

DISABILITY BIOETHICS

Introduction to *The Disability Bioethics Reader*

Joel Michael Reynolds and Christine Wieseler

The field of bioethics emerged against a tumultuous backdrop. The not-so-distant history of state-sponsored eugenics in Britain, the USA, and Germany loomed large as highly publicized biomedical events in the middle of the 20th century sparked novel public awareness of the relationship between medicine and ethics (or the lack thereof) across the globe. These included the Tuskegee Study and Guatemala Experiments, Jim Crow medical care, and the development of unprecedented life-sustaining technologies ranging from ventilators to artificial heart valves. Yet, even in its infancy, bioethics was not one field, but many. That is still true today and, in many ways, even more so. “Bioethics” includes academics, medical practitioners of every stripe, policy and public health experts, and, increasingly, scientists whose research ranges across the life sciences. If one considers the impact of modern biomedicine on contemporary life, this should not be surprising. Practices of health care are at once scientific—finding empirical answers, saving lives—and political—concerned with constraints like resource distribution and inflected by a host of legal, social, and political considerations.

In light of this, the questions bioethicists ask are expectedly broad and touch nearly every aspect of life: what purpose does the practice of medicine serve? What does it mean to care for another person? Or for groups of people, non-human animals, land, and the earth itself? Is life sacred? How does one define need, harm, risk, and benefit? What counts as life? Who owns life? Who decides where life begins and ends? Who decides whose care can be withheld or limited and whose cannot? What medical research should be conducted and how, when, where, with whom, and by whom? By exploring questions such as these, *The Disability Bioethics Reader* introduces you to the field of bioethics. Unlike other bioethics readers, however, you will learn about core issues in the field through the lens of, in the light of, research in philosophy of disability and critical disability studies (Wieseler 2015; Davis 2016; Hall 2019; Cureton and Wasserman 2020; Reynolds and Burke 2021).

To explain why we take this approach and to give context to its historical import, let us return to the claim that bioethics is not one field. “Bioethics” is an umbrella term spanning an interdisciplinary, intradisciplinary, and transdisciplinary cluster of inquiries; it is loosely tied together by moral questions that arise in the study of organic life and the many fields, domains, and industries that investigate, engage with, and seek to act upon life’s processes. This cluster

is massive, for it includes any and all investigations of ethical, social, and political issues that arise from the ever-growing intersection of biomedicine, health-related industries, and contemporary life. The range of topics bioethicists study is thus staggering—from the use of human embryonic materials in basic research to the moral status and treatment of chimpanzees or other non-human animals to the proper procedures for vaccine distribution at local, national, and international levels; from the ethical issues facing surgeons, general practitioners, or NICU nurses to the biosecurity risks posed by changes to multilateral geopolitical instruments like NATO to the legal implications of copyright law for therapeutics developed via the contemporary tools of genome editing such as CRISPR-Cas9. The list goes on and on. And it's not just the field of bioethics that is diverse—it is also the professions in which it is practiced or applied and which it supports. There are academic bioethicists, typically people with PhDs whose job entails some combination of teaching, research, and service at a college or university. There are also clinical bioethicists who work in hospitals, of which there are two primary types: people with PhDs in fields such as philosophy or sociology who work alongside doctors and nurses, and people with core training in medicine who have gained expertise in bioethics through programs, seminars, certification, or other sorts of additional educational accreditation and training. Given this breadth in the field of bioethics or, rather, breadth in the many fields and practices that make up what falls under the umbrella term “bioethics,” we will begin by defining what we mean by “disability bioethics.”

I Disability Bioethics

In her ground-breaking 2008 work, *Disability Bioethics: Moral Bodies, Moral Difference*, Jackie Leach Scully writes,

Disability ethics, like feminist ethics, is a form of ethical analysis consciously and conscientiously attentive to the experience of being/having a “different” embodiment. Where feminist ethics' concern is with the non-normativity introduced by gendered bodies, however, disability ethics looks at the embodied effects of impairment.

