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Conceptualizing Disability Ethics in the Age of CRISPR

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Abstract

The incipient gene-editing technology, CRISPR (clustered regularly interspaced short palindromic repeats), has raised critical ethical questions regarding the elimination of genetic defects, potential risks about the efficacy and downsides of its use, and parental and medical agency over modifying the genetic material of future generations. This paper will first explain what CRISPR is and how it compares to previous technologies used to modify genes, such as TALENs and ZFNs. After describing the possible short and long-term expectations for CRISPR's applications, I provide a survey of the ethical concerns addressed by the medical community and how they differ from those that worry some advocates for marginalized communities due to the history of eugenics. I will rely on the work of Joel Reynolds, George Estreich, Alison Kafer, and Elizabeth Barnes that problematizes the cultural values and medical assumptions behind gene-editing and its potential use as a tool for a new wave of eugenics. I explain how the tragic narrative of disability has come from a societal perspective influenced by a position of power and must be re-examined. Many disability ethicists argue that their disability is crucial to their identity and determines a *different* yet not *lesser* existence. The idea that gene-editing could be used as a tool in eliminating disability perpetuates a tragic narrative of disability that not only degrades the lives of the disabled, but is incomplete. I end with a contemplation of the concrete ways in which CRISPR could benefit people with severe health conditions, while remaining aware of the dangers involved in the idealization of gene-editing that the discourse has propagated.

Keywords: Philosophy, Disability, Ethics, CRISPR, Eugenics, Gene-editing

Conceptualizing Disability Ethics in the Age of CRISPR

Introduction

The gene-editing tool CRISPR has created a vision of promise about the capacities for humans to control the direction of their own evolution. At the same time, it has raised serious ethical questions concerning effectiveness and safety, the likelihood of unintended consequences, equal accessibility, and the ethical principles driving the desire for gene-editing. After explaining how CRISPR functions and planting its origin story within the larger context of gene-editing and reproductive technologies, I explain some of the benefits it is projected to produce as suggested by researchers working with it. I then contrast the way gene-engineering is portrayed as revolutionary and promising with a survey of some of the major ethical concerns with its use, emphasizing comparisons made between it and eugenics. Stemming from points addressed in disability studies, I critique the rhetoric behind the idea that gene-engineering would be better for everyone. Relying heavily on the work of Alison Kafer, Elizabeth Barnes, Joel Reynolds, and George Estreich, I argue that the ways that gene-engineering has been proposed to improve humanity amplify ableist ideology which, affects all people but can create concrete harms for disabled people. At the end of the paper, I question the approach taken towards gene-editing regarding the desirability of choice and the value of control. If we are committed to improving the health and well-being of all communities, I draw upon Reynolds who suggests we are seeking a scientific solution to a social problem. Although CRISPR may provide some benefit, the hope for control over future generations is problematized by disability theory, which reveals how gene-editing technology may exacerbate ableist assumptions that negatively affect disabled people and society as a whole. Ultimately, CRISPR projects a vision that is likely unattainable and not necessarily desirable.

How CRISPR Functions and How it Differs from Similar Technologies

CRISPR/Cas9 is a gene-editing technology that can cause changes to DNA in cells, potentially curing genetic diseases. Jennifer Doudna and her research team invented this tool using the adaptive immune system, CRISPR, found in many bacteria. In said bacteria, CRISPR aids in fighting viral infections by detecting viral DNA. Ca9 is a protein that is part of the CRISPR system, which helps to eliminate the viral DNA once it has been located. When a virus infects a cell, it injects its DNA into it. CRISPR allows for DNA to be removed from the virus and inserted into the chromosome, which is the DNA of the bacterium. Once the bits of the virus's DNA are extracted, they are inserted as a site called CRISPR (clustered regularly interspaced short palindromic repeats). By doing so, cells record the viruses they have been exposed to over time and can transmit them to the next line of cells created from those originally exposed to the viruses. A "chemical cousin" of DNA, RNA, is created after the bits of DNA have been inserted into the bacterial chromosome. This replica, RNA, can bind to the Cas9 protein to form a complex that can search through all the DNA in the cell that match the sequences in the RNA. Once other viral DNA are located, Cas9 can make a double-stranded break in the DNA helix, cutting out the viral DNA. Upon the removal of the viral DNA, the cells can repair themselves by connecting the ends of the broken DNA with a small change in the sequence or by integrating a new piece of DNA at the site of the cut (Doudna 6:15-6:20). Doudna, the American biochemist who led CRISPR's discovery, explains in her TED Talk, how the tool has harnessed this system for genetic engineering. When used, CRISPR can make purposeful breaks in the DNA and trigger the repair mechanism in cells to mimic this biological process. Essentially, the CRISPR/Cas9 tool functions in eliminating parts of DNA that are thought to cause harmful effects.

