Nicole Giannetti

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**The Fight Against the Devaluation of Disabled Lives**

**Introduction**

What constitutes a life of quality? Are there ever life situations that appear worse than not being alive? These two questions have been fundamental in the development of the field of bioethics, and captures much of what bioethics has said about disability. With the rapid advancement of medical technology, humans have developed and are continuing to develop the power to save and sustain the lives of many people despite significant illnesses and disabilities. However, bioethicists have argued that there should be limits to how medical technology should be used for these purposes.[[1]](#footnote-1) Few bioethicists identify as members of the disabled community, and the majority of them prize the intellect and rationality. The values and perspectives of bioethicists profoundly influence their assessments of the quality of life of disabled people. Peter Singer, professor of bioethics at Princeton University, has become notorious in the disability community for his numerous troubling quality-of-life judgments pertaining to disabilities. The goal of this paper is to outline how Singer’s utilitarian values, in regards to bioethics, and definition of personhood have consequently devalued the lives of those who identify as disabled.

**Peter Singer: A Utilitarian Framework For Life**

Many people argue that Peter Singer is the most influential philosopher alive. Singer is best known for his work in bioethics and the animal rights movement. Although Singer’s work is celebrated within many animal rights groups, disability activists often meet his work with resistance and outrage. What has Singer’s work done to garner such strong reactions from the disability community? In many of his books and articles pertaining to bioethics and disability, Singer argues that disabled infants should be killed at birth if the parents choose to do so. Singer relies on the fundamental principles of utilitarianism to build such an argument. A major issue I have with Singer’s work is how he develops it within a utilitarian framework, and this commitment to utilitarianism is what sheds light on his perspectives on disability.

Utilitarianism is all about how to minimize suffering and maximize non-suffering, and an action is right if, and only if, it maximizes one’s well-being.[[2]](#footnote-2) Consequently, within a utilitarian perspective disability is viewed as a negative, tragic, and undesirable thing. Sunaura Taylor writes in *Beasts of Burden,* “If disability is viewed as a negative, as tragic, as lack- which is the dominant view of disability in the United States and elsewhere- then it is easy to see why it would be considered undesirable, as something to be avoided within a utilitarian perspective”.[[3]](#footnote-3) Singer writes in his book *Animal Liberation*, that it is “flying in the face of reality” to deny that on average disabled people “live less worth living lives of people who are not disabled”.[[4]](#footnote-4) By stating “less worth living”, Singer is essentially arguing that disabled people have a lower quality of life compared to those that are not disabled. In an excerpt from Singer’s *Practical Ethics* called “Taking Lives: Human” he further explains his radical utilitarian viewpoints on the topic of infanticide by stating,

When the death of a disabled infant will lead to the birth of another infant with better prospects of a happy life, the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second.[[5]](#footnote-5)

 Singer approaches this ethical issue surrounding infanticide from a strictly utilitarian perspective, believing that only the consequences of a given act determine right from wrong. Therefore, actions are morally right if they increase happiness and decrease pain for the greatest number of people. Singer’s promotion of the devaluation of disabled lives stands on no empirical basis, but rather on rational philosophy.

 I find it concerning to use rationality as a means for maximizing happiness because society does not function on Peter Singer’s utilitarian paradigm. Societal happiness is also dependent on a person’s life being lived to its full capacity, regardless of maximizing happiness for the many. Overall it is clear that Singer relies heavily on the principles of utilitarianism to defend his viewpoints on disability, but that is only one aspect of his argument. Personhood and what it means to be a person is another major part of Singer’s argument. Singer uses these definitions to further justify why the quality of life for people with disabilities is lower compared to nondisabled people.

**Singer’s Definition of Personhood**

Singer argues “a being is a human being, in the sense of a member of the species Homo sapiens, is not relevant to the wrongness of killing it; rather, characteristics like rationality, autonomy, and self-consciousness that make a difference”.[[6]](#footnote-6) Singer distinguishes between two different classes of life, persons and nonpersons- human versus nonhuman is not the morally defining line for him. Defining personhood by characteristics such as autonomy, self-consciousness and rationality, Singer finds and creates cases of humans who are not, by his definition, persons. Sunaura Taylor points out that Singer’s conception of personhood is not isolated, but rather follows a long philosophical tradition which brings to light how such a horrific way of thinking has continued to last through time.[[7]](#footnote-7)

