

To Exist is To Resist: Existentialism & Disability

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Ours is an age of stunning scientific achievement. It is an age in which, thanks to the advent of prenatal screening technology, countries like Iceland stand on the precipice of wholly eradicating Down Syndrome from its land, with 80-85 percent of women opting for a prenatal screening and a majority of them opting to abort should a genetic marker for Down Syndrome be registered.¹ It is an age that could see human beings attain powers once consigned to Gods alone, as for example in August of last year scientists were able to successfully conduct genetic editing on an embryo using their technology termed CRISPR, and utilized that technology to rectify a mutation known for causing a deleterious heart condition.² As we inch ever closer to the era of what the disability community terms designer babies, babies without any “defects” or “impairments” whatsoever, and who are paragons of our conventional understanding of wellness, we must confront a harsh truth about our society. We, born of impairments both physical and mental, have long had to navigate a world predicated on contempt, maltreatment, and disinterest for the bodies and experiences we possess, but these developments signal a shift. They signal not only that ableism need no longer manifest itself overtly, such as the knife attack in Japan by a former care employee that resulted in the deaths of 19 disabled people,³ but also that ableism may be concealed and engaged in heartily by science under the banners of progress and a healthier society. This maturation of ableism poses a question of the utmost pertinence to myself and all those who possess membership in the disability community: what is the meaning of our lives? But before one can answer that, the scope of the struggle disabled people face in the midst of an ableist society committed to their erasure needs to be adequately apprehended.

Japanese philosopher and bioethicist Masahiro Morioka articulated our struggle against the ableist violence suffered by us via the existence of such technologies and advancements in his paper “Painless Civilization and Fundamental Sense of Security: A Philosophical Challenge in the Age of Human Biotechnology,” as follows:

The first problem is that it psychologically disempowers existing disabled people. If such technologies become prevalent in society, many ordinary people gradually come

¹J. Q. A. Lajka, “‘What kind of society do you want to live in?’: Inside the country where Down syndrome is disappearing,” *CBS News*, CBS Interactive (14 August 2017), available online at URL = www.cbsnews.com/news/down-syndrome-iceland/.

²A. Park, “CRISPR: Scientists Fix Genetic Disease in Human Embryos,” *Time* (2 August 2017), available online at URL = <http://time.com/4882855/crispr-gene-editing-human-embryo/>.

³M. Rich, “Japan Knife Attack Kills 19 at Center for Disabled,” *The New York Times* (25 July 2016), available online at URL = www.nytimes.com/2016/07/26/world/asia/knife-japan-stabbing-sagamihara.html.

to think[,] in front of them, “Why were congenitally disabled people like you born in the age of prenatal screening?” and “I wish you were not born.” Surrounded by [these kinds] of unspoken words and glances, disabled people are gradually deprived of the power to affirm themselves and the courage to live. In such a society, the majority of people would choose to abort severely disabled fetuses; to existing disabled people, this means that the majority of people do not wish to live with them. Even if they don’t speak out, their unconscious attitudes and glances would naturally express their inner thoughts about disabled people. Looking at such attitudes many times, disabled people will come to fully realize that they are unwelcome guests to the whole society, and this consciousness deprives them of self-affirmation as people with disability.⁴

Morioka goes on to assert later in the paper that another effect of prenatal screening technologies which, we could also ascribe for our purposes to the existence of genetic editing technology, is the loss of what Morioka terms the “fundamental loss of security.” Security in this sense, according to Morioka, is when one’s existence is welcomed unconditionally into a society. Existing disabled people are deprived of this sense of security and instead internalize a sense of occlusion within their respective society when they see the existence of such technologies and arrive at the conclusion that their birth wasn’t necessarily desired, but rather a product of luck for occurring before the realization of these technologies.⁵ Consequently, disabled people feel their sense of security eroded when society accepts and encourages the development and existence of these technologies. In the absence of security, the disabled body is one in a state of anxiety, an anxiety that those with disabilities have lives that don’t matter and have no power to create their own destinies, which instead are decided by the whims of others. The disabled body is one that resides on the periphery of a world whose science, policies, institutions, etc., seem committed to its absolute erasure.

