# THE DISABILITY BIOETHICS READER

Eds. Joel Michael Reynolds & Christine Wieseler

[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 surrounding topics such as euthanasia, physician aid-in-dying, pre-implantation genetic diagnosis, prenatal testing, selective abortion, enhancement, patient autonomy, beneficence, quality of life, and health care rationing all tend to be premised on shared and implicit assumptions regarding disability and quality of life, 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, overall health outcomes.

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 the 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 activism, disability studies, and philosophy of disability; the 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; prenatal testing, selective abortion, and disability theory; genetics and genomics; intellectual disability and neurodiversity; ethics and diagnosis; and epistemic injustice in healthcare.


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| **I. History, Medicine, and Disability** | |
| 1. A Short History of Modern Medicine and Disability | Michael Rembis |
| 2. Eugenics, Disability, and Bioethics | Robert Wilson |
| 3. Disability Theory | Joel Michael Reynolds |
| **II. Bioethics: Past & Present** | |
| 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 |
| **III. Philosophy of Medicine & Phenomenology** | |
| 7. Health and the Philosophy of Medicine | Sean Aas |
| 8. The Lived Experiences of Illness | Havi Carel |
| **IV. Prenatal Testing and Abortion** | |
| 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 |

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| 12. Wrongful Birth | Desiree Valentine |
| **V. Disability, The Life Course, and Well-Being** | |
| 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 |
| **VI. Issues at the Edge & End of Life** | |
| 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 |
| **VII. Disability, Difference, and Healthcare** | |
| 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 |
| **VIII. Intellectual Disabilities, Mental Illness, and Neurodiversity** | |
| 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 |
| **IX. Disability Bioethics: Connections & New Directions** | |
| 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 |
| **X. The Ends of Medicine: Caring, Curing, and Justice** | |
| 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 *Brilliant Imperfection* | Eli Clare |