BEASTS OF BURDEN

ANIMAL AND DISABILITY LIBERATION

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They are all beasts of burden, in a sense, made to carry some portion of our thoughts.

—Henry David Thoreau
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The full name of my medical diagnosis is arthrogryposis multiplex congenita. According to the medical field, arthrogryposis is relatively rare, occurring in 1 out of every 3,000 births, but this statistic does not include the many goats, dogs, cows, rats, toads, and foxes who are born with arthrogryposis every day. In cows the condition has its own name, Curly Calf, and is found often enough on factory farms to have been the subject of an article in Beef Magazine’s December 2008 issue.1

As with many diagnoses, “arthrogryposis” covers a broad range of attributes. All of the people with arthrogryposis that I have ever met look and move differently, but they are similar enough to be recognized by those of us who are in the know. Some of us are affected only slightly in a few joints, and some of us are affected more considerably. The most common form of arthrogryposis is amyoplasia. Reading over the traits of amyoplasia, I recognize myself: “shoulder—internal rotation deformity; elbow—extension and pronation deformity; wrist—volar and ulnar deformity; hand—fingers in fixed flexion, and thumb-in-palm deformity; . . . knee—flexion deformity; foot—clubfoot deformity”2

I no longer have clubfeet; they were straightened during the first few years of my life. I have scars on my knees from where my legs were surgically straightened as well. These surgeries seem to have enhanced my range of motion, and I think the medical intervention was helpful to me. Yet I often wonder what different motions and abilities I would possess if my body had been kept the way it was. I find myself wondering how I would have gotten by if I had not had these surgeries and were that much “more disabled.” How would I have adapted?

A few years ago I saw a woman rolling down a San Francisco street in her wheelchair.
recognized the woman’s curved hands and narrow shoulders as signature marks of arthrogryposis. I had met many arthro (as my best friend with osteogenesis imperfecta calls us) in my life but never someone who so vividly resembled my mental image of how I would look if I hadn’t had surgeries as a baby. The woman sat with her legs folded in her wheelchair, as if she were in a yoga position. Her feet were curved inward, and her arms seemed slightly less strong than mine. My mom had always described the baby me sitting in the lotus position. (Twenty-nine-plus years post-surgery, I have never been able to get back in this position.) I stared at the woman and thought to myself, “I’m so glad I had those surgeries. What would I do if I couldn’t stand every once in a while?”

A few years later I saw her again. We were eating at the same restaurant. I was struggling a bit, as I usually did in public, to use the fork with my extremely weak hand. At home I would often just put the handle part of the fork in my mouth to pick up food, lay it down on the plate, and then pick up the handle side with my hand ever so slightly to put the correct end of the fork in my mouth. This process was very quick and comfortable for me—but not as quick and comfortable as forgoing the fork altogether, which I also did only in the privacy of my home. As I sat frustrated, having internalized all the ableist pressure not to be seen as weird, or gross, or, well, disabled, the woman was elegantly enjoying her meal without the use of her hands or a fork. She was, as I had been told when I did that the same, eating “like a dog.” Like a graceful and confident dog. Despite my modicum of “abledness” compared to this woman, I was not at all more liberated or free. In that moment I felt my ableness tethering me to conventions that were in fact stifling me. I realized that, even as a self-identified disabled activist and scholar, my own ableism ran so deep that I had been projecting it onto the “more disabled” body I had as an infant before medical intervention.
My “naturally” occurring disabled body, compared to my medically altered body, is a point of fascination for me. Yes, it’s probably a bit narcissistic, but it has also been a visceral opportunity for me to explore my own ableism and internalized oppression. I am attached to the body I have now: my feet that I can stand on but can never flex; my legs that hold me up, bipedal, but only briefly and with a posture “like a monkey.” Nonetheless, I am confident that without surgery I would have been attached to my sitting body as well. I would have had issues with it, frustrations, but I would have learned things from it too, and it would have been mine.

Where is my natural body? At what point did I have one? My disability was caused by U.S. military pollution in the town where I was born. Everything about my story is typical: the military and its industries secretly dumping toxic chemicals in unlined pits in the ground for decades; the poor, largely nonwhite neighborhoods that were affected; and the fact that the pollution was directly poisoning the San Xavier Indian Reservation. My body was formed with the help of toxic chemicals, heavy metals, airplane degreasers—the mundane detritus of militarization.

It is hard for me imagine my “natural” body—I never had a “natural” body to imagine. Because my mother unknowingly drank toxic waste from the faucet in our kitchen, as a fetus I was already being altered by society, by culture, by “man-made” products. Does this make me altogether unnatural?

I realize I am cavorting dangerously close to the cliché of the disabled person wistfully imagining her able-bodied self before or without disability. But what I am actually trying to find is a state of nature—a body without human intervention.

I see my own body as inseparable from human society—but what body isn’t? In a time when honeybees are disappearing and polar bears are drowning due to humans’ impact on the
environment, it’s easy to appreciate how the whole earth is impacted by human intervention. More to my point, however, is the reality that we can never see nature through lenses that are not our own; we can never separate something called “nature” from our human perceptions of it. The stories we tell ourselves about nature are inevitably filtered through thousands of years of human culture and embodiment. My initial perception of the woman with arthrogryposis was that her body must be naturally more challenging than mine. I assumed her body was harder to inhabit based on my own preconceptions about how a body should naturally move and be in space. But what is this “nature” on which my judgments were based? And how was I defining it?

The idea of a “state of nature,” a nature before or without human culture, is a powerful one. It has informed our philosophical theories, our political systems, and our opinions about which bodies we deem livable, capable of pleasure, and which we deem exploitable, consumable, and edible. But is this thing we call nature actually justifying these judgments and distinctions, or are we?
10. All Animals Are Equal (But Some Are More Equal Than Others)

Peter Singer is a utilitarian philosopher whose 1975 book *Animal Liberation* is often credited with starting the modern animal rights movement.¹ Although he certainly does not deserve all the credit, there is no doubt that Singer’s book helped bring extraordinary attention to the movement. He introduced the animal rights debate into philosophical discourse while simultaneously making it accessible to a broad population.