The project of erasure can be traced back to the economic shift from feudalism to capitalism. In their paper “Capitalism and Disability,” Marta Russell and Ravi Malhotra describe disability as situated in the social context of feudalism and how it transformed with the establishment of capitalism. Under feudalism, disabled people, while facing the stigma of their impairments being cast in religious terms as either good or evil, were able to participate in economic life with it being predicated on the rural production process. With the shift to capitalism specifically in the form of the Industrial Revolution, complications began to arise with disabled workers who were once very productive under the agrarian economy of feudalism. To quote Russell and Malhotra:

As work became more rationalized, requiring precise mechanical movements of the

⁴ M. Morioka, “Painless Civilization and Fundamental Sense of Security: A Philosophical Challenge in the Age of Human Biotechnology,” *Polylog* 6 (December 2005), available online at URL = <<http://www.lifestudies.org/painlessense.html>>.

⁵ Morioka, “Painless Civilization and Fundamental Sense of Security : A Philosophical Challenge in the Age of Human Biotechnology.”

body, repeated in quicker succession, impaired persons — the deaf or blind, and those with mobility difficulties — were seen as — and, without job accommodations to meet their impairments, were — less “fit” to do the tasks required of factory workers, and were increasingly excluded from paid employment.⁶

Since bosses needed workers to function like machines, disabled people began to become further excommunicated from the labor market, and soon after “disability” as a social phenomenon to be controlled would be born. Invoking the words of Russell and Malhotra once again:

Industrial capitalism thus created not only a class of proletarians but also a new class of “disabled” who did not conform to the standard worker’s body and whose labour-power was effectively erased, excluded from paid work. As a result, disabled persons came to be regarded as a social problem and a justification emerged for segregating them out of mainstream life into a variety of institutions, including workhouses, asylums, prisons, colonies and special schools.⁷

With impairments having evolved into the social condition we know as disability, violence of all stripes was soon to follow. In 1927, the U.S. Supreme Court in the case of *Buck v. Bell*, upheld Virginia's law of the forced sterilization of people regarded as genetically unfit. This judicial mandate set the precedent from which thirty other states would follow suit, resulting in the forced sterilization of 70,000 people.⁸ The structural violence against disabled bodies was never dismantled, but merely became more opaque in its machinations. Today we deal with social epidemics like an alarming incarceration rate of over 32% of state and federal prisoners with disabilities,⁹ an unemployment rate of 8.4%,¹⁰ and a poverty rate of 32% for people 18-30 years old with disabilities, and that number climbs when you shift age brackets and account for race, gender, etc.¹¹ Given the multifaceted nature of the yoke of our oppression, given how unwanted our impairments are in society, given that we are fettered by the social condition of disability that society imposed upon us, and given that the instruments man has developed and the methodologies that govern them seem committed to

⁶ M. Russell and R. Malhotra, “Capitalism and Disability,” *Socialist Register* 38 (2002): 211–228, available online at URL = <www.socialistregister.com/index.php/srv/article/view/5784>.

⁷ Russell, Marta, and Ravi Malhotra. “Capitalism and Disability.”

⁸ “The Supreme Court Ruling That Led To 70,000 Forced Sterilizations,” *NPR* (7 March 2016), available at URL = <www.npr.org/sections/health-shots/2016/03/07/469478098/the-supreme-court-ruling-that-led-to-70-000-forced-sterilizations>.

⁹ “Disabilities Among Prison and Jail Inmates, 2011-12,” *Bureau of Justice Statistics (BJS)*, available online at URL = <www.bjs.gov/index.cfm?ty=pbdetail&iid=5500>.