(11)

Scully makes clear in that book that disability bioethics involves more than merely paying attention to certain pockets of empirical research. It must also involve active uptake and integration of the analysis, understanding, and interpretation of the lived experiences of disabled people. Furthermore, and as we argue in more detail below, it must also involve an ethical commitment to *centering*—not just noting—those experiences. Tellingly, in her 2013 book, *Bioethics and Disability: Toward a Disability-Conscious Bioethics*, Alicia Ouellette makes a related argument, tying it more directly to longstanding concerns over bias against disabled people.

Bioethicists who dismiss the disability perspective are making a mistake...If the evidence [demonstrates] that the story of disability need not be the story of tragedy and that biased and disproven assumptions about life with disability are at play in medical decision-making, then it is the business of bioethics to work with disability experts to figure that out and to work to eliminate that bias.

(2011, 69)

Combining Scully and Ouellette's insights, one arrives at the idea that disability bioethics involves a combination of empirical and non-empirical commitments.¹

In this spirit, *disability bioethics* for us refers to bioethical inquiry that involves, at minimum, the following three aspects:

- 1 A critical relationship to common narratives and “common sense” claims concerning disability.
- 2 Theory and practice rooted in *critical* disability scholarship, with an emphasis placed on testimony by and work from disabled people as well as an emphasis placed on participatory models of research and practice.²
- 3 Inquiry committed to increasing justice and equity for people with disabilities.

Put differently, the last qualification means: disability bioethics is grounded in *disability justice* (Brown 2011, Piepzna–Samarasinha 2018; Lewis 2021). This is contentious, for it raises the question of how one distinguishes between the academic and the activist. Without getting into the weeds of that longstanding debate (see Stramondo forthcoming), if one engages in bioethical inquiry *without* the aim of increasing justice and equity for people with disabilities (not to mention other oppressed groups), we think one is engaged in a very different sort of project than that of this volume and the sort of work we hope becomes mainstream in “mainstream bioethics.” That claim might lead one to wonder: why do we hold onto the term “disability bioethics” and not instead push for a change to what counts as “bioethics” itself sans qualification? It is our hope that eventually it will be a given that “mainstream” bioethics takes the approach we are here advocating, but in the meantime, we find it helpful for pedagogical, research, and other purposes to use a distinct term that picks out, among other things, the three aspects detailed above.

II Appreciating the Need for Disability Bioethics

Bioethicists who don’t “do” disability bioethics often share four types of unexamined assumptions about disability. First, their positions tend to be in line with the medical model of disability, which narrowly and solely conceptualizes disability at the level of an individual’s body (Reynolds 2022). Second, bioethicists too often endorse, implicitly or explicitly, what Elizabeth Barnes terms *bad-difference* views of impairment, which hold that impairment inherently and inevitably reduces quality of life (QOL) and would do so even apart from the removal of social factors such as stigmatization, induced poverty, inaccessibility, and, in a word, inequity (Goering 2008; Barnes 2016; Campbell and Stramondo 2017; Scuro 2018; Amundson 2022). Third, bioethicists’ arguments too often involve biological determinism, biological reductionism, and/or defenses of strong objectivity (Wieseler 2016; Amundson 2022). When bioethicists rely on such suspect accounts, it leads to fundamentally inaccurate conceptions of human bodies and lives. Fourth, bioethicists too often assume that disabled experiences can be analogized from able-bodied experiences and thus do not regularly draw upon evidence grounded in the lived experiences of people with disabilities (Miserando 2003; Landry 2022).

This leads to bioethical discussions about disability that (i) in fact conflict with the lived experiences, perspectives, and interests of disabled people, (ii) fail to take into account the troubled historical relationship between medical practice and people with disabilities, and (iii) ignore the larger social, cultural, and political forces that oppress people with disabilities and thereby ignore a core component of social determinates of health for this large and varied population. Insofar as the perspectives of disability rights advocates and disabled people remain marginal within everything from introductory textbooks to scholarly monographs in bioethics, the state of scholarship across the field further compounds this issue. This creates serious problems, for it can lead students, medical professionals, educators, and scholars to think that disability, and

the relationship of disability studies to bioethics more specifically, is an apolitical issue and that research concerning disability in general and the lived experiences of disability in particular are not essential to bioethical inquiry.