As kids interested in animal rights, my siblings and I read many books on animal and environmental issues, but the one I remember most was *Animal Liberation*. I knew who Peter Singer was by the time I was ten. He was one of my heroes growing up. His ideas about animals reached many people, and his book had a major impact on the discussion of animal rights, selling hundreds of thousands of copies since its initial publication. It also brought Singer himself into the public eye in a way few philosophers achieve.

I remember thinking that anyone who would write a book called *Animal Liberation* must be someone I’d like. Imagine my dismay a decade later when I learned that much of the disability community hates the guy.

In a provocative essay on the life of objects, disability studies scholar Eunjung Kim explained, “Given that the expansion of rights to sentient nonhuman animals in Singer’s argument has not

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¹ The book was published in 1975 as *Animal Liberation*.
² The quote is from Stephan Drake of Not Dead Yet (a group that protests assisted suicide) in an article titled "Connecting Disability Rights and Animal Rights—A Really Bad Idea."
necessarily ensured the recognition of some individuals with disabilities as human beings, disability studies scholars have been understandably reluctant to step outside the boundary of human beings.”

What has Singer’s work done to garner such strong reactions? In many of his books and articles he has argued that some disabled babies should be killed at birth and that some profoundly intellectually disabled people lacking specific cognitive capacities are not full persons. He has made numerous troubling quality-of-life judgments about living with a disability, insisting that it’s “flying in the face of reality” to deny that on average disabled people’s “lives are less worth living than the lives of people who are not disabled.” This work has understandably led many disabled activists to distrust him, as well as the larger animal rights movement.

Although Singer’s arguments in Animal Liberation did not require a utilitarian view (though they worked within one), his commitment to utilitarianism sheds light on his perspectives on disability. Utilitarianism is interested in how to minimize suffering and maximize non-suffering or, as philosopher Jeremy Bentham wrote two hundred years ago, how to create “the greatest good for the greatest number of people.” If disability is viewed as a negative, as tragic, as lack—which is the dominant view of disability in the United States—then it is easy to see why it would be considered as undesirable, as something to be avoided, within a utilitarian perspective. The creation of a binary between suffering and non-suffering is one of the things that makes Singer, and utilitarianism more broadly, difficult to accept in disability studies. As we will see, the focus on suffering and its separation from non-suffering is limited and problematic.
It’s also important to note that, despite often being referred to as the “father of animal rights,” Singer does not actually use the language of rights but rather relies on equal consideration. He writes, “The basic principle of equality does not require equal or identical treatment, it requires equal consideration. Equal consideration for different beings may lead to different treatment and different rights.” In other words, equal consideration does not demand that we give animals the right to vote or treat them just as we do human beings; rather, it requires that we take their feelings (their “interests”) into consideration when making decisions that affect their lives.

Singer argues that the concept of human equality is jeopardized if we base our ideas that all human beings should be given equal consideration on anything other than sentience. If we choose any other trait on which to base this belief—be it physical or intellectual—then we run the risk of excluding certain human beings. In Animal Liberation, he uses this logic to make an argument that sounds remarkably anti-ableist. He writes, “The claim to equality does not depend on intelligence, moral capacity, physical strength, or similar matters of fact. There is no logically compelling reason for assuming that a factual difference in ability between two people justifies any difference in the amount of consideration we give to their needs or interests. . . . It is an implication of this principle of equality that our concern for others and our readiness to consider their interests ought not to depend on what they are like or on what abilities they may possess.” Singer has in fact stated clearly that “the principle of equal consideration of interests rejects any discounting of the interests of people on grounds of disability.”

Singer argues that equal consideration ought to be based on sentience, because “the capacity for suffering and enjoyment is a prerequisite for having interests at all, a condition that must be satisfied before we can speak of interests in a meaningful way.” However, as we have
seen and as Singer explains, nonhuman animals are also sentient. To ignore the interests of nonhuman animals when they are also conscious beings who share the same capacity for having interests that grounds our own equality is nothing short of discrimination—speciesism. Singer therefore concludes that we must acknowledge sentient animals’ interests and reconsider the suffering that animals endure for the benefit of humans. This has heavy implications for our interactions with animals, especially those we eat, wear, and use for research.

Since the vast majority of meat and animal products come from factory farms, which are described in unflinching detail throughout Animal Liberation, and since these places are exceedingly well documented to be bastions of cruelty, Singer advocates a vegan diet. However, he is clear that he is not arguing that killing animals is necessarily wrong. It is the suffering inflicted upon them that he is most concerned about.

Singer does not end his argument at sentience, because if sentience were the only ability that really mattered morally in terms of a right to life, then it would be as bad to kill a chicken, say, as a human being (as long as both were killed painlessly). Like most people, he has a hard time believing this. Causing the same amount of suffering, whether to a chicken or a human being, is equally bad. Killing painlessly, according to Singer, is a different matter.

Animal advocate and philosopher Steven Best explains Singer’s argument well, writing that Singer attempts “to distinguish between two different classes of life, not humans and nonhumans, but persons and nonpersons.” Best continues, “Defining personhood as the possession of traits like the capacity to feel and reason, self-awareness and autonomy, and the ability to imagine a future, Singer finds cases of humans who are not, by this definition, persons (e.g., the comatose) and nonhumans who are persons (e.g., great apes and possibly all mammals).” Singer suggests that the more cognitively complex a being is, measured by its
understanding of death and its sense of itself through time, the more value that being will place on keeping itself alive. For example, within his framework killing a conscious neurotypical human would be worse than killing a chicken, because humans are rational beings who are aware of death and who experience themselves through time—they have goals and plans for the future that go beyond simply finding the next meal or sexual partner. The loss of a human’s unfulfilled dreams adds to the wrongness of her or his death. So while cognitive capacities other than sentience don’t play a role in the principle of equal consideration when it comes to suffering, they do play a role when it comes to killing.