While CRISPR is not the first genome engineering technology, it is considered quite distinct from previous tools in genomic manipulation. With CRISPR, scientists can delete or insert specific DNA with unprecedented precision, and it is programmable, which similar technologies are not. Zinc finger proteins (ZNFs) were the first nucleases used for genome editing and were used to recognize 3-6 nucleotide triplets in order to target a sequence (Yeadon 2). TALENs is the closest comparable technology, and as of CRISPR's initial testing in 2015, TALENs had considerable advantage in terms of specificity. TALENs (Transcription Activator-Like Nucleases) can, in theory, modify any part of the genome, while CRISPR has only a 70% chance of success in targeting a DNA sequence in any given stretch of DNA sequence (Samy 2). CRISPR is currently more susceptible to affecting off-target genes and thus causing unintended effects. However, CRISPR is much simpler than TALENs and will be more cost effective, which is why it has attracted so much attention. There is hope that with more research and lab testing, the probability of off-target effects can be dramatically reduced.

Gene-editing offers many potential benefits that excite scientists and medical professionals. CRISPR would allow scientists to learn the basis of genetic diseases for researching the relation between genes and corresponding phenotypes. There are opportunities for CRISPR to assist as a diagnostic rather than only gene-editing. It could possibly be used to record data over time, track cells in a developing embryo, or sequence rather than manipulate the genome. Prior to CRISPR, scientists were able to observe correlations in people between those with certain genomes and certain genetic diseases, yet the introduction of CRISPR could allow for testing to determine whether such a mutation is causal. Although there are many possibilities to use the technology beyond modifying the genome, this is its primary reason for causing so much commotion in the scientific and medical communities. Estreich quotes Doudna's *A Crack*

in Creation in which she lists different genetic diseases that CRISPR has helped develop potential cures for, “achondroplasia (dwarfism), chronic granulomatous disease, Alzheimer’s disease, congenital hearing loss, amyotrophic lateral sclerosis (ALS), high cholesterol, diabetes, Tay-Sachs, skin disorders, fragile X syndrome, and even infertility” (17). Many of these conditions cause a shortened life-span, extreme pain, and abnormal cognition. Currently, some of these can be examined with pre-natal screening but CRISPR could allow for the possibility of eliminating these conditions.

Before proceeding, there are two basic distinctions worth mentioning at present about the use of CRISPR. The first is the distinction between therapeutic and cosmetic applications. Therapeutic uses would be those used for curing conditions such as cancer or certain genetic diseases, while cosmetic applications include changing eye color or genes that affect personality traits. While CRISPR is in its beginning stages, if further research could be conducted on the relation between genes and phenotype, there is potential for being able to use CRISPR to change the genome in ways that extend beyond curing conditions that seem harmful to enhancing certain abilities or character traits. The second distinction is between editing the somatic and the germ stem cells. When editing somatic cells, the effects would change only the person whose genes are being edited. However, CRISPR can also be used to edit germ stem cells. Edits made to the germ stem cell are passed on to offspring, thus permanently altering the genome of not only one person, but their familial line. If CRISPR were to become ubiquitous, humans could radically change their genomic future. These distinctions become important in considering the possible ethical ramifications of CRISPR.

As previously mentioned, off-target effects are more likely with CRISPR than TALENs, however, Doudna was worried about more than only safety precautions. Even if the technology

was developed for maximum accuracy and precision, there are ethical considerations that remain related to the idea of creating designer humans and permanently altering the gene-pool. In 2015, due to this concern, Doudna called for a global pause in the clinical application of CRISPR because she realized that companies and venture capitalists invested in those companies would be hoping to commercialize the technology and that it could be used for enhancements as well as therapies. She compared this decision she and her colleagues made to the moratorium on molecular cloning in the 1970s. This moratorium was held in order to conduct more testing in order to better develop the technology. Although making CRISPR more accurate would mitigate the off-target effects, there is still a high risk for unintended consequences down the line. There is a wide range of ethical issues that arise from CRISPR, yet the technology also offers the possibility for what many believe to be great improvement in medicine and the abilities of the future of humanity.

Possible Benefits of CRISPR and its Vision of Promise

CRISPR has generated intrigue not only because of its possibilities for curing genetic diseases, but for making significant changes to what we thought were given aspects of being human. This technology can allow scientists to trace the causation between genes and their phenotypes, leading to further development in eliminating diseases that cause extreme pain and shortened life-span. However, if it were only thought to have the potential to cure some disease, it would not have created this kind of air of hope. As CRISPR is only in its beginning stages, it is the promise offered by what gene-editing represents that draws attention. The idea of modifying humanity in our own image posits the ability of control and possibility of becoming transhuman; it is a sci-fi fantasy made to seem tangible with CRISPR's initial development.