III The Stakes of Disability Bioethics

The difference between doing disability bioethics and doing non-disability bioethics (or “regular” bioethics) has high stakes. If one is a clinical bioethicist, it will impact what, how, and whether one will communicate with patients and clinicians about complex ethical issues. It will also impact how and whether one treats patients in a number of respects, including vis-à-vis certain diagnoses, prognoses, treatment options and plans, and referrals. If one is an academic bioethicist, it will impact what, how, and whether one argues in scholarly journals about issues that often have significant practical, real-world consequences. Unfortunately, though, insights, methodologies, and research from disability activism and scholarship have too often been simply ignored, not taken seriously, or misrepresented across bioethics’ 50-plus-year history.³ This is especially frustrating given the fact that central debates in bioethics, as well as in public health, focus upon issues that disproportionately affect disabled people. Topics including euthanasia, physician aid-in-dying, pre-implantation genetic diagnosis (PGD), prenatal testing, selective abortion, enhancement, resource allocation, and emergency rationing—among many others—are *all* premised on shared and implicit assumptions regarding disability, especially in relationship to QOL.

In short, doing disability bioethics *well* involves careful consideration of where one turns for data, how one interprets and otherwise reflectively analyzes that data, who is at the table—and brought to it—with respect to decision-making at basic, clinical, and translational levels, and the values upon which one’s research more generally is anchored. Biomedical research, treatment, and engagement with Autistic people⁴ is a powerful example here—some people, and far too many medical professionals, think that by listening to the parents of Autistic people, they are thereby plugged into the disability community. That is false and can be damagingly so. Some of those who think this way aren’t even aware of the Autistic Self Advocacy Network (ASAN) or the very serious concerns regarding organizations like Autism Speaks. An essential aspect of disability bioethics involves research. If you are a clinician or clinical bioethicist who wants or needs, given the demands of one’s job, to learn about X (understanding this as a random variable indicating a particular impairment), where do you go for information? If your first answer is “a genetics textbook,” this should cause pause. Such a resource might be useful, but it should not be definitive and, we think, it should certainly not be the *only* source to consult. One’s patient living with X or who identifies as X is, before all else, a *person*, and research that focuses upon and takes up their life as they in fact experience it is essential to any number of clinical considerations relating to their care and health outcomes.

The majority of bioethicists and medical professionals today are able-bodied people, and a number of studies have suggested that nondisabled people are likely to estimate the QOL of disabled people to be much lower, on average, than disabled people themselves report. Healthcare professionals are not immune from this phenomenon. In a recent survey of 714 practicing physicians in the USA published in *Health Affairs* by Iezzoni et al., 82.4% report that people with significant disability have worse quality of life than nondisabled people (2021). This judgment directly conflicts with decades of social scientific research suggesting that people with significant disability, just as with non-significant disability, experience similar, not lower levels of QOL as nondisabled people. That study also reports that only 40.7% of the physicians surveyed

expressed confidence in their ability to provide the same quality of care to disabled patients as they do to nondisabled patients. These findings are worrisome on a number of fronts, but especially with respect to the following three implications: (1) there is a substantial discrepancy between how physicians conceive of the relationship between QOL and significant disability and how disabled people in fact experience it, (2) there may be a link between this discrepancy and the quality as well as the equity of care of disabled patients, and (3) this issue on the whole has not improved in a statistically significant way for decades.

