

# THE DISABILITY BIOETHICS READER

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[NB: The overview and TOC below are *drafts*; the final published version may be different]

## Volume Overview:

Introductory and advanced textbooks in bioethics focus almost entirely on issues that disproportionately affect disabled people and that centrally deal with becoming or being disabled. However, such textbooks typically omit critical philosophical reflection on disability, lack engagement with decades of empirical and theoretical scholarship spanning the social sciences and humanities in the multidisciplinary field of disability studies, and avoid serious consideration of the history of disability activism in shaping social, legal, political, and medical understandings of disability over the last fifty years. For example, longstanding discussions on topics such as euthanasia, physician aid-in-dying, pre-implantation genetic diagnosis, prenatal testing, selective abortion, enhancement, patient autonomy, beneficence, non-maleficence, and health care rationing all tend to be premised on shared and implicit assumptions regarding disability, and especially in relation to quality of life, yet with too little recognition of the way that “disability” is itself a topic of substantial research and scholarly disagreement across multiple fields. This is not merely a concern for academic and medical education; as an applied field tied to one of the largest economic sectors of most industrialized nations, bioethics has a direct impact on healthcare education, practice, policy, and, thereby, the health outcomes of existing and future populations.

It is in light of these pressing issues that *The Disability Bioethics Reader* is the first reader to introduce students to core bioethical issues and concepts through the lens of critical disability studies and philosophy of disability. *The Disability Bioethics Reader* will include over thirty-five chapters covering key areas such as: critical histories and state-of-the-field analyses of modern medicine, bioethics, disability studies, and philosophy of medicine; methods in bioethics; concerns at the edge-and end-of-life; enhancement; disability, quality of life, and well-being; prenatal testing and abortion; invisible disabilities; chronic illness; healthcare justice; genetics and genomics; intellectual disability and neurodiversity; ethics and diagnosis; and epistemic injustice in healthcare.

<b>I. History, Medicine, and Disability</b>	
1. A Short History of Modern Medicine and Disability	Michael Rembis
2. Eugenics, Disability, and Bioethics	Robert Wilson
3. Disability Theory	Joel Michael Reynolds
<b>II. Bioethics: Past &amp; Present</b>	
4. A Critical History of Bioethics	John Evans
5. Methods within Bioethics	Alison Reiheld
6. Selections of “Disability Bioethics: From Theory to Practice”	Rosemarie Garland-Thomson
<b>III. Philosophy of Medicine &amp; Phenomenology</b>	
7. Health and the Philosophy of Medicine	Sean Aas
8. The Lived Experiences of Illness	Havi Carel
<b>IV. Prenatal Testing and Abortion</b>	
9. Abortion, Disability Rights, and Reproductive Justice	Elizabeth Dietz
10. Selections of “Where Is the Sin in Synecdoche?”	Anita Silvers & David Wasserman
11. Being Disabled and Contemplating Disabled Children	Jackie Leach Scully

12. Wrongful Birth	Desiree Valentine
<b>V. Disability, The Life Course, and Well-Being</b>	
13. Selections of "Disability, Ideology, and Quality of Life: A Bias in Biomedical Ethics"	Ron Amundson
14. The Challenge of Chronic Conditions: The Case of Chronic Pain	Emma Sheppard
15. Chronic Illness and Well-being	Lydia Nunez Landry
16. Disability and Aging Studies: Obstacles and Opportunities	Erin Lamb
<b>VI. Issues at the Edge &amp; End of Life</b>	
17. The Case of Jahi McMath	Yolonda Wilson
18. Minimally Conscious States, Disability, and Civil Rights	Joseph J. Fins
19. Bioethical Issues in Dementia and Alzheimer's Disease	Tia Powell
20. Physician Aid-in-Dying: A Disability Theory of End of Life	Harold Braswell
21. Suicidism and Sanism	Alexandre Baril
<b>VII. Disability, Difference, and Healthcare</b>	
22. Disability Bioethics and Race	Andrea Pitts
23. Deaf Gain and Bioethics	Teresa Blankmeyer Burke
24. Medicalization, Stigma & Health: Insights from Fat Studies	Anna Mollow
25. Disability Bioethics & Trans Health	Jamie L. Nelson
<b>VIII. Intellectual Disabilities, Mental Illness, and Neurodiversity</b>	
26. Defining Mental Illness & Psychiatric Disability	Laura Guidry-Grimes
27. Intellectual Disability, Risk, and Autonomy	David Wasserman & Kevin Mintz
28. Mad Carework: On Inconvenient Complications to Patient Choice and Psychiatric Detention	Erica Hua Fletcher
29. Disability and Temporality: The Case of Ashley X	Christine Wieseler
<b>IX. Disability Bioethics: Connections &amp; New Directions</b>	
30. Feminist Philosophy & Disability Bioethics	Lauren Guilmette
31. Disability Bioethics and Epistemic Injustice	Anita Ho
32. Disability Rights and Non-human Animal Rights	David Peña-Guzmán
<b>X. The Ends of Medicine: Caring, Curing, and Justice</b>	
33. Improving Access within the Clinic	Lisa I. Iezzoni & Nicole Agaronnik
34. Function and the Goals of Biomedical Technology	Joseph Stramondo
35. Why Kindness Isn't Enough: On Justice	Eva Feder Kittay
36. Selections of <i>Brilliant Imperfection</i>	Eli Clare