In showing the role of pop culture in shaping how the lofty vision of CRISPR is created, I detail the way that gene-editing is framed on a popular YouTube channel based in exploring scientific and philosophical concepts with animated explanations. The Kurzgesagt channel currently has 11.9 million subscribers and the video, "Genetic Engineering Will Change Everything Forever," illuminating this futuristic dream, has over 16 million views. The video begins with explaining how the invention of the internet, smartphones, and advanced automation have revolutionized the business world as well as our personal lives. It then dives into the process of selective breeding of plants and animals; they were once experimented with at random based on apparent physical traits. Yet, with the discovery of DNA, it become much more precise and soon labs were able to create genetically modified organisms. Now, many food products are made using GMOs—though they still inspire some controversy, they are hard to avoid. The development and vending of genetically modified organisms also drastically changed agriculture and the options available to any common person shopping for groceries. It is not the fact that these technologies exist that is quite as impressive as how quickly society abandoned their fears about the new technology and adopted them into everyday use. We not only accept them as commonplace, but rely heavily upon them. After building tools for genetically modified plants and animals, we can now apply it to ourselves. The channel places the gene-editing of humans in the context of creating of GMOs, which suggests this is a natural, and even inevitable, progression.

While genetic engineering as a concept has fascinated professionals from many fields, up until quite recently it has entailed a complicated, lengthy and costly endeavor; this changes with CRISPR. With CRISPR the cost of genetic engineering decreased by 99%, the length of running experiments for it have reduced from about a year to several weeks, and the required equipment

is minimal in comparison to previous technologies. As mentioned before, CRISPR is programmable and needs only a copy of the DNA that one wants to modify and enter the system into a living cell. Three central optimistic possibilities are presented by Kurzgesagt's video: the end of disease, the creation of designer babies, and the end of aging. The first appears to be the least controversial and closer in imagination. In 2015, HIV was removed from living cells using CRISPR in a lab. The next year, CRISPR was used in HIV infected rats and removed 48% of the virus from the rats' cells. With more time and research, CRISPR's use could be extended to eliminate HIV, Herpes, cancer and other harmful diseases. This potentially life-saving research is already on its way, as the first clinical trial for CRISPR on cancer treatment was approved in 2016 in the U.S. In under a month, China agreed to use CRISPR modified immune cells on lung cancer patients. In addition to these, genetic diseases could also be 'cured', such as hemophilia and Huntington's disease. Many genetic diseases are caused by a single 'incorrect' letter in one's DNA; a new version of Cas9 designed specifically for this purpose was already in the works in 2016. While overcoming disease would be an impressive achievement, the edits would be made to individuals. Gene-editing on embryos would be a huge step away from somatic cell editing. CRISPR inspires loftier aims that radically change our conception of what it means to be human.

The idea that sparks much of the excitement in the video is that it could be used on the germline—that is, using CRISPR on human embryos could bring unprecedented power to changing the course of humanity. In 2015 and 2016, scientists in China had already experimented with CRISPR on human embryos and had some success. The gene changes made in embryos can be passed on to their offspring. If genetic engineering in embryos became as commonplace as smartphones, billions of people would be choosing to make changes to not only their children, but the future gene pool of humanity. These changes would begin as therapeutic

ones such as eliminating a disease, and then to ones that could boost health—such as an improved immune system (Kurzgesagt 9:49). Health-based enhancements could be extended to ones that improve fitness capabilities, then to those based on appearance and intelligence. Moving beyond enhancing features, we could begin to make drastic changes to our longevity. Two-thirds of deaths are due to age-related causes, and CRISPR could be used to develop preventions against aging. This could potentially end or significantly slow down the aging process. Those alive today may be the first to benefit from this. Looking to the future, anti-aging therapies could be used for preserving humans for lengthy space travel in search of other planets to inhabit, and in coping with the environmental conditions present on them. While many of these developments may seem way off, some extremely so or not even be possible, genetic engineering sparks imagination for the possibilities of the future and the role that humans themselves would have in creating them. As far off as they may appear, they are likely to become commonplace soon after the options become available.

This popular video displays CRISPR as the beginning of a solution to all health-based issues with the possibility of even stopping aging altogether. Although this video is not an advertisement and does mention that CRISPR remains in its early stages and could require some difficult choices to be made, it is viewed as extremely promising. Genetic engineering is viewed as a natural and beneficial progression for humanity and as inevitable. In *Fables and Futures: Biotechnology, Disability, and the Stories We Tell Ourselves*, Estreich warns of the ways advertisers for genomic technology and prenatal screening can prey on the public by positioning their products as necessary. He points out that the main challenge is not asserting that their product is completely effective, but arguing that there exists a problem in the first place. As we see in this YouTube video, gene-editing is presented as the key to imagining radical changes to

humanity, whereas the precision of the tool in question is less important. Advertisements and pop culture representations alike generate enormous amounts of hype about novel technologies that are typically out of proportion with the benefit they are able to produce. This hype tends to overshadow the ethical concerns it raises.