¹⁰ United States Department of Labor, *Office of Disability Employment Policy*, available online at URL = <www.dol.gov/odep/>.

¹¹ M. Morris, “Poverty and Disability in America Matter,” *The Huffington Post* (28 March 2016), available online at URL = <www.huffingtonpost.com/michael-morris/poverty-and-disability-in-b-9557142.html>.

the erasure of our collective existence, the question of what the meaning of a disabled life in an ableist space is forcefully reasserts itself.

Karl Marx believed that the only thing worse than material poverty, was the poverty of the human experience. To articulate this sentiment more fully, Marx believed that because of market society and the force of capitalism, that human beings were divorced from their labor and so could not engage with it on an aesthetic, spiritual, etc. level. To illustrate, if a person assembles a bicycle for a giant bicycle manufacturer for meager wages, that person cannot even appreciate their aesthetic and technical ability of manufacturing a bicycle, because they are divorced from their labor, which is to say, it doesn't really belong to them. Marx believed that capitalism reduced human beings to the labor they could expend for the wealthy classes and business owners Marx termed the bourgeoisie. I believe the disabled of the world are experiencing a similar poverty thanks in large part to the historical forces described by Russell and Maholtra, informing present material conditions of ableist oppression that sees widespread inaccessibility, incarceration, etc. At the same time, the paradigm of biological normativity exerts itself in the medical world via the aforementioned screening technologies committed to our erasure.

It becomes clear in light of these facts that disabled beings cannot define the meaning of their lives while in the throes of the ableist and capitalist system. Therefore, as a collective, what imbues our existence with meaning is the struggle against these very forces whose dismantling amounts to our liberation. To put it succinctly, the disabled subject is an oppressed subject, and as such, the meaning we have in our lives is that of resisting this oppression. Once that resistance is carried out and every disabled person has endowed themselves with liberty and equality among their able-bodied peers, can a discussion be had of a fuller and more robust existentialism of disability. As such, this paper will be devoted to an account of what the struggle both is and is not.

Our struggle first and foremost, must never capitulate to the same capitalist system whose machinations caused our social condition in the first place. What does it mean to capitulate, as I situate this action in the context of struggle? To capitulate is to protest where the ableist society says you can protest without its workings becoming inconvenienced. To capitulate is to permit the struggle to be reduced to a slogan, one that can be printed and placed on shirts and bumper stickers, only for the profits such commodities generated, but not to go to disabled people of color who are not receiving adequate medical care, or to our comrades who are incarcerated, but to be gorged on by our oppressors gleefully. To capitulate is to have our struggle succumb to fetishism and policing by those who benefit from our social condition, and the conditions of capitalism and subjugation more generally. It is here that I agree with the Communist theorist Mao Zedong, whom in his brief essay *Combat Liberalism* writes:

Liberalism is extremely harmful in a revolutionary collective. It is a corrosive which eats away unity, undermines cohesion, causes apathy and creates dissension. It robs the revolutionary ranks of compact organization and strict discipline, prevents policies from being carried through and alienates the Party organizations from the masses which the Party leads.¹²

Liberalism has no place in our struggle, for liberalism lends credulity to genocide via medical authoritarianism when it gazes upon both us and those who actively seek our erasure and state that we should hear both sides. Liberalism thinks that striking a blow against ableism amounts to a non-disabled actor portraying disability positively or “progressively” in a film. While the terrain of culture and media is indeed one where ableism must be resisted, doing so by means that occlude our voices and is apathetic towards authentic representation is pernicious and counterproductive. Ultimately, the problem with liberalism is that it is just isn’t radical enough for the purposes of the project of dismantling ableism and liberating the disabled body. So long as a streak of liberalism runs through our activities, the best we can hope for is that the way the system that oppresses us conceives disability is more palatable to us rather than us engaging in our own radical re-imagining of what disability is and can be.

To be able to conduct this re-imagining I speak of, one must first and foremost, be endowed with the power of self-determination which is to say, the power to critique oppressive structures and to put forth a vision of your life your will would aim to see materialize. One such example of this self-determination comes from the writer Ariel Henley. When the film *Wonder Woman*, starring Gal Gadot, came out, it was signaled as a huge cultural achievement. A strong, powerful, and heroic female figure who was fully realized and not truncated as a sexual object had taken center stage and had done so to critical acclaim everywhere. Finally, women and little girls had a hero they could celebrate and positive representation from which they could draw inspiration. Yet, as Henley would point out, there was one glaring issue with *Wonder Woman*, and that is that one of the villains, Dr. Poison, has a facial disfigurement. This is no coincidence, as it is a tired trope in Hollywood that the aesthetic qualities a human being possesses has a correlation to their overall moral character or to put it more simply, to be ugly is to be evil and to be beautiful is to be good. As Henley eloquently puts it:

At one point during the film, there’s a flashback to Dr. Poison pre-disfigurement, but viewers never find out what exactly happened to cause the lower side of Maru’s face to become disfigured. Her character is relatively one-dimensional, and her evil intentions are never fully explained. Not only did *Wonder Woman* fail to provide an explanation surrounding Maru’s appearance, but it also failed to explain why Maru was intent on working with the German army in the war, and why she was dedicated to developing

¹² Available online at URL = <https://www.marxists.org/reference/archive/mao/selected-works/volume-2/mswv2_03.htm>.

a sadistic chemical weapon that could penetrate gas masks, leaving nobody safe. What viewers do know is that she wears a flesh-toned ceramic mask to both cover and disguise her facial difference: Not only is her face supposedly the impetus of her taste for vengeance, it is also simply unattractive and societally unacceptable.¹³

Henley wields her voice and her gifts as a writer to buck against the oppressive essentialist claim that to have a craniofacial disorder is to possess a dearth of moral character. Henley reclaims the right of essence, the power of self-determination, by critically examining the ableist messages embedded in media the public at large either passively or vociferously with the intent of being well meaning, consume.

Henley's essay is a microcosmic instance of someone's asserting their humanity and critiquing their oppressor utilizing the vehicle of popular culture, which could potentially alter the notion of disability possessed by the consciousness of our able-bodied counterparts. The culture of ableism, while important to engage and combat with the force of our creativity, wit, etc., it is only one facet of the overall system that needs to be overhauled. It is here where we discuss the other side of resistance, confronting the material conditions head on. When we are in the midst of this confrontation, one maxim must be at the forefront of our thoughts above all others: by any means conceivable. I say "conceivable" instead of "necessary" because the struggle asks not for a voiding of the conscience, but for an actualization of all capabilities that can service the struggle.

I shall make a distinction between two different courses of action that necessitate two distinct sets of capabilities. The first course of action is civil disobedience, and the second is violent revolution. In regards to civil disobedience, I invoke this term as an umbrella that covers actions such as protests, occupations of institutions, etc. Both these avenues of action are legitimate towards the ends of overthrowing ableism. Those with disabilities have a history of civil disobedience, dating back at the very least to 1977, when disabled activists in Berkeley California occupied the Department of Health, Education, and Welfare for twenty-five days in order to have anti-discrimination regulations issued.¹⁴ Political philosopher John Rawls legitimizes civil disobedience with a line of argument to the effect that if the proper legal channels have failed to enact change –which, given that the disabled are a minority and our equity goes against the best interests of the powerful is incredibly likely—then civil disobedience must be undertaken.¹⁵

¹³ A. Henley, "As A Woman With A Facial Disfigurement, This 'Wonder Woman' Villain Pisses Me Off," *Ariel Henley*, (7 July 2017), available at URL = <www.arielhenley.com/home/2017/7/7/as-a-woman-with-a-facial-disfigurement-this-wonder-woman-villain-pisses-me-off-bustle>.