Just consider how this issue played out during the COVID-19 crisis. In a December 2020 National Public Radio (NPR) piece, investigative reporter Joseph Shapiro detailed the story of a woman with intellectual disabilities who sought medical care at the start of the COVID-19 pandemic in the small, rural town of Pendleton in Oregon, USA. She needed a ventilator, but her physician denied it, citing her “low quality of life.” He asked her to sign a form that would allow the hospital to deny her further care. After threats of lawsuits, this woman was transferred to another hospital where proper care was offered, and she recovered. Oregon Senator Sara Gelser told NPR: “Nothing happened to that hospital. Nothing happened to that physician...the health authority confirmed that, in fact, that was a coerced do-not-intubate order, they confirmed it happened... but there was no sanction.” Shapiro further reports, “the state records that NPR obtained show other people with disabilities were denied coronavirus tests or treatment when they showed up at hospitals with symptoms.” Such blatant cases of discrimination on the basis of disability have been so widespread during the COVID-19 pandemic across the globe that the United Nations put out guidelines to try and mitigate the problem (2020). The Iezzoni et al. study adds fuel to the larger body of evidence that people with disabilities do in fact receive worse—prejudicial, or otherwise inequitable—forms of health care compared to than their nondisabled counterparts (Reynolds & Peña-Guzmán 2019). This is yet another piece of evidence for the necessity of disability bioethics as an approach to—we would hope *the primary* approach to—doing and learning about bioethics.

Furthermore, we highlight this study to note that engagement with disability bioethics is not just a demand relative to education and the academy. As an applied field tied to one of *the larger economic sectors of most industrialized nations*, bioethics impacts healthcare education, practice, and policy in countless ways. It is in light of such pressing issues about the state of bioethics education and scholarship and their real-world impact that we have developed *The Disability Bioethics Reader*.

IV Language and Content

A note on language: we encouraged contributing authors to use their preferred nomenclature concerning disability instead of attempting to make it homogenous across the volume. There is no consensus (globally, nationally, and even at more narrow levels like “across disability studies” or “across disability activism”) concerning the terms “disabled people” vs. “people with disabilities,” etc. There is generally consensus, however, that euphemisms like “uniquely abled” or “differently abled” are misguided. In short, people use different terms for different reasons, reasons that are often context dependent. We ourselves purposely switch between “disabled people” and “people with disabilities” to signal this plurality of views.

We agree with Eli Clare’s statement in *Brilliant Imperfection: Grappling with Cure* that “trigger warnings are in essence tools for self-care and collective care” (2017, xx). In terms of content warnings, we recognize that some of the topics into which this reader delves are likely to be difficult. Although we cannot anticipate how individual readers will respond, we expect that

the following topics may be triggering: discussion of eugenics, psychiatric hospitalization, medicalized abuse, epistemic and other forms of oppression, and suicide, among others. Chapter titles and abstracts generally provide information that can assist you in determining when you may need self-care and/or collective care.

V The Design of *The Disability Bioethics Reader*

This reader is designed for use in undergraduate and graduate courses in colleges and universities, medical school education, continuing medical education courses, and other continuing medical education credit opportunities. Though we intend it to be of interest in any and all bioethics-related courses, it will be of special interest for teachers approaching bioethics from various critical perspectives, including feminist philosophy, critical philosophy of race, gender and sexuality studies, feminist science studies, and science and technology studies. We have been blessed by the fact that this project has been collaborative from the beginning. We solicited, received, and incorporated constructive feedback from a wide range of disability activists, disability studies scholars, disability-conscious healthcare professionals, and others all the way from the project's inception to its final production and concerning everything from its framework to specific topics to authors to include. We placed priority on selecting authors with relevant lived experience where possible and on the inclusion of multiple chapters exploring tensions and opportunities for future engagement between disability bioethics and other fields of study (e.g., critical race theory, feminist bioethics, fat studies, trans studies, aging studies, and animal studies). We have had the great joy of working with and learning from our exceptional authors, together shaping chapters, topics, and arguments through lively conversation, deliberation, and constructive disagreement.