Survey of the Ethical Concerns Regarding CRISPR

Technological Errors

The controversy surrounding CRISPR comes from many different angles, but one of the simplest is that which comes from the concern of the advancement of the technology. One of the reasons Doudna and her colleagues called for a pause on CRISPR's clinical application is because of the fear that the technology is not advanced enough. Scientists know little about the relationship between genes and environment or how they both affect phenotype. If progress continues without certainty of what contributes to a specific phenotype, scientists could attempt to use CRISPR to manipulate genes in situations in which the problem lies elsewhere. Scientists could cause unintended consequences in a person by mistakenly attributing a problem to a gene rather than the environment. There have already been instances in which CRISPR has failed to be effective or has caused consequences that were not predicted to occur. There are also unknown effects that could be caused by having a technology such as this one available on the market. Perhaps, if used in a few special cases or as a last resort in the absence of similar, less invasive, alternatives, the possible problems would never reveal themselves. However, if it becomes widespread, biological issues may arise on the level of the species. It is difficult to predict the amount of time necessary to radically change the gene pool of the human species. However, if certain traits were considered more valuable than others and it became possible to eliminate traits that were considered less desirable, the gene pool could become less and less

diverse. This happening on a large scale could have dangerous, unknown effects we should avoid.

(Un)equal Accessibility

Another ethical question regarding CRISPR is that of the accessibility to the technology. As briefly mentioned, there are biological issues that could arise were the entire human population given access to this technology for cosmetic as well as therapeutic purposes. However, there are social questions regarding the distribution of this resource were it to come to fruition, and to the usefulness of the technology to minority groups due to the already unequal access to medical and scientific knowledge. One aspect of the question is whether this technology would be available to all ethnic populations equally. The direct-to-consumer genetic testing company 23 & Me, for example, has more data on people with European descent than people of any other ethnicity and thus is able to provide more accurate and complete information on those whose ethnic history originates in Europe (Zhang 1). On a similar vein, CRISPR would require subjects for testing before being ready for mass clinical or commercial use. In order to ensure the health care of all communities, willing participation from different ethnic groups would be helpful for CRISPR's development. However, due to the historic mistreatment of racial minorities in the United States, there is bound to be reluctance for racial minorities to subject themselves to experimental medical testing. There are many such instances in recent history in which medical professionals have purposefully withheld information from clients and used racial minorities for medical tests without or against their consent (Hildebrant and Marron 2). One of the most notable instances of mistreatment was that caused by the U.S. Public Health Service Tuskegee Syphilis Study on African Americans, yet there is a history of malpractice in the U.S. as well as internationally. Because minority populations are less likely to participate, the data on

the genome lacks diversity, thus, it will be harder to construct therapies for minority populations where there is less data on their genetic makeup. However, the consequences of inequality will extend beyond the amount of data included.

In addition to a lack of data in order to properly develop the technology for all ethnic groups, many scenarios in respect to distribution suggest a likelihood of inequity to CRISPR access. Some advocates for racial justice worry that CRISPR will not be promoted to all people equally and minorities may not receive adequate information about its purpose, benefits, and risks. In her book, *Feminist, Queer, Crip*, Kafer explains that use of reproductive technology is difficult to access due to discriminatory practices against marginalized people. She raises the case of Kijuana Chambers, an African American, blind, lesbian woman who was denied in vitro fertilization (IVF) treatment on the basis that she had not been approved to rear a child (Kafer 81). After suing based on the Americans with Disabilities Act, arguing that non-disabled people did not have to provide evidence for parental qualification, she was denied.

The accessibility to CRISPR upon its development is also likely to be limited due to financial resources. If CRISPR is only available to the wealthy, it could cause an even greater disparity in health between socio-economic classes. Some studies already show a correlation between IQ and wealth, if CRISPR could be used by the wealthy to enhance intelligence, athleticism and prevent against aging in their offspring, they could drastically increase the gap between the powerful and powerless. The existence of a useful technology will not ensure it is accessible to all, yet the vision that these technologies use to receive funding is one that is aimed at improving a shared future.

The Question of Eugenics

Then comes the question that seems to cause the most controversy: would CRISPR begin a new wave of eugenics? The concept that humans should take the genetic development of the species into their own hands is not new. The eugenics of the 20th century was rooted in social Darwinist ideology, based in the idea that only some were worthy of life and should be able to reproduce. With the development of animal breeding a belief that genetics could be used in humans to breed for desirable traits arose. The ideology was such that suffering could be reduced in the population, and put forth that children have the right to be 'well-born' (Jones 4:21). Stemming from this concept, however, was such that the 'wrