## BIOETHICS AND DISABILITY

*Bioethics and Disability* provides tools for understanding the concerns, fears, and biases that have convinced some people with disabilities that the health care setting is a dangerous place and some bioethicists that disability activists have nothing to offer bioethics. It wrestles with the charge that bioethics as a discipline devalues the lives of persons with disabilities, arguing that reconciling the competing concerns of the disability community and the autonomy-based approach of mainstream bioethics is not only possible, but essential for a bioethics committed to facilitating good medical decision making and promoting respect for all persons, regardless of ability.

Through in-depth case studies involving newborns, children, and adults with disabilities, *Bioethics and Disability* proposes a new model for medical decision making that is mindful of and knowledgeable about the fact of disability in medical cases. Disability-conscious bioethics will bring together disability experts and bioethicists to identify and mitigate disability bias in our health care systems.

Alicia Ouellette is a Professor of Law at Albany Law School and a Professor of Bioethics in the Union Graduate College/Mt. Sinai School of Medicine Bioethics Program. Her recent publications include *Shaping Parental Authority over Children's Bodies* and *Growth Attenuation, Parents' Choices, and the Rights of Disabled Children*. She is also a coeditor (with Laurence McCullough and Robert Baker) of the *Cambridge Dictionary of Bioethics* (2011).

Before joining the law faculty, she served as an Assistant Solicitor General for the State of New York. As ASG, she briefed and argued more than 100 appeals on issues ranging from termination of treatment for the terminally ill to the responsibility of gun manufacturers for injuries caused by handguns. She continues her advocacy work in select cases and was lead counsel on the law professors' brief submitted in support of same-sex couples who sought the right to marry in New York State.

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### *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

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# **BIOETHICS AND DISABILITY**

## **Toward a Disability-Conscious Bioethics**

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Cambridge, New York, Melbourne, Madrid, Cape Town,  
Singapore, São Paulo, Delhi, Tokyo, Mexico City

Cambridge University Press

32 Avenue of the Americas, New York, NY 10013-2473, USA

[www.cambridge.org](http://www.cambridge.org)

Information on this title: [www.cambridge.org/9780521110303](http://www.cambridge.org/9780521110303)

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First published 2011

Printed in the United States of America

*A catalog record for this publication is available from the British Library.*

*Library of Congress Cataloging in Publication data*

Ouellette, Alicia.

Bioethics and disability: toward a disability-conscious bioethics / Alicia Ouellette.

p. cm. – (Disability law and policy series)

Includes bibliographical references and index.

ISBN 978-0-521-11030-3 (hardback)

1. People with disabilities – Legal status, laws, etc. – United States. 2. Discrimination against people with disabilities – Law and legislation – Moral and ethical aspects – United States. 3. Medical ethics – United States. I. Title.

KF480.O94 2011

174'.957–dc22 2011000624

ISBN 978-0-521-11030-3 Hardback

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Frontmatter

[More information](#)

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*To Jacob, Molly, and Sam. You give me reason to believe.*

Contents

<i>Preface</i>	<i>page xiii</i>
Introduction	1
1. The Struggle: Disability Rights versus Bioethics	12
I. An Introduction to and Short History of the Disability-Rights Community	15
II. Introduction to and a Brief History of Bioethics	29
2. Clashing Perspectives and a Call for Reconciliation	47
I. Perspectives and Teachings in Bioethics	49
II. Perspectives and Teachings from the Disability-Rights Community	57
III. Points of Friction	67
IV. A Call for Peace	68
3. Infancy	72
I. The Case of Sydney Miller	78
A. Views from the Disability Community	86
B. Views from Bioethics	91
II. The Case of Emilio Gonzalez	105
A. Views from the Disability Community	109
B. Views from Bioethics	119
III. Observations	126

Contents

4.	Childhood	137
	I. Lee Larson’s Boys	140
	A. Views from the Deaf and Disability Communities	146
	B. Views from Bioethics	153
	II. The Case of Ashley X	161
	A. Views from the Disability Community	169
	B. Views from Bioethics	173
	III. Observations	183
	Addendum: National Association for the Deaf Position Statement on Cochlear Implants	188
5.	The Reproductive Years	194
	I. The Case of Valerie N.	201
	A. Views from Bioethics and the Disability Community	206
	II. The Case of Bob and Julie Egan	214
	A. Views from Bioethics and the Disability Community	220
	III. Observations	230
6.	The Adult Years	237
	I. Mary’s Case	241
	A. Views from the Disability Community	242
	B. Views from Bioethics	244
	II. The Case of Larry McAfee	245
	A. Views from the Disability Community	248
	B. Views from Bioethics	253
	III. The Case of Scott Matthews	258
	A. Views from the Disability Community	262
	B. Views from Bioethics	263
	IV. Observations	266