All of this being said, a reader such as this should be seen, we hope, as a snapshot of a wide range of living, ongoing, and complex research projects. This volume does not represent all that is going on in disability bioethics. *Far from it!* As anyone who has ever edited a volume of this size knows, the original plan and shape has transformed over the last many years as we have gotten and responded to feedback, as authors (and thereby topics) unfortunately had to drop out or happily dropped in, and as constraints of the real world played out as they always do.

We welcome and look forward to feedback from teachers, students, practitioners, and others about your experience of using this reader. Just as with disability justice, disability bioethics is an evolving enterprise. We cannot say with confidence where disability bioethics is headed, but we are thrilled for you to be part of the journey and are so excited for whatever lies ahead. The idea for this volume started thanks to an experience we had over and over again: colleagues from around the globe asking us what readings to include on disability in their bioethics classes. So, to all of those friends and colleagues, and to their students, here is just a taste of what's out there.⁵

Notes

- 1 In addition to Scully and Oullette, for further research and arguments concerning how to think about “disability bioethics” and also what that term should mean, both definitionally and programmatically, see Shakespeare (2014); Stramondo (2016); Parens (2017); Garland-Thomson and Iezzoni (2021); Garland-Thomson (2022). As the very existence of and diverse content in this volume makes abundantly clear, that list of references just touches the surface of the many ways in which “disability bioethics” has been building (even if unevenly and contestedly) since at least the 1990s.
- 2 When we say “critical” disability scholarship, we mean research that does not simply report statistics or present humanistic or social scientific analyses of disabled people, but research that instead seriously engages testimony, activism, and scholarship by disabled people and, further, that treats as its interpretive north star how people with disabilities in fact experience and understand their lives.

- 3 There is some anachronism at play in this claim since the field of disability studies didn't really materialize until the late 1970s/early 1980s (expectedly, the rise of modern disability *activism* predates the academic field; in the USA and UK, it is typically dated to the mid-late 1960s/early 1970s). The field of bioethics is usually said to originate in the late 60s; see Evans, "A Critical History of Bioethics," this volume. Still, by the heyday of bioethics—keeping in mind that it did not fully "take off" in certain respects until the mid-1980s or so—the field of disability studies and the presence of disability activists on the national stage were established. For example, the national *Society for Disability Studies* (renamed to that in 1986) was established in 1982 and the international journal *Disability & Society* (renamed to that in 1994) was established in 1986.
- 4 We use the language of "Autistic people" and "Autistic person" following Lydia X. Z. Brown. See "Identity-First Language," Autistic Self-Advocacy Network. <https://autisticadvocacy.org/about-asan/identity-first-language/>. Accessed September 1, 2020. This post clarifies: "ASAN intern Lydia Brown originally published this article August 4, 2011 on their blog *Autistic Hoya* under the title 'The Significance of Semantics: Person-First Language: Why It Matters.'"
- 5 Acknowledgments: The editors would first like to thank all our fantastic contributors as well as Andy Beck at Routledge for his constant support for this project. We individually thank Nancy Berlinger, Tom Cole, Elizabeth Dietz, Kristie Dotson, Nick Evans, Rosemarie Garland-Thomson, Lauren Guilmette, Josephine Johnston, Gregory E. Kaebnick, Eva Feder Kittay, Alex Levine, Becca Longtin, Erik Parens, David Peña-Guzmán, Diane Price-Herndl, Gaile Pohlhaus, Rhonda Rayman, Jennifer Scuro, Millie Solomon, Gail Weiss, Gregor Wolbring, and Rachel Zacharias. Joel would like to thank his students at the University of Massachusetts Lowell and Georgetown University, who provided feedback on some of the chapters that ended up in this volume. He is also grateful for everyone at The Hastings Center for their wisdom and support during the germination of this project. We want to give a huge thanks to Ari Watson, who tirelessly helped get the project over the finish line. Thank you, Ari! Special thanks to Laura Guidry-Grimes for truly pivotal feedback on and suggestions for this introduction, its framing, and how we describe and think about "disability bioethics" more generally.

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