¹⁴ Russell and Malhotra, "Capitalism and Disability."

¹⁵ K. Brownlee, "Civil Disobedience," *The Stanford Encyclopedia of Philosophy* (Fall 2017 Edition), E.N. Zalta (ed.), available online at URL = <<https://plato.stanford.edu/archives/fall2017/entries/civil-disobedience/>>.

Another thesis put forth by Rawls can best be expressed as the imperative to possess an intersectional consciousness. Rawls believes that cooperation with other minority groups, for example, people of color, women, Trans folx, etc., is essential for any justification of civil-disobedience, for any civil-disobedience that thwarts the social movements/progress of other minority groups should be regarded as illegitimate.¹⁶ Those with disabilities fully immersed in the struggle find these terms agreeable, for they understand that disability is a social identity that can be bestowed upon anyone regardless of any preexisting identities. All disabled people must unite and fight all institutions of oppression, because racism, transphobia, sexism, etc., all feed ableism when the identities of the respective forms of discrimination intersect. It is not sufficient for white, cis, male, hetero, etc., people with disabilities to be emancipated from ableism. Unless we all are, it is unequivocally worthless. So for those who can engage in civil disobedience, they should be encouraged to join with Trans disabled people, disabled people of color, and disabled people of all other lived experiences who know oppression and subjugation, in order to unite and occupy buildings, overcrowd the streets, flood social media, etc., and undertake all forms of civil disobedience of which you are capable. For ableism is no accident, and must be greeted with any force we can muster.

It is from this point that we turn to the question of terrorism and its employment. In our post 9/11 world, the term “terrorism” seemingly carries a racial connotation as well as a religious one. When we hear the term “terrorism,” it is supposed to provoke our senses to conjure up imagery of Muslims engaging in suicide bombings or attacks with the imprint of ISIS left behind. But it must be remembered that what terrorism actually amounts to is a set of tactics, generally violent in character, undertaken with the intent of causing political change. It is in this regard that terrorism should not be covered from or gazed upon with trepidation. Terrorism instead, should be embraced as a last resort when the systemic violence of ableism has become too unbearable to continue meeting with endurance. Nevertheless, the embracing of terrorism should not be conflated with an abandonment of conscience. But the collective conscience of the disabled should be informed by the ethics of revolution put forth by the anarchist Errico Malatesta.

Malatesta legitimizes violent opposition to capitalism, and for our purposes, to ableism, by explaining that any system whose authority rests upon a foundation of violence can only be overthrown with violence in kind. Malatesta says:

I think that a regime which is born of violence and which continues to exist by violence cannot be overthrown except by a corresponding and proportionate violence.¹⁷

¹⁶ Brownlee, “Civil Disobedience.”

¹⁷ A. Fiala, “Anarchism,” *The Stanford Encyclopedia of Philosophy* (Spring 2018 Edition), E.N. Zalta (ed.), available online at URL = <<https://plato.stanford.edu/archives/spr2018/entries/anarchism/>>.

Furthermore, Malatesta asserts that terrorism should never be committed to violence for its own sake, or to put it another way, brutality should never be an end in itself but always towards the end of the dismantling of an unjust and abusive system. This is a critical point to raise from which we can distinguish ourselves from terrorist groups like ISIS, or from the United States when it engages in imperialism. For our end goal is not the promotion of fear so that the vulnerable and victimized may forfeit of their liberties, but to throw off the yoke of ableism and to establish a more egalitarian relationship between the disabled body and the society with which it is situated. So if disabled prisoners wish to riot and revolt over their inhumane conditions, they should do so with force equal to the extent to which their very being is suppressed. If disabled people of color are tired of receiving inadequate medical care, may they forcefully occupy hospitals, psychiatric institutions, etc., until these deficiencies are redressed. Any violent means that disabled people of all walks of life are capable of and comfortable employing, are justified insofar as they serve the end of liberating themselves from ableist oppression.