It is important to note that Singer thinks that all infants, whether disabled or not, are not full persons because they do not have all the attributes that fit the criteria for personhood. So, how does Singer differentiate between the killing of a disabled infant and the killing of a nondisabled infant? Singer compares the two not by which one has more of a right to life than the other, but which one has a higher quality of life. Singer suggests that the more cognitively complex a being is, the more value that being will place on keeping itself alive. By killing a neurotypical infant who has future prospects and goals, you are also destroying the child’s unfulfilled dreams. In his complex calculation of quality of life, Singer also takes into consideration the feelings and desires of the family and community. He states, “It is different when the infant is born with a serious disability. Birth abnormalities vary, of course. Some are trivial and have little effect on the child or its parents; but others turn the normally joyful event of birth into a threat to the happiness of the parents, and any other children they may have”.[[8]](#footnote-8) Singer’s definition of personhood, and utilitarian outlook on disability has left many outraged. It is important to examine the arguments of people who are in opposition to Singer’s work in order to understand why Singer’s thoughts are a problem, and not just offensive.

**My Thoughts on Peter Singer**

When reading through Peter Singer’s work on disability, I quickly noticed that he relies heavily on hypothetical situations to support his argument. In his work, Singer refers to a wide range of disabilities (i.e. Down syndrome, spina bifida) in a hypothetical sense. By using various hypothetical medical diagnoses, Singer assumes that we all can predict the capabilities and quality of life that people with disabilities have or will have. However it is impossible to tell what quality of life one will definitively have based on his or her medical diagnosis. Furthermore, there is no way for us to predict the future abilities of an infant, which is why I find it troubling that Singer is a proponent of infanticide. Singer’s use of utilitarianism to construct his arguments is absurd. Humans are inherently emotional beings. When relying heavily on the principles of utilitarianism when rating the quality and value of a person’s life, Singer completely takes away the emotional aspect of humans. This is not to say that utilitarianism has no use in human life, but in regards to how society perceives disability we can’t rely on a theory purely based on rationality.

While reading Singer’s work it was obvious to me that Singer knows very little about the disabilities he’s discussing due to a lack of empirical evidence in his argument. Singer only understands disability through a medical model, in which disability is seen as a biological drawback that needs intervention and should be avoided As well, Peter Singer is a man that does not identify as disabled and has no connection to the disability community. Why does Peter Singer think he’s in a position to justify the devaluation of life when he as no idea what he is talking about? He rarely includes the voices of disabled people, and refuses to grapple with the perspectives of the disability communities. The combination of a utilitarian outlook on life, the use of a strict set of guidelines for defining personhood, and lack of empirical evidence in Singer’s arguments, Singer both judges and consequentially categorizes disabled people as less valuable. Moving on, I want to incorporate the voices of those who identify as disabled and how they confront the ideas of Singer that I have presented. I want to bring in the perspective of three key figures in the disability community- Eli Clare, Harriet McBryde Johnson and Sunaura Taylor. All three of which take on Singer’s arguments in different ways, and resist against the devaluation of life no matter the physical and cognitive abilities of an individual.

**Eli Clare**

Eli Clare is a white, disabled, transgender, author, poet, and disability activist. Clare’s groundbreaking work, *Exile and Pride,* is essential to the history and future of disability community and disability rights. As well, Clare’s revelatory writing about his experiences as a white, disabled, transgender established him as one of the leading writers in the disability community. Singer’s work on disability often puts those with disabilities on the defense, having to prove to him and his supporters why their lives are worth living. During a protest against Peter Singer at the University of Vermont, Clare stated, “I wouldn’t have made Peter Singer’s criteria” in response to Singer’s justification of infanticide of disabled infants.[[9]](#footnote-9) Clare often writes of a dilemma that people with disabilities often face, which is feeling pressure to compromise themselves by denying their own struggles or risk feeling the wrath of albeism that has been perpetuated by people like Singer. In his book *Exile and Pride* 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 albeist shit, but there is nothing simple or near about kindling the latter while transforming the other”.[[10]](#footnote-10) When Singer devalues the lives of people with disabilities, he does not allow room for the pain and frustration, which is an essential experience for many. Singer turns suffering into this unique aspect of disability, consequently oppressing people with disabilities. However, Clare brings to light that suffering is universal to all people and that suffering isn’t a defining feature of disabilities.

