Two opposing sociopolitical forces are now shaping the future of humanity in liberal societies. Once force is liberal eugenics and the other force is individual human rights, or what is called liberty interests. These opposing ideological and sociopolitical forces -- carried out through practices, laws, and covenants—present us with a moral conflict between using medical technologies for eugenic selection in the interest of procreative liberty and population health and the promise of liberal societies to provide justice, equality, and inclusion for all members of the social order.

Let me begin by laying out the historical development of this ideological and sociopolitical conflict in the 20th century west. Eugenics is the ideology and the practice of shaping a particular human community according to its shared values by controlling who reproduces, how they reproduce, and what they reproduce.¹ To understand the place of eugenics in modern liberal societies we can think about eugenics as historically divided between what is called the old eugenics and the new eugenics. The old eugenics begins in 1883 when Darwin’s cousin coins the word eugenics, meaning the science of good genes, and it ends in 1946 at the end of World War II with the Nuremberg trials.² Eugenics is comprised of negative and positive eugenics. Negative eugenics sought to bring disease, disability, and human anomaly under control by eliminating people with medicalized conditions. Negative eugenics begins early on in the 20th century with the language and rationale of the best and the worst, the worthy and unworthy,
as a way to assign differential value to human beings. In 1920, a book titled The Authorization of the Destruction of Life Unworthy of Life by the psychiatrist Alfred Hoche and the law professor Karl Binding underwrites eugenic killing. In 1939, one of the first orders Hitler gives in World War II authorizes his personal physician to undertake a secret program mercy killing program that quickly expands to wide ranging euthanasia as a population shaping strategy, first on the basis of medical conditions and later on the basis of ethnic and racial identity. Along with a negative eugenics of elimination, at the same time emerges a positive eugenics that sought to increase through reproductive technology and selective reproductive engineering what a community considered to be the best people.

The United States enacted negative eugenics, expressed as involuntary sterilization laws and practices that were authorized by the famous 1927 Buck and Bell trial in which the Supreme Court Justice Oliver Wendell Holmes proclaims that what he calls three generations of imbeciles are enough. In addition, positive eugenics encourages the supposed best people to reproduce by rewarding their procreation and authorizing their liberty to do such through such practices as most perfect baby contests, fitter family contests, and eugenic public campaigns urging reproduction of the ostensibly worthy and best and discouraging reproduction of what counted as the worst or the unworthy. The climate for people with disabilities during the eugenics era in the United States and worldwide was toxic enough for people with disabilities that US President Franklin D. Roosevelt, who used a wheelchair every day of his life, never allowed himself to be shown as a wheelchair user publically or in what we now would call social media.
In the 1940s the Nazi regime carried negative eugenics to its logical conclusion with the eugenic euthanasia program called T4, which developed the mass gassing policies and technologies that the historian Henry Friedlander has called the opening act of the Holocaust. In her book *Eichmann in Jerusalem: A Report of the Banality of Evil*, the political philosopher Hannah Arendt expresses the moral objection to state-sponsored negative eugenics such as the T4 program by saying that political regimes aught not to determine who should and who should not inhabit the world.

A new eugenics authorized by liberal choice rather than state enforcement begins in 1946 and continues through the present. This new liberal eugenics is justified most fully by some utilitarian philosophers and trans-humanists. The philosopher Julian Savulescu, for example, claims we have “the moral obligation to create children with the best chance of the best life.” The concept of “the best” here creates a hierarchy of value among the lives people live and by extension the people who live those lives. Savulescu extends this moral claim from pathology to preference as a justification for eugenic selection by saying couples should “select embryos or fetuses which are most likely to have the best life based on available genetic information including information about non-disease genes.”

To advocate shaping human communities through reproductive technologies that select for and against human traits understood by parents or health care providers as “the best” moves reproductive technology out of medical diagnosis, prognosis, and treatment and into the realm of free market economics in which parental preferences determine who should and should not
inhabit the world. Thus, medical science and technology carry out this new eugenics under the auspices of the autonomy of the parent as patient rather than the authority of the early 20th century state. This eugenic selection through medical practices authorized as individual autonomous reproductive choice is carried out at all developmental stages of human procreation, from the genetic to the embryonic to the fetal to the neonatal.