It follows that if one were able to kill beings who don’t have these cognitive capacities without causing them to suffer, it would not be as wrong to kill them as it would be to kill other beings who do—as long as the good consequences of doing so outweigh the bad (a complex calculation in Singer’s work that involves the feelings of family, friends, and numerous other factors). In fact, according to Singer, if the being in question were sentient but had none of the attributes of personhood he describes, killing them painlessly and instantly might not be wrong at all. These arguments are widely accepted when it comes to nonhuman animals. Singer’s logic is invoked in Michael Pollan’s book The Omnivore’s Dilemma to explain why it is not wrong to eat animals who come from what Pollan calls a “good farm”: if a chicken simply lives in the now and has no concept of death, what would be wrong with killing her if it were done painlessly? Of course Pollan is presuming chickens don’t have these abilities, which is debatable to say the least—Singer himself has changed his view and now thinks chickens do have future-oriented interests.

Of course, some humans also lack the abilities Singer mentions—specifically, infants and some severely intellectually disabled people. He therefore argues that if we are willing to say that
animals are sometimes not full persons and that killing them painlessly can be justified, we have to be willing to say the same of human beings who lack the abilities that would make them full persons as well. To be clear, he is not arguing that it is always okay to kill a nonperson but rather that killing a nonperson is less wrong than killing a person, as long as it is done in a way that does not produce suffering and as long as the killing produces more good than bad.

It is easy to see where this logic can lead and why so many disabled people regard Singer as, well... scary.

If Singer had left his argument in its simpler form, with the principle of equal consideration based on sentience, Animal Liberation would have been a remarkably anti-ableist book. His argument would have addressed the risks of “using cognitive capacity as a registrar of a being’s moral worth,” in Michael Bérubé’s phrase. But he didn’t. Despite Singer’s focus on sentience, in the end he rethrones rationality as the dictator of personhood by arguing that the life of a full person is more valuable—because of the interests and desires that would be frustrated were it to end—then the life of a nonperson, who couldn’t have desires and interests that would be frustrated. Despite the fact that Singer is radically challenging species barriers—human versus nonhuman is not the morally relevant dividing line for him—such an argument clearly has negative consequences for animals who do not have certain capacities. It also clearly has negative consequences for intellectually disabled humans. Within such a framework, these populations invariably become categorized as less valuable.

In Singer’s framework the attributes that make someone a morally relevant being, a person versus a nonperson, belong to a long philosophical tradition; they are not his invention. Broadly speaking, personhood has countless different meanings and definitions depending on cultural and historical factors, and this particular tradition of personhood belongs to the history...
of liberal humanism. Thus this definition has been shaped by value systems and histories that cannot be separated from histories of oppression and exclusion, which continue to frame who we understand as morally valuable, who is discardable, and who we believe has a right to her or his own life.

Throughout his work Singer discusses a wide range of issues that are relevant to questions of disability, including infanticide and euthanasia. It would take a separate book to do justice to these arguments and the many others that emerge from his framework of personhood. Instead let me focus on two important questions about his theories: Are the capacities Singer pinpoints adequate for judging moral worth? And is it even possible to analyze who does or does not have specific capacities? I will show that trying to answer these questions quickly confronts us with a variety of philosophical and political conundrums and pushes us up against the boundaries of our own systems of knowledge. I will start with my second question, focusing mainly on disability.

Perhaps the most urgent problem with Singer’s use of disability generally is that he understands it solely through a medical model, in which it is seen as a negative biological drawback that needs intervention and should be avoided. The other problem, as many disability scholars and activists have pointed out, is that Singer knows very little about the disabilities he’s discussing. He rarely includes the voices of disabled people themselves and certainly does not grapple with the perspectives of disability rights and justice communities. Most of his resources on disability either come from the medical establishment or from parents and legislation invested in the medical system. To be clear, Singer is not alone in his limited understanding of disability. As Licia Carlson has pointed out, philosophers have long seen
disability—particularly intellectual disability—as a self-evident category that is objectively undesirable. In his work Singer refers to a wide range of disabilities to support various arguments he makes—spina bifida, cerebral palsy, Down syndrome, “severe intellectual disabilities,” anencephaly, hemophilia. He repeatedly assumes that one can predict the capabilities and quality of life a disabled individual has or will have based on such a diagnosis without acknowledging that medical science repeatedly has proven to be extremely bad at such predictions (as we saw in the case of Anne McDonald, the woman who was institutionalized for the first sixteen years of her life, as well as in medical professionals’ historically low expectations for people with Down syndrome). All of the disabilities listed above are vastly different from one another and are each extremely variable. It is impossible to tell what capacities someone with spina bifida or Down syndrome might have simply based on her or his diagnosis. It is similarly difficult to judge a disabled individual’s future abilities at infancy, which is the stage many of Singer’s most controversial arguments focus on (such as infanticide).

Although Singer often bases his arguments on specific court cases, stories that have made it into the media, and statements by medical practitioners and family members (as well as the occasional disabled person), Singer also uses hypothetical situations or an “all else being equal” clause rather than real cases or experiences (something common to many philosophers). A good example of such a hypothetical is in a famous debate with Singer that disability rights lawyer and Not Dead Yet member Harriet McBryde Johnson wrote as a remarkable essay called “Unspeakable Conversations,” published in 2003 in the New York Times Magazine. Johnson tells the story of a family she grew up with who took care of an unresponsive family member, a teenage girl. Singer then poses a question: “Let’s assume we can prove, absolutely, that [an]
individual is totally unconscious and that we can know, absolutely, that the individual will never regain consciousness. Assuming all that, don’t you think continuing to take care of that individual would be a bit—weird?’ Johnson replies, ‘No. Done right, it could be profoundly beautiful.’”

Regardless of one’s own views on this particular hypothetical, it’s important to point out, as Eunjung Kim does, that such a rhetorical move takes us out of real life because “the absoluteness presumed by Singer is medically impossible.” Sometimes the hypothetical nature of his statements is clear, as in the example above, but often it is not. Singer repeatedly uses qualifying phrases such as “all else being equal” or “I will assume that,” but the most subtle form of this sort of argumentation is evident in the use of words such as “severe”—the “severely disabled,” the “severely intellectually disabled,” those with “severe spina bifida”—which he relies on to give shape to the individual or group he is discussing. What defines the category of “severe”? Who decides what counts as “severe”? Am I severely disabled? I certainly have been called so. Should I hope that I am not? Should I defend my intellectual capacities and independent living skills and reject the label out of fear of being associated or confused with those who are “more disabled” than I am? Unlike the porous and broad meaning of “disability”—a word that has come to reflect the potential for community building and solidarity across difference in many disability communities—philosophical and medical framings of “severe disability” presume undesirability, objective tragedy, and potentially a lack of personhood.