 Unlike Singer, Clare uses the social model of disability in opposition to the medical model. In his essay, “Stolen Bodies, Reclaimed Bodies: Disability and Queerness” Clare states,

Disability, not defined by our bodies, but rather by the material and social conditions of ableism; not by the need to use a wheelchair, but rather by the stairs that have no accompanying ramp or elevator. Disability activists fiercely declare that it's not our bodies that need curing. Rather, it is ableism--disability oppression, as reflected in high unemployment rates, lack of access, gawking, substandard education, being forced to live in nursing homes and back rooms, being seen as childlike and asexual--that needs changing.[[11]](#footnote-11)

Rather than focusing in on the physical problems that disabilities can bring to an individual, Clare locates these problems in the social injustices of the world. These social injustices of the world are what mark the bodies of those with disabilities as less valuable. Although Clare recognizes that physical disability can bring about many difficulties for an individual, it is the world we live in that perpetuates this idea that oppression from disability is centered solely in one’s body. Clare explains that it’s not the disabled bodies that need to be fixed; it is the disability oppression that needs to be changed. On the other end of the spectrum, we have people like Peter Singer arguing that the best solution for disabled people is to end their lives. I admire how Clare fights the battle against the albeism voiced by Singer, and many people like Singer. Clare does not deny that with a disability comes physical suffering, but extinguishes the idea that disabilities are engulfed in pure suffering. By voicing against the devaluation of disabled peoples’ lives, Clare brings power back to the disability community.

**Harriet McBryde Johnson**

Harriet McBryde Johnson was a disabled author, attorney, and disability rights activist. In 2002, Johnson accepted an invitation to debate Singer at Princeton University. In 2003, Johnson graced the cover of *The New York Times Magazine*, having a featured article “Unspeakable Conversations”. In her article, Johnson writes about her experience spending a day at Princeton University, where she challenged Singer’s contention that severely disabled infants could be ethically euthanized. Like Eli Clare, Johnson does not downplay the harsh realities that come with living with a disability, but asserts that those struggles do not take value away from a person’s life.

To justify my hopes that Peter Singer’s theoretical world- and it’s entirely logical extensions- won’t become real, I’ll invoke the muck and mess and undeniable reality of disabled lives well lived. That’s the best I can do right now.[[12]](#footnote-12)

During her conversation with Singer, Johnson expressed how important it is to examine closely the issues of quality of life, because such ideas have a profound impact on the way people understand disability. Johnson does believe that conversations about quality of life are useful to a certain extent, but when keeping in mind these issues, one must be mindful of what assumptions, stereotypes, and prejudiced opinions are at the root of our own positions. Johnson’s main counter argument to Singer is that the presence or absence of a disability doesn’t predict quality of life. She draws from personal experiences by making comparisons between herself and her siblings and how they each have a combination of gifts and flaws that are so distinctive that they can’t possibly be measured on the same scale. Johnson asks, “Are we worse off?” and continues by stating,

I don’t think so. 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.[[13]](#footnote-13)

Johnson is not afraid to admit that having a disability does impact one’s quality of life, but takes issue on how Singer distorts disabled lives by arguing that their lives have lower quality and is less pleasurable than one without any disability.

 When I read about Singer’s views and assumptions of disabled lives I always come away feeling enraged. However, when Johnson found herself in a seemingly impossible situation of engaging with Singer, someone she felt believed she shouldn’t have been allowed to live, she found that he was unfailingly polite and kind.

Even as I am horrified by what he says, and by the fact that I have been sucked into a civil discussion of whether I ought to exist, I can’t help being dazzled by his verbal facility. He is so respectful, so free of condescension, so focused on the argument, that by the time the show is over, I’m not exactly angry with him.[[14]](#footnote-14)

Johnson argues that by allowing yourself to dehumanize Singer was to fall into the same web Singer is caught in. What makes Johnson’s writing so powerful is that she takes a step back from pinpointing Singer as this monster, but rather reflects on the main problem of what Singer has been saying. Although Singer is a particularly vocal proponent of the idea that disability is a negative experience, his ideas simply take common beliefs about disability to their natural conclusions. The major problem is not Singer, but the way society has made disability out to be and how the voices of people like Singer try to give validity to such dangerous ideas. Johnson 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.[[15]](#footnote-15)

Regardless of how radical Singer seems to be, he is still able to make many of his arguments because our society, and the current medical establishment share many of his views. Although Johnson passed away in 2008, her words and her courage live on. Johnson will always be honored and remembered in the disability community as a courageous warrior who spoke out against the albeist forces that for too long have dominated society’s view on disability.