One might indict me with the charge that my language amounts to nothing more than hyperbole and fury informed by ignorance. Indeed, one quandary that is certain to be put forth to me is “But if we are to entertain your argument, then we would have to accept as a consequence that every movement that posits itself as a liberating project on the right side of history is endowed with the justification of revolutionary violence. If we are to thrust the world into such chaos, you must have a greater means of justification than the self-perception of a collective of marginalization. What, besides your perception of and experiences with “oppression” most immediately, gives your violence authority?” To which I answer, history. History is what endows us with the legitimacy to employ revolutionary violence. Our legitimacy is derived from history, because by charting the historical progress of systemic violence, the full force of the realization that in order to alter the systemic violence, the material conditions that perpetuate it must be dismantled, becomes apparent to the consciousness of the oppressed.

Consider the history of eugenics, which most people assume was a product of Nazi Germany during World War II. I have already discussed in this paper the legal sterilization of disabled people in the United States thanks to the Supreme Court decision of *Buck v. Bell*, which led to the sterilization of 70,000 disabled people, and the philosopher Robert Wilson has noted that in Alberta, Canada from 1928 all the way to 1965, that a fellow academic served as chair of the Alberta Eugenics Board and authorized 2,832 sterilization orders.¹⁸ Furthermore, Wilson notes that as late as 2012, women and girls with intellectual disabilities were being sterilized in Australia. These aren't the only records, as one can learn a great deal of eugenics history at <http://eugenicsarchives.ca/>. The very recent history of eugenics alone

¹⁸ R. Wilson, “Eugenics Today: Where Eugenic Sterilisation Continues Now,” *Aeon* (8 June 2018), available online at URL = <<https://aeon.co/essays/eugenics-today-where-eugenic-sterilisation-continues-now>>.

illuminates to us the historical progress of systemic violence against disabled bodies. For whether such institutions are situated in a fascist society, a democratic society, or generally any society that is informed by the idea of bodily/biological normativity, ableist violence will take root and these same institutions will enact it regardless of political climate. To turn the tide against bodily normativity, its greatest benefactors must be dealt with by any means conceivable but perhaps most imperatively, through revolutionary violence.

However, having stated all this, I am also mindful that disabled people either may not be capable of such actions, or they may meet the possibility of such actions with trepidation, because the response by the ableist apparatus will be significantly greater than the initial act, and disabled people don't wish to lose any more than they have. To both groups I say, that if this be the case, it is imperative that, at the very minimum, you engage in civil-disobedience as opposed to suffering in silence. Moreover I will state here and now that I don't believe ableism will quake at the sight of a petition or a mass of bodies traversing spaces intended for protesting in a peaceable manner. These methods are disproportionate to the mass incarceration, the genocide via screening technologies, the police brutality, etc., employed by the State in its oppression of disabled bodies. If we are to get anywhere, then we must speak the same language as our oppressor, but also ensure that our discourse is guided by more just ends.

We must commit to this, for erasure not only goes beyond eugenic technologies, but also is an activity that is realized by our very language. For when words like "cure," "defective," "burdensome," "lame," etc., are associated with disability and the experiences that accompany being disabled, this language serves to invalidate those experiences and prevent them from participating fully in and benefiting from democratic life. By engaging in civil disobedience and violent resistance, we shift the language of this discourse and subsequently, posit the disabled body in a new social and political context more conducive to the purposes of a more just society. Society has conditioned people to utilize this language, which of course is how it ascended to conventionality. This language in turn, legitimizes the horrid acts of ableist violence and props up the existence of ableist institutions.

All of this comes together to give birth to our struggle, and to constrict the means by which we can define our own lives. Only by demonstrating overt opposition to this deeply entrenched ableism both linguistically and materially, can an existence not predicated on suffering and hardship, subjugation, and oppression be envisioned.