Arguments made in a vacuum sidestep the messiness of consciousness and suffering and in the process create definitions of moral worth that are based on little more than fiction. Yet by also bringing up specific disabilities and individual cases throughout his writing, Singer
dangerously conflates hypothetical examples, medical diagnoses, and murky categories with actual disabled people and populations.

To begin to assess my first question—are the capacities Singer singles out adequate for judging moral worth?—it might be helpful to ask another: what if ways of being and experiencing outside Singer’s value system were also understood to confer personhood? He has written that it’s not enough to have a sense of time that reaches only as far into the future as the next meal or sexual encounter. But why not? What about animals who prepare for the winter? Or pregnant animals who prepare for birth by building homes or saving food? Or, to ask similar questions for those humans with “severe” intellectual disabilities, what about looking forward to sensations one finds pleasurable? As we have seen, intelligence and emotional complexity take myriad forms. It is presumptuous to assume that certain concepts of the future and death are the only capacities that can lead individuals to value their lives. Who’s to say there aren’t other ways in which sentient creatures might experience themselves as living and dying beings? We know that various animals will go to extreme measures to save themselves from death, including causing themselves extreme pain (such as when an animal gnaws off her own paw to free herself from a trap). It is clear that animals struggle to survive, even if they may not know that they could die at any time or that there is such a thing as death.

Disabled scholars and activists have long theorized the idea of “crip time.” Crip time means many things to many people and acknowledges that we live at different speeds, that our very sense of time is shaped by our experiences and abilities. Time is relative. Ann McDonald writes, “I live life in slow motion. The world I live in is one where my thoughts are as quick as anyone’s, my movements are weak and erratic, and my talk is slower than a snail in quicksand.” Disability fosters a different sense of pacing, of progress, sometimes even of
lifespan. If time can change so drastically for those of us for whom mundane tasks such as getting dressed, preparing a meal, or speaking take longer, then how might time be reconceptualized for those who have profound intellectual differences or for the great variety of animals? It is very easy to jump from crip time to what we might call animal time—for example, species whose lifespans are only a few hours, days, or weeks certainly must have a different conception of time than those who live for one hundred or two hundred years. Whereas Singer’s conception of time is rooted in Western notions of progress and future-oriented goals, crip time asks us to think about time as variable and changing with our embodiments.

The capabilities that Singer and other philosophers like him espouse as necessary for moral value are subjective and embedded in ableist, neurotypical, and speciesist frameworks. That some beings lack capabilities valued by neurotypical humans tells us little about other morally relevant capabilities these beings may possess—capabilities that may be rooted in sensuality, in aesthetics, or in alternative temporalities. Even if certain capacities do make the sentience of some beings more nuanced than that of others, it should not follow that we have the right to take the lives of those we believe to be less “complex.”

Where does moving away from a limited definition of personhood take us? I am unwilling to return to the framework of human exceptionalism that says all human life has moral worth, while the lives of nonhuman animals do not. Does this mean instead that the lives of all sentient beings are equal? Are we to say that the killing of a human and a chicken are equally wrong? I would rather leave these uncomfortable questions unanswered than embrace theories of personhood that demean the moral worth of intellectually disabled people and nonhuman animals. If our theories lead us to such conclusions, then they are not good enough or complete enough. As confusing as these questions are, it is not of the utmost important to me to answer.
them: to be forced to pit the values of different lives against one another is to take a philosophy of hierarchy for granted. I would rather ask how we can begin to create a world in which choosing between the lives of animals and the lives of humans (whether disabled or able-bodied) is understood as a false dichotomy.

I got a chance to meet with Singer in person during his recent visit to Berkeley. Sitting across from the person I had admired so much as a kid was an ambivalent experience, especially since he is quite nice and fun to have a conversation with. Even Johnson wrote that she liked Singer despite herself.  

During my time with Singer, I asked many of the usual questions that people ask him: questions about sentience and personhood, about the difference between causing suffering and ending life. I wanted to make sure that I asked him questions that accurately represented his ideas, because it’s easy to misunderstand him or to oversimplify his arguments into negative sound bites. I still failed at times, conflating things he had written about different issues or unconsciously exaggerating his positions. He would call me out during these moments, and in turn I called him out when he said something stereotypical or presumptuous about disability.

After this went on for quite a while, I finally asked the question I’d been wanting to ask him for ages: does he think there are any possible positive effects disability can have on society and on individuals? Singer is so attached to his equation of disability with suffering that I wanted to see what would happen if he tried to think about it in other ways.

He seemed intrigued by my question and replied that he thought all people need obstacles to overcome on an individual level, that it builds character and can be satisfying to face challenges, and that perhaps certain disabilities could be satisfying in this way. But as far as
disability having a positive effect on the world as a whole, he was more hesitant. Although he thought caring for and helping disabled people could develop certain altruistic qualities in others, he also thought there are already enough people on the planet who need support, such as those living in poverty. “In terms of diversity,” Singer said, “I’m not sure. I think it is good to meet people who are different in a variety of ways, but again we have a lot of differences already in the world between people that we need to try and work out . . . so I’m not sure whether there’s something distinctive that we get when we have people with disabilities. Maybe there is; maybe there are different things that we perceive. It’s something that certainly can be considered.”

“Let me ask you this, then, and I’m asking in all seriousness,” I replied. “I’m wondering if you think those of us within the disability community who believe disability does have positive aspects, if you think we are just kidding ourselves. Are we just making the best out of a bad situation?”

Singer paused. “I do think there is something in that,” adding, “I do think that people have that tendency. . . . But you know, I can’t say that for sure. . . . I think it would be arrogant of me to be saying that that’s always the case.” He continued, “You know, I do ask people when they say something like that, I say, ‘Does that mean if somebody offered you a pill that could cure your disability or cure your child’s disability and it would cost two dollars and there were guaranteed to be no side effects that you would not use that?’ And I think most of them would use it. Virtually all of them would use it. And if so, I think they are saying they are making the best of a bad situation.”