**Sunaura Taylor**

Sunaura Taylor is a disabled artist, writer, and disability rights activist. In Taylor’s book *Beasts of Burden,* she dedicates chapter 12, “All Animals Are Equal (But Some Are More Equal Than Others)”, to discuss several of Singer’s viewpoints on disability. Similarly to Johnson, Taylor explains to her readers that she does like Singer in spite of his offensive views on disability. I was intrigued to find that two prominent figures in the disability community were able to look past Singer’s offensive viewpoints, and take time out of their day to have a civilized conversation discussing why Singer believes disabled lives are less valuable than nondisabled lives.

 During Taylor’s conversation with Singer she asked him,

 Let me ask you this, then, and I’m asking in all seriousness, I’m wondering if you think those of us within the disability community who believes disability does have positive aspects, if you think we are just kidding ourselves. Are we just making the best out of a bad situation?[[16]](#footnote-16)

I found this to be a very interesting question because it forces Singer to try and take on the perspective of a disabled person. Singer came back with another question, asking Taylor if someone were to offer her a pill that would cure her of her disability, would she take it? Following up with his question, Singer made the assumption that most people with disabilities would choose to take the pill. Taylor took issue with the troubling “cure question” that seemingly plagues the disability community. People like Singer too often assume the answer to the question is self-evident. Taylor argues that what needs to be challenged is the inherent and universal assumption that disability is objectively undesirable, and that such attitudes on disability are the only reasonable ones. The conclusions Singer makes on disability are out right offensive, however the main issue is largely in how Singer argues his points. Taylor explains that Singer’s “rhetorical use of stereotypes about disability, his assumptions about suffering, and his commitment to rationality as the only tool capable of defining personhood” is what she seeks to challenge.[[17]](#footnote-17)

Further on in the conversation Taylor went asked Singer if disability can offer anything positive to the world. Taylor recaps Singer’s answer stating, “his reply imagined disability as something negative that can potentially teach people about struggle, about overcoming, and about care.”[[18]](#footnote-18) This common sentiment suggests that the only useful thing about disabled lives is how they teach nondisabled people how to be more compassionate. Taylor pushes past these albeist assumptions, and further explains why disability matters for many reasons- things about interdependence and challenging normalcy. Singer, and society in general, has made disability out to be this terrible thing, as something that is not “normal”. Disability “can present new paradigms for understanding how and why we care for one another and what kinds of societies we want to live in.”[[19]](#footnote-19) The voices, such as Taylor’s, that seek to eliminate such attitudes, help us all to “look for the value in ways of living that are not necessarily centered around efficiency, progress, independence, and rationality.”[[20]](#footnote-20) Through Taylor’s beautifully written words, she returns the value to disabled lives that were stolen by Singer, and by society.

**Final Remarks:**

Singer’s controversial concept of personhood has important implications for people with disabilities. Singer believes that people with severe disabilities should not be considered persons. As well, Singer argues that people with less severe disabilities who are still considered persons, may still have a lower quality of life compared to people who are not disabled and therefore it may be desirable to remove them from society so that resources can be used for someone with a perceived potential to achieve more in life. Singer is mistakenly devaluing the lives of millions of peoples simply because they are disabled.

As Eli Clare explains in his book, *Exile and Pride: Disability, Queerness, and Liberation* “The disability rights movement, like other social change movements, names systems of oppression as the problem, not individual bodies. In short it is albeism that needs the cure, not our bodies.”[[21]](#footnote-21) Eli Clare, Harriet McBryde Johnson, and Sunaura Taylor all beautifully articulate a compelling argument against the ableist framework that shapes Peter Singer’s work on disability. Singer dangerously conflates his own hypothetical examples with actual disabled communities. By drawing upon personal experiences, Clare, Johnson, and Taylor fight back against the hypothetical foundations in which Singer draws his justifications from. However these three figures do not fight just against Singer, but against the albeist mindset that has been ubiquitously continued throughout society. It is society’s present culture of albeism, which is only bolstered by Singer’s philosophy that needs to be eliminated, not people with disabilities.

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