The effect of these multi-stage eugenic selection practices is to increasingly standardize modern liberal communities by reducing human biological and social diversity and with that the social acceptance for people with disabilities. For example, routine eugenic selection at the fetal stage reduces human diversity by targeting the particular iconic condition, Down syndrome, a collection of human traits that are not of themselves pathological. The result is that the U. S. population of people so identified is now reduced by 30 percent, and up to 90 percent of the fetuses diagnosed through prenatal screening are selectively aborted. Medical practice to reduce human variation on the basis of quality-of-life evaluation receives support from the utilitarian philosopher Peter Singer who advocates eugenic selection through neonatal euthanasia in 1985 in a book called *Should the Baby Live?* in which he makes the provocative claim “we think that some infants with severe disabilities should be killed.” Eugenic selection as reproductive liberty also underpins the use of prenatal diagnosis in sex selection in some cultures where male children are preferred, is altering the gender ratio and causing as a result of this social violence. Liberal eugenics, then, creates a conflict in modern liberal societies between the right to procreative self-determination and the right to life for people with disabilities and other groups that societies devalue. By reducing social human and biological
variation in communities, eugenic selection not only creates a culture of intolerance for groups subject to social discrimination but it violates the common good.

At the same time that liberal eugenics expands as medical technologies increase the possibilities for eugenic selection, from the wreckage of the Holocaust arises in the mid-20th century the reenergized concept of 18th-century egalitarianism in the form of the human rights movement. Inaugurated in 1948 with the Universal Declaration of Human Rights that follows the Nuremberg trials, expansive social justice movements emerged in support of broadening and securing human rights. These movements produced a collection of human rights covenants--documents, agreements, treaties, laws, and policies--that codify the concept of equal worth and dignity among all persons. The social and political work of these covenants starkly contrast to the logic of worthy and unworthy, the best and the worst, at the heart of liberal eugenics.

The human rights covenants that arise from the interlocking United States civil rights movements of the mid 20th century, for example, press for social justice through replicating the language and reasoning of the central claim of 1948 Declaration of Human Rights that “all human being are born free and equal in dignity and in rights.”13 The civil and human rights movements by and for women, blacks, people with disabilities, and gay people changed the shape of American civic culture, all institutions, the built environment, and public consciousness with the sweeping laws, policies, and practices these justice movements demanded and enacted. This series of civil rights legislation in the United States, culminating with the
Americans with Disabilities Act of 1990, mandated protection from discrimination and equal
treatment under the law for people with disabilities. As with all political and cultural
covenants, implementation proves to be an ongoing challenge that always falls short of
aspiration. These ambitious disability justice laws, based as they are in human rights concepts
transformed people with disabilities from medical cases into political subjects.

The multinational human rights era has continued into the 20th and 21st centuries through a
of Persons with Disabilities (UNCRPD), adopted in 2006 and signed by 172 states and the
European Union, protects people with disabilities and ensures a more extensive set of rights
than the Americans with Disabilities Act by mandating support for people living with disabilities
and affirming disability culture. The most capacious pronouncement of the UNCRPD comes in
the “Right to Life” Article of the Preamble, which “reaffirm[s] that every human being has the
inherent right to life,” and holds “states parties” to an obligation to “take all necessary measures
to ensure its effective enjoyment by person with disabilities on an equal basis of others.” Such a commitment to the equal rather than differential worth of persons with disabilities
challenges the rationale and practice of liberal eugenics by claiming that people with disabilities
have a right to be in the world and benefit the common good.

Alongside utilitarian liberal eugenics in contemporary philosophy, the knowledge tradition from
which egalitarianism and human rights emerges in the 18th-century, we find a durable human
rights understanding that counter utilitarian liberal eugenics. In his 2003 book The Future of
Human Nature, Juergen Habermas opposes eugenic selection by claiming that humans should “grow” organically from their own distinctive essence rather than be “made” according to the preferences of other people. This claim for the autonomy of all beings to develop into themselves without interference sets limits to the reproductive liberty of parents. Following such reasoning, the political philosopher Michael J. Sandel makes The Case Against Perfection by framing reproductive practice that selects both for and against particular traits as hubris, a striving for mastery that precludes openness to the gifted character of human distinctiveness and significance.

Nonetheless, because scientific development and medical practice enacts liberal eugenics under the auspices of health, patient autonomy, reproductive liberty, and a free market ethic of medical care, medical science and healthcare in technology-rich societies gate keep who does and does not inhabit the world through eugenic selection at the preconception and prenatal stages of human development. Utilitarian liberal eugenics of the best and worst dovetails effectively with a pathological interpretation of living with disabilities, calls upon a reductive common sense ableism, and traffics in disability exceptionalism, the unexamined assumption that people with disabilities will necessarily suffer more and have a lower quality of life than non-disabled people.

In modern liberal orders, this more firmly established and institutionalized pathological understanding of disability and illness dominates over the emerging and increasingly vigorous sociopolitical human rights understanding of people with disabilities as a rights bearing
population with a distinctive identity, history, and culture. And yet, the political rather than the pathological understanding of living with disabilities is gaining currency in the developed and developing world. Ten percent of people worldwide live with disabilities. At 56 million, Americans with disabilities are the largest minority group, and a growing constituency in the US and other wealthy nations as demography shifts and new disability categories such as neurodiversity, psychiatric disabilities, disabilities of aging, and learning disabilities emerge. So even though disability is an experience, identity, and culture that people generally enter unexpectedly and unwillingly, when people inevitably transition into disability, as we all will do over a lifetime, or when disability enters our lives through family and those close to us, the infrastructure for the sociopolitical understanding of disability supported by human rights covenants waits for us all when we are ready to access it. We all are either active patients or patients in waiting. This robust collection of covenants provides us all with a political, cultural, technological, material, and legal support system for living with disabilities as equal citizens.

Harriet McBryde Johnson’s 2003 New York Times Magazine article, “Unspeakable Conversations: The Case for My Life” illuminates the conflicting perspectives of a disability rights position and a liberal eugenics position on bioethical decision-making ranging from physician-assisted suicide, reproductive technologies and counseling, advance directives, life-sustaining treatment protocols, distribution of resources, and more. I have offered Johnson’s narrative as an argument about Arendt’s warning about judging who should inhabit our shared world, suggesting that Johnson’s story shows us how—in the words of Nancy Mairs in Waist High in the World: A Life among the Nondisabled—“to conceptualize not merely a habitable
body but a habitable world: a world that wants me in it” (63). 22

I want to offer a genealogy from Arendt to Johnson about who should and should not inhabit the world concerns liberal eugenic debates in bioethics, but more broadly it is a conversation about how human variations or ways of being world are valued or discredited. I have suggested elsewhere that Johnson’s story of her meeting with Peter Singer is contribution to narrative bioethics and feminist disability studies. Here, I take that argument further by offering Johnson story as a case for the right to life by people with disabilities. (I also understand that the phrase “right to life” is at this moment politically contaminated through its appropriation by the fundamentalist right.) Johnson’s narrative of her right to be in the world, what she calls “the case for my life” stands as a case for the liberty to be oneself, as articulated by Juergen Habermas, as an exercise of individual liberty authorized by the human rights concept of a right to life expressed in The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). In other words, Johnson’s narrative claim of the right to be herself stands in direct opposition to the procreative beneficence, or liberty interests in individual family making put forward by utilitarian philosopher Julian Savelescu. Johnson’s claim that she is indeed not worse off opposes then the utilitarian index of “the best.”

Here is how Johnson puts forward her argument for her own right to life as an argument against liberal eugenics. Johnson’s New York Times Magazine article, subtitled “The Case for My Life,” is a first-person account of her two formal, professional public encounters with Princeton University’s endowed professor of ethics, Peter Singer. Johnson was a wheelchair-using
disability rights lawyer, advocate, and activist who worked and lived in Charleston, South Carolina. Singer’s influential scholarship has steadfastly argued for killing disabled newborns as a reasoned, ethical, utilitarian principle.

The argument embedded in Johnson's story is not only that disabled people should not be eliminated from the world but rather that they should be sustained more fully. Is a guide through the habitable world Harriet McBryde Johnson made for herself and lived fully. The bioethicist Jackie Leach Scully has argued that this way of knowing the world that comes with living through a disabled body “thinking through the variant body.” Such knowledge producing perspective yields “experiential gestalts,” or ways-of-knowing shaped by our embodiment that are distinctive from the ways of knowing that a nondisabled body develops as it interacts the world built to accommodate it. Johnson's vivid presence and subjugated knowledge narrated in her stories conceptualize the habitable world Nancy Mairs calls for: the kind of world that wants disabled people in it.

Johnson’s provocative rhetorical question with which she begins her narrative is: "Should I Have Been Killed at Birth?" This question is both an allusion to and a displacement of Peter Singer's equally provocative 1985 book title, Should the Baby Live?, subtitled “The Problem of Handicapped Infants.” This is the book in which Singer makes the strongest argument for euthanizing disabled newborns. From its beginning, Johnson's story gives particularity to such abstract "problem... infants" by presenting herself through both image text to readers as a distinctive person embedded in family, mutually satisfying interpersonal relations, and
meaningful engagement with the world-- not as a disembodied "problem." The narrative convention of a dramatic first line strengthens her self-presentation as person rather than case. Her opening declarative sentence, "He insists he doesn't want to kill me." consists of the bookended pronouns “he” and “me,” joined by the active verb "kill" to transform an abstract theoretical “problem” into a story of specific people in living relationship.

With this first-person narration, Johnson claims the narrative privilege of defining the terms and presents a worldview from within the body and life of the narrative "I." With this she establishes herself as a rights bearing individual with liberty interests to be herself in the world. The controlling narrative perspective and claim to individual liberty is always narratively situated in a distinctive material place and time from which the knowing of her per story radiates. By placing herself as both first-person narrator and main character, Johnson not only puts herself in the center of the story but relegates all other characters, including Singer, to secondary positions. Indeed, by assigning Singer the position of third person “he,” Johnson contains his story and his claims within her own story and voice. The third person is always the other of the narrative, and Singer becomes the third person of Johnson's narrative similarly to the way the disabled infant is the third person other of Singer's syllogistic argument for euthanizing people such as the one Johnson has become.

[In relegating Singer to a third person character, Johnson's strong first-person narration ventriloquizes Singer’s claims. His ethical arguments and authoritative voice appear through Johnson's strong declarative translation: "He wants," she writes, “to legalize the killing of
certain babies who might come to be like me if allowed to live. He also says he believes that it should be lawful under some circumstances to kill, at any age, individuals with cognitive impairments so severe that he doesn't consider them 'persons.' Wielding the third-person pronoun “he” and the first-person pronouns "my" and "me," Johnson defangs Singer's point of view without ever quoting him directly: "...he says,” she goes on, “my family and doctors might put me out of my misery,...and no one [would] count it [as] murder" (Johnson, 1).28

Johnson's own succinct claim comes to us as a direct fact rather than a position: She states simply “the presence or absence of a disability doesn’t predict quality of life" (4). The story she tells constitutes evidence to support this claim. Thus, Singer’s words, voice, and point of view are not present in Johnson's narrative. Her strategy of first-person narration has overtaken Singer's voice, rendering him absent in the way he would render disabled people like her absent from the world.

What Johnson calls “the presentation of myself...” (7) that is a necessary fact of her everyday life as a disabled person takes on great authority. The character of Johnson emerges through detailed self-description as the story moves forward. "To keep myself upright,” she tells us, “I lean forward, rest my rib cage on my lap, plant my elbows beside my knees. Since my backbone found its natural shape, I've been entirely comfortable in my skin" (2). This perpetual evidence of Johnson's material existence, her occupation and navigation of physical space in a built environment, asserts her presence in the world. Such an ontological narrative counters Singer's logic of disabled lives as problems to be solved through elimination. This "perpetual [narrative]
“emergence” argues for making a habitable world that includes people with disabilities rather than eliminating them. 29

Disability presence as an exercise in individual liberty

The ethical work of Johnson’s story is to narrate disability presence: "I'll invoke the muck and mess and undeniable reality of disabled lives well lived.” This “reality” shows Mairs’ “habitable world: a world that wants me in it” (63). 30 This presence of disabled life contradicts prejudicial understandings of what disability studies scholar Alison Kafer calls our “grim imagined futures” (2). 31 This narrative of a lived life, a presence, rather than absence of disabled people contradicts as well the neoliberal eugenics of enhancement, improvement, and the range of technological interventions to erase disability from the human condition. 32

Perhaps even more than medical treatment and rehabilitation, becoming disabled requires adjusting to new functioning, appearance, and social status. It requires learning how to flourish as a person with disabilities, not just living as a disabled person trying to become nondisabled. Awareness about disability rights and identity help people understand the rights, protections, and benefits of identifying as disabled. Awareness of disability culture, history, arts, and education increases and promotion of quality of life, dignity maintenance, access, self-determination, and cultural proficiency for living effectively with disabilities. This broad network of human rights covenants provides the ideological and legal infrastructure for us to live as people with disabilities.


8 Kevles DJ. In the name of eugenics: genetics and the uses of human heredity. New York: Knopf; 1985.


21 Bioethicists here I am considering liberal eugenicists include Peter Singer, Nicholas Agar, Julian Savelescu, Jeff McMahon (get others from earlier work) while there are certainly differences amongst the positions, this school of bioethics supports in one way or another the rationale to eliminate disabled people on the basis of liberal choice, a utilitarian rationale, and the largely a question assumption that disability significantly reduces quality of life. Because the intentional focus of this article is Harriet McBryde Johnson, not these philosophers and bioethicists, I will not detail their arguments or cite their specific work.

22 Cite Arendt, Hubbard, Politics of Women’s Biology, 178-198; Kevles, in the Name of Eugenics 1985 book, Mairs.
24 In Practical Ethics (2009), Peter Singer makes the case for killing people, in particular infants and disabled people, as a reasoned, utilitarian principle as a way to argue against and show the flaws in the argument for the sanctity of human life principle as an absolute position uninflected by utilitarianism or liberalism. Related to his critique of vitalism as a bio conservative position rooted in Judeo-Christian culture, Singer argues for killing disabled people
as conscienceless newborns or sufferers in order to put forward his position of secular speciesism. The word “killing” is the semantic choice of Peter Singer in his intricately reasoned argument for euthanizing disabled infants. His argument for killing disabled people is thus less an argument for this position then it is an argument against the logical flaws in conservative vaguely nonsecular positions which hold to a moral boundary between human and nonhuman life forms.

25 See JBI article

27 Scully, Disability Bioethics. Also see Patricia Hill Collins, Black Feminist Theory on subjugated knowledge, perspectivalism, epistemic privilege, and oppositional consciousness are all developed feminist theory terms for this knowledge building.
28 Singers' position is one of moral arrogance. In other words, Johnson's narrative shows Singer's willful unknowing, his privilege of ignorance that comes from his able-bodied, normate position. Singer has embodied privilege which allows him an "epistemology of ignorance."
31 In Feminist, Queer, Crip (Bloomington, IN: Indiana University Press, 2013), Alison Kafer explains what could be an extended definition of Singer’s unexamined premise of “worse off”: “If disability is conceptualized as a terrible unending tragedy, then any future that includes disability can only be a future to avoid. A better future, in other words, is one that excludes disability and disabled bodies; indeed, it is the very absence of disability that signals this better future. The presence of disability, then, signals something else: a future that bears too many traces of the ills of the present to be desirable” (2).
32 Literary narratives of disability material presence which offer an account of situated knowledges of disability can serve as anti-eugenic narratives (similar to antiracist). I am fully aware of the critical interrogation of presence, experience, representation, and—of course—identity, which is particularly robust critique just now within disability studies.