“You see, I think most parents would use it, but most disabled people would not use it,” I replied confidently.

“So you wouldn’t use it?” Singer was clearly surprised.
“There’s no way I’d use it!”

“Really?” he asked, even more surprised.

“Disabled people are asked that all the time,” I said. “I think the fact that disabled people may answer ‘no’ is a really complicated thing for able-bodied people to understand.”

“So try to tell me more why you wouldn’t use it,” Singer said, genuinely trying to figure this out.

I hesitated. *What do I find valuable about disability?* I remember thinking. *How do I even begin to answer that?* Here was my big chance to explain to Peter Singer why disability matters. I searched my brain for reasons—things about interdependence and challenging normalcy. But before I could gather my bullet points in my head, the artist in me burst forth with a reply.

“I’m an artist, and so I think about creativity a lot. Being disabled gives you a completely new way of having to interact with the world. . . . For instance, I was never taught by anyone how to use my mouth to do things. There is a certain level of creativity and innovation that goes into every single thing, which some people might find really frustrating, but for many of us who are actually living it, it’s a very liberating thing to not have every aspect of your body already defined. . . .”

Singer seemed amused but also interested. “I could list numerous reasons why I value disability and other disabled people and why I wouldn’t take the two-dollar pill,” I said.

I had the distinct feeling that we were like two beings from different planets trying genuinely to make sense of one another.

“But not all people with disabilities are artists or even think of their lives as art,” Singer pointed out.
“Yes, but it’s not only artists who feel that way. I happen to know a lot of artists, but I think there are many disabled people who value disability for the ways it gives a different perspective on the world.”

Singer looked thoughtful. “It’s true that Harriet [McBryde Johnson] basically said the same thing—she was happy. And she was not an artist . . . she was a lawyer.”

Why wouldn’t I take the $2 pill? Then I could run through open fields! Dance in circles on the beach by moonlight! Run up and down flights of stairs!

In her book *Feminist, Queer, Crip*, Alison Kafer writes that the repetition of the cure question, and “the fact that disabled people are consistently expected to address it, is part of what gives the question its strength, its compulsory and coercive power. It has become inescapable, and the answer is assumed to be self-evident.”

Despite ableist assumptions, disability is often incorporated into the lives of disabled people rather than stopping us from living fully. This does not mean that we necessarily enjoy being disabled all the time; it simply means that we live with it. It is not the be-all and end-all of our lives. We do not (or at least many of us don’t) live our lives regretting all the things we cannot do, all the barefoot steps on the beach we would have taken were we not disabled.

When I told Singer that disability is creative, I was thinking about disabled dancer, artist, and poet Neil Marcus, who has said, “Disability is not a ‘brave struggle’ or ‘courage in the face of adversity’ . . . disability is an art. It’s an ingenious way to live.”

I love this quote. It resonates with me both as an artist and as a disabled person going about my daily life, trying to figure out creatively how to reach something or to get somewhere. Marcus’s statement challenges the idea that disability is simply lack; what’s more, it asks us to
look for value in ways of living that are not necessarily centered around efficiency, progress, and rationality. Disability studies scholar Robert McRuer provocatively asks, “What might it mean to welcome the disability to come, to desire it?” It challenges us to see the sensuality, the unruliness, the beautiful potential of living alternative ways of moving through space and of being in time. Disability can be liberating, exhilarating, a place of freedom from the continual work our society demands of us to be “normal.”

More effort should be made to understand the creative, aesthetic, and sensual realities of individuals who lack the ability to express themselves through rationality and language. Consider a story told to me by Susan Schweik, a professor of English and disability studies at University of California, Berkeley. A young girl with “severe” intellectual disabilities lived in a nursing home. Every day the girl sat in the same spot on the floor, rocking back and forth and looking at the wall. She would do this for hours. One day a nurse got the idea to sit on the floor where the girl usually sat and try to see what it was she was experiencing. What he saw was a shadow, and he realized that when he rocked back and forth, the light created an intricate and beautiful moving pattern on the wall.

Although watching a shadow for hours every day may not seem like a particularly enjoyable or meaningful activity to many people, the story makes us consider the particular experiences that people with “severe” intellectual disabilities can have—experiences that no doubt can be deeply pleasurable and meaningful, even as they remain largely unknowable to the rest of us. Such a story could challenge assumptions that disability is only suffering and lack. The unknowability of the experiences of people with disabilities, which vary widely, make arguments about quality of life and personhood fundamentally problematic to me.
As Harriet McBryde Johnson expressed so thoughtfully in her conversation with Singer, it’s important to examine closely these issues of quality of life and suffering, because such ideas have a profound impact on the way people understand disability. As shocking and extreme as Singer’s ideas may seem, they are rooted in widely held beliefs that disability is an inherently negative state that should be avoided. Kafer writes, “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.” Singer is a particularly vocal proponent of such views, which understandably has led him to be a target of criticism from the disability community. Yet his ideas simply take common beliefs about disability to their natural conclusions. As Johnson suggests, the ubiquity of such opinions makes it difficult to pinpoint Singer’s views as particularly horrible and single him out as some kind of monster. She writes, “If I define Singer’s kind of disability prejudice as an ultimate evil, and him as a monster, then I must so define all who believe disabled lives are inherently worse off. . . . That definition would make monsters of many of the people with whom I move on the sidewalks, do business, break bread, swap stories and share the grunt work of local politics. It would reach some of my family and most of my nondisabled friends.”

Singer is able to make many of his arguments because many of his views already are widely shared by our society and medical establishment. He cites work by dozens of doctors to support the medical and quality-of-life claims he makes about certain disabilities, but he fails to recognize the biases medical professionals tend to hold against disability. He writes, “Many doctors and theologians, including those who are quite conservative in their moral thinking, agree that when a patient’s prospects of a minimally decent quality of life are very poor, and
there is no likelihood of improvement, we are not obliged to do everything we could to prolong life. For example, if a baby is born with severe disabilities incompatible with an acceptable quality of life . . .”

But what exactly is an acceptable quality of life and who decides? Doctors, theologians, and parents of disabled children often have very different answers to these questions than disabled people themselves do. When it comes to infanticide, Singer and medical professionals usually discuss extremely difficult situations involving infants born with large parts of their brains missing or with disabilities that cause extreme amounts of pain and drastically shortened life spans. The particularities of such extreme cases are complicated and admittedly far from clear-cut. I should note that, perhaps in contradiction to some disability activists, I am not settled on whether I disagree with Singer about conclusions he draws about ending life in some cases. Although these conclusions are undeniably troubling, for me, it is how Singer argues—his rhetorical use of stereotypes about disability, his assumptions about suffering, and his commitment to rationality in defining personhood—that I most seek to challenge. Singer and the medical establishment whose work he relies upon repeatedly stray from the subtleties of particular cases, betraying their prejudice against things as various and broad as intellectual capacity, use of a wheelchair, dependency on other people (needing help with eating and toileting, for instance), life on a ventilator, and so forth. In this way, such quality-of-life arguments move beyond extreme cases of infant distress, as we saw in Singer’s opinions of having a child with Down syndrome and of disabled people’s lives as “less worth living.” In such examples, he is not making a case about life and death—he is clear that his work is not in any way suggesting ending the lives of kids and adults with disabilities. Rather, in these moments, he is using the association of disability in general with a lesser quality of life to build
the framework of his larger arguments. In my opinion, this is one way in which Singer goes very
wrong.

Disability activists tend to cringe at the phrase “quality of life,” as it has too often been
linked to an ableist justification for the death of disabled individuals. When nondisabled
individuals talk of wheelchairs, catheters, needing help with toileting, diminished intellectual
capacity, or a general “lack of independence,” they are basing their assumptions on imagined,
rather than lived, experiences. It is difficult, if not impossible, to separate any of these
experiences’ inherent negativity from the negative cultural and social symbols they have
become. Is needing help to wipe your ass inherently horrible? As someone who did need this sort
of help as a child and who has countless friends who continue to navigate that need with dignity
and humor as adults, I don’t think so. In my own experience, it began to be uncomfortable for me
only when I realized other people found it embarrassing, when it felt like this help was becoming
burdensome to those providing it, and when I (wrongly) assumed it meant I could never be
independent, move away from home, or have a partner. As in my case, it is the stigma around
being a burden and needing help that is so often the issue, rather than the help itself. Given the
power to choose who provides one’s care, and when one is assured that it need not be
embarrassing or shameful, the effect of such close care on one’s quality of life becomes far more
nuanced.

Johnson poignantly asks, “Are we ‘worse off’”?

“I don’t think so,” she writes. “Not in any meaningful sense. There are too many
variables. For those of us with congenital conditions, disability shapes all we are. Those disabled
later in life adapt. We take constraints that no one would choose and build rich and satisfying
lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own. We have something the world needs.”

Even when disability impacts one’s quality of life, it is then a disturbing leap to argue that person’s life is less worth living than one without any disability. At the same time, none of this is to say that conversations about quality of life are never useful—the point is that we need to examine these issues with great care and individual attention, while being mindful of what assumptions, stereotypes, and prejudiced opinions underpin various positions.

In an article on Singer, Steven Best quotes disability rights activist Sarah Triano saying that she is “absolutely confounded by the fact that Singer can so brilliantly make an argument for a social model of animal rights, but cannot seem to apply the same logic to disability. Is it impossible for him to imagine that certain humans might actually be subjected to the same kinds of oppression as animals?” While Singer can clearly understand animals as living in an oppressive and discriminatory environment, he is unable to see that his arguments about disabled people’s lives being less worth living are themselves born of discrimination. Best writes, “If in describing the suffering of animals Singer calls for their liberation, not their euthanasia, why then, Triano wonders, does he advocate killing infants sure to experience suffering in their lives rather than advocate social changes that might minimize their pain?” This is one of the most contradictory aspects of Singer’s work. He is explicit that just because a view seems like “common sense” or is widely held about animals does not mean the view is ethical or shouldn’t be questioned. Yet “commonsense” views are exactly what Singer uses to defend his thoughts on disability.

One of the most frustrating things about Singer’s work is the way he puts disabled people on the defensive: we have to prove to him and his supporters that our lives are just as worth
living as able-bodied lives. Yet Singer is not obligated to prove that our lives are less worthy, because he has an ingrained culture of ableism, and what numerous disability scholars have called a system of compulsory able-bodiedness, on his side. Arguments that describe disability as a negative, a drawback, or as something to be cured rely on the idea that it is simply “natural” and “normal” to think disability is a bad thing—it is “common sense,” and everyone knows it. As Fiona Campbell writes, “Regimes of ableism have produced a depth of disability negation that reaches into the caverns of collective subjectivity, to the extent that the notion of disability as inherently negative is seen as a naturalized reaction to an aberration.”

I see my own defensiveness in my conversation with Singer. I was not content to say that some of us would not take the $2 pill—I said “most.” But surely there are a lot of disabled people who do not enjoy being disabled, would laugh at calling it creative, and would no doubt be overjoyed at the thought of a cure—not necessarily because of ableism and internalized oppression, but because of loss, pain, or personal desires. What I should have told Singer is that it’s fine if some people regret being disabled..., but that doesn’t mean we all do.

But even this response gives these questions far too much power. The cure question—as well as an overemphasis on suffering—has the effect of creating a false dichotomy between disability pride and medical intervention. Kafer argues that it is compulsory able-bodiedness and able-mindedness that is of concern, not “individual sick and disabled people’s relationships to particular medical interventions,” and that “a desire for a cure is not necessarily an anti-crip or anti-disability rights and justice position.” She clarifies that she is not talking about cures but “speaking here of a curative imaginary, an understanding of disability that not only expects and assumes intervention but also cannot imagine or comprehend anything other than intervention.”

The fact that many individuals desire cures, regret their disability, or suffer a great deal from
disability is not the issue. What needs to be challenged is the ingrained and ubiquitous assumption that these things mean that disability is objectively undesirable and that such feelings are the only reasonable response to disability.