Contents

7.	The End of Life	271
	I. The Case of Theresa Schiavo	273
	II. The Case of Sheila Pouliot	281
	III. Views from the Disability Community	289
	IV. Views from Bioethics	295
	V. Observations	298
	A. Constitutional Implications	300
	B. Discrimination	305
8.	Toward a Disability-Conscious Bioethics	315
	I. Working toward Reconciliation	317
	A. Listening and Understanding	318
	B. Acknowledging Fears, Biases, and Alliances	327
	C. Unearthing Common Ground	329
	II. Taking Action: Developing Disability-Consciousness in Bioethics	331
	A. Principles	333
	B. Protecting Against Abuse: The Role of Process	342
	III. Disability-Conscious Bioethics in Action	344
	A. Disability in Infancy: Sydney Miller and Emilio Gonzalez	345
	B. Disability in Childhood: Lee Larson’s Boys, Ashley X	350
	C. The Reproductive Years: William Peace, Valerie, and the Egans	356
	D. The Adult Years: Mary, Larry McAfee, and Scott Matthews	357
	E. End-of-Life Decisions: Sheila Pouliot and Terri Schiavo	361
	IV. Conclusion – and a Call to Action	362
	<i>Index</i>	367



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## Preface

Much has changed during the years in which I have been working on this book. For one thing, disability is no longer a shadow issue in bioethics. When I first started my work, I rarely heard the phrase “disability perspective” in discussions with bioethicists. A three-day conference might include a single sparsely attended session on disability issues. Disability is now part of the conversation. More and more often, articles by disability experts appear in bioethics journals and texts. In the past year alone, I have participated in several national bioethics conferences devoted exclusively to disability issues. These developments give me hope that the field is ripe for change. Nonetheless, the transformative change I’d like to see – a movement toward a bioethics that incorporates disability as a central issue and engages disability experts in the enterprise – will take more than a series of conferences and articles. The real work will take place on the ground floor – in medical education, in hospitals, in the courtroom, in law schools, in government – wherever the work of bioethics is done. This book is my contribution to that work.

In the end, this is a book about collaboration, which is especially fitting given the teamwork that went into its creation. Although the mistakes and omissions are mine alone, I share credit for the worthwhile sections with many people. I am enormously grateful to my colleagues at Albany Law School, especially Dede Hill and Christine Chung who provided invaluable feedback and support in every possible form

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Frontmatter

[More information](#)

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and at all times of day and night. I am also grateful to Dale Moore and Kathy Katz for convincing me I had something worthwhile to say; to James Gathii for being my constant sounding board; and to Tim Lytton, who always asks the hardest questions. From outside the law school, I owe special thanks to Bob Baker, who took a chance in giving me my first position in bioethics, to William Peace, whose challenging feedback shaped my arguments, and to Kathy Cerminara, Elizabeth Pendo, Jane Greenlaw, Jennifer Bard, Amy Campbell, Sean Philpott, and all the others who have commented on drafts, pushed my ideas forward, or simply disagreed with me. This project would have been impossible without the incredible efforts of Fredd Brewer and Laurie Dayter who kept me on task through the years. A special thanks to Fredd for refusing to let me sweat the small stuff during the last, final push. I have been fortunate to have the help of many capable student research assistants over the years. Jessie Cardinale, Alaina Bergerstock, and Ashley Torre deserve special note for their enormous contributions to this book.

Sadly, two of the people who taught me most of what I know about life with disability, Harriet McBryde Johnson and Paul Longmore, died while I was writing the manuscript. This would not have been the same book, and I would not be the same person, had I not been lucky enough to have crossed their paths. Their written contributions and life examples will continue to educate and inspire generations to come, but I mourn their early deaths and will forever regret that they did not live long enough to see how far I've come, and to explain the ways I still don't get it.

Finally, I thank my family. You gave me the space and strength to carry on. You are my everything. I hope I've done you proud.