Trying to prove whether disability is bad or good, whether it causes suffering or not, is ultimately a hopeless game, and it distracts from more important questions about vulnerability, variability, and what kind of world we want to live in. As we’ve seen, disability is also not only a lived experience, it’s an ideology and a political issue that requires critical engagement. Disability is part of the reality of living in a body—any body. Disability should be understood, as Kafer writes, “as political, as valuable, as integral.”

I hope this chapter shows how much effort is spent within disability communities trying to prove our lives aren’t tragic. Disabled scholars and activists have had to invest a lot of energy in dispelling certain stereotypes about tragedy and suffering, as these oversimplified tropes have played an essential role in naturalizing disabled people’s inequality. After all, as feminist movements have long taught us, labeling something as personal versus political is an excellent way for those in power to deny discrimination and inequity. These tragedy narratives are tools of oppression and abuse. They are the stories that convince us that we are not valuable and don’t deserve jobs, education, romantic companionship, or a place in society. Striking a balance between admitting hardship and denying disability can be extremely challenging, as the supposed tragedy and undesirability of disability lead directly to discrimination. Disabled people are too often left in a quandary: they can compromise themselves by denying their own struggles or risk fanning the flames of ableism.

Compounding this dilemma is the simple fact that most of us can’t easily separate and label our suffering and experiences. Disabled author and poet Eli Clare writes, “On good days I
can separate the anger I turn inward at my body from the anger that needs to be turned outward, directed at the daily ableist shit, but there is nothing simple or neat about kindling the latter while transforming the other.” The inevitable tangle of external ableism, discrimination, and oppression with internalized ableism, pain, sadness, and loss makes disability a challenging, if not impossible, experience to unpack neatly. It is crucial when considering disability to leave room for pain, which is a very real experience for many disabled people, and for the mourning that can come with living in a disabled body or mind. It is, however, also crucial to question continually why we feel the way we do and to remind ourselves that suffering and mourning are not unique to disability.

To use a personal example, early on in my relationship with my partner, David, I was sometimes embarrassed and saddened that I could not hold his hand when we went on strolls together. At first this emotion might seem rooted in my physicality—my arms and hands are simply too weak to do this. Sure, we could make some sort of contraption that would keep my hand near his, but no piece of adaptive technology would let me hold his hand, palm to palm, spontaneously, whenever we chose. I mourned this. But at a certain point I realized that this scenario was not just personal and was not the simple product of my body’s “lack of function.” How would my notions of how a couple is “supposed” to interact differ if he and I had grown up in a culture where images of disabled or interabled couples were abundant, if we had seen people strolling together the way we do? Would I have felt the same loss or would I have felt more confident that the way my body expresses affection is a valid one?

Our personal lives are deeply entangled with our sociopolitical world, so much so that even private moments of mourning and loss can’t easily be isolated from the social environment. At the same time, it would be a form of denial to imagine that none of my challenges stem from
my body, a denial that limits my ability to explore theoretically, politically, and artistically the implications of my physicality. Disability is not something that simply happens to me, as a strict social model of disability would have it; disability is, rather, an integral part of who I am, both in my creativity and in my challenges. By acknowledging the disability within my body, I am not only realizing my limitations, I am also allowing myself to examine my disabled body as a creative site with the potential for new ways of interacting with and understanding the world. It is essential that disabled people take ownership of our suffering, of our moments of “undesirability,” and tell our own narratives, because as David so aptly put it, “The ableist world does not own disabled people’s suffering.” We all suffer, but suffering does not negate our other experiences.

When I asked Singer if disability can offer anything positive to the world, his reply imagined disability as something negative that can potentially teach people about struggle, about overcoming, and about care. To Singer and many others, the only positive potential of disability is as a teaching opportunity for able-bodied individuals on how to be more compassionate. What this narrative misses is that disability can help all of us ask bigger questions about culture, politics, independence, productivity, efficiency, vulnerability, and the possibility of empathy and solidarity across difference—including across species. Disability asks us to question our assumptions about who counts as a productive member of society and what sorts of activities are seen as valuable and worthwhile. Disability asks us to question the things we take for granted: our rationality, the way we move, the way we perceive the world. It can present new paradigms for understanding how and why we care for one another and what kinds of societies we want to live in.
As Paul Longmore, a disability studies writer and historian, wrote, “Beyond proclamations of pride, deaf and disabled people have been uncovering or formulating sets of alternative values derived from within the deaf and disabled experience. . . . They declare that they prize not self-sufficiency but self-determination, not independence but interdependence, not functional separateness but personal connection, not physical autonomy but human community.” These “values” of disability—of which I hope a broader definition of community than human will at some point be one—have historically been devalued, but they are ways of being that grow ever more important as the world we live in becomes more interconnected and its resources shrink.

The question still lingers: how can disability movements be expected to build bridges with animal rights movements? My first response is to point to the abundant amount of criticism Singer’s work has garnered from animal advocates and to recognize the alternative conceptions of animal justice laid out by feminists in particular. My second is to call on disability movements to consider their own fear of difference.

It has been suggested to me numerous times that disability movements are resistant to animal issues not only because of the ableism voiced by Singer and others but because of their own speciesism. I think this is undoubtedly true, as it is evident in many of the responses to Singer that have been voiced by disabled people and their allies. For example, Harriet McBryde Johnson brilliantly challenges Singer’s arguments—she combats assumptions about quality of life with incredible wit and finesse—while at times she also seems to bask in her lack of concern for animals, asking her assistant to make sure the sheepskin that she has draped on her wheelchair is visible. Perhaps Johnson’s resistance to animal issues is understandable. She
writes, “As a disability pariah, I must struggle for a place, for kinship, for community, for connection. Because I am still seeking acceptance of my humanity, Singer’s call to get past species seems a luxury way beyond my reach.”

I am empathetic to such a position. I also find it troubling. For one thing, denying someone else’s justice because you do not yet have your own is never a good idea. But for another, I am convinced we cannot have one without the other. Disability oppression and animal oppression are intimately tied together. Perhaps the most striking proof of this is that the things in Singer’s arguments that make it ableist also make it speciesist.

By holding up particular capabilities related to rationality as the registrar of moral worth, Singer’s arguments not only reinforce a hierarchy of ability but also a hierarchy of species. Within this framework, species whose capabilities resemble (neurotypical) human capabilities are granted more protections. Those whose capacities we don’t understand, or whose qualities are debatable, are then at risk of continued exploitation, ownership, and death. It’s an anthropocentric framework that tries to solve complex problems of consciousness and personhood by delineating blurry differences between suffering and killing and by emphasizing the value of reason.

Contrary to what one might think of work by the “father of animal rights,” Singer’s writing is regularly used to justify commodifying and killing animals. His work has popularized an emphasis on suffering, which has limited animal ethics conversations to focus on lessening egregious cruelty instead of challenging the causes of animal exploitation and asking what animals need to flourish. With tens of billions of animals living life in terribly brutal conditions, it is not surprising that so much of the conversation within animal ethics has focused on suffering, of course, and I do not want to minimize the importance of raising awareness about
animal cruelty. Nonetheless, the focus on suffering has its pitfalls and has not always led people to value the lives of animals.

Animal welfare, largely viewed as the most popular and mainstream branch of animal ethics advocacy and philosophy, has been powerfully influenced by Singer’s theories around suffering. At the risk of generalizing a multifaceted term that can include both radical and conservative conceptions of human/animal relations, animal welfare in general sees animals as beings who must be treated responsibly because they can suffer but whom we can still use for our own benefit. Most Americans believe in some form of animal welfare, as can be seen in a Gallup poll done in 2003 showing that 96 percent of Americans believe there should be some limitations on how we can exploit animals. Those who advocate for animal welfare recognize that animals are sentient beings who can feel pain, but they do not necessarily believe in challenging anthropocentrism, the status of animals as commodities that can be bought and sold, or the killing of animals for human pleasure. The amount of suffering that an animal can endure before it is deemed unnecessary remains widely debated. Animal welfare legislation mainly focuses on making animal industries less cruel in targeted ways: banning gestation crates for pigs, for instance, or giving veal calves enough space in their pens to lie down and turn around. Such legislation, as minor as it is, is nonetheless hard to get passed. Although recognizing animal suffering is crucial to improving how we treat them, focusing only on suffering leads us to ignore that animals may in fact value living itself.

At a certain point in the conversation between Singer and Johnson, he asks her how she can “have such high respect for human life and so little respect for animal life.” She retorts, “People have lately been asking me the converse, how you can have so much respect for animal life and so little respect for human life.” After a brief exchange in which Singer begins to tell her
why in his view animals deserve our concern, Johnson replies, “Look. I have lived in blissful ignorance all these years, and I’m not prepared to give that up today.”

Singer, of course, can reply the same. Why shake up his perfectly logical, impeccably reasoned theories when he could just live in blissful ignorance of disability?
Notes

9. State of Nature


10. All Animals Are Equal (But Some Are More Equal Than Others)


4 Singer, Animal Liberation, 191–92. It’s important to note that Singer thinks all human infants are not full persons, because they do not yet have the continuation of self that children and adults do. He makes it clear that infants nonetheless still have interests (such as avoiding pain) because they are sentient, but he doesn’t think they have the same right to life as adults. This admittedly controversial position doesn’t directly relate to disabled people, and I won’t be addressing it in this book.
Throughout his career Singer has discussed a wide range of disabled infants—those who have spina bifida, cerebral palsy, hemophilia, Down syndrome, and profound intellectual disabilities—and in each instance he argues that infanticide can be justified. Because he is a utilitarian, he takes many factors into consideration to try to find the outcome that will minimize suffering: the feelings of the birth parents, the likelihood that other parents might want to adopt the child, how the resources and time spent prolonging a life might otherwise be spent, whether a “replacement baby” could bring the parents more happiness if they chose to conceive again, and of course the quality of life the infant will have as he or she grows older.

Singer does ask one valuable question that is rarely quoted: “If society decides that severely impaired infants must live, is society prepared to take on the task of giving them adequate care?” In Should the Baby Live? The Problem of Handicapped Infants (New York: Oxford University Press, 1985), co-written with Helga Kuhse, Singer writes about the inadequacies of institutions, which are often overpopulated and understaffed, and about the lack of government funding for alternative care. It’s an important point: if we agree that severely disabled infants have a right to survive, how are we to make a better place for them within our society? Singer does support improvements to services for disabled people but, instead of trying to find examples of how such necessary care might be done better, ultimately points to infanticide as a solution.

5 Jeremy Bentham, Fragment on Government (1776).

6 Singer, Animal Liberation, 2.

7 Ibid., 4–5.

8 TK
Personhood is a controversial subject among philosophers. Generally speaking, the term is used differently in philosophy than its everyday conflation with the term “human being.” Philosopher Lori Gruen writes that in the philosophical tradition “the notion of ‘personhood’ is used to identify the value or worth of someone, and it has also been used to identify who has ‘rights’ and who is the subject of ethical duties and obligations.” Lori Gruen, “Entangled Empathy: An Alternate Approach to Animal Ethics,” in The Politics of Species, ed. Raymond Corbey (New York: Cambridge University Press, 2013), 57.


Johnson, “Unspeakable Conversations.”

Peter Singer, in discussion with the author, April 17, 2012.


Neil Marcus, TK.


Susan Schweik, in discussion with the author, June 26, 2012.

Kafer, *Feminist, Queer, Crip*, 2.

TK

Peter Singer, *Writings on an Ethical Life* (New York: HarperCollins, 2001), xvii. The sentence continues, “For example, if a baby is born with severe disabilities incompatible with an acceptable quality of life, and the baby then develops an infection, many doctors and theologians would say that it is permissible to refrain from giving the baby antibiotics.”

TK

Best, “Philosophy Under Fire.”

Ibid.

Fiona Campbell, *Contours of Ableism* (New York: Palgrave Macmillan, 2009), 166.

Kafer, *Feminist, Queer, Crip*, 27.

Ibid., 3.


39 TK


41 Johnson, “Unspeakable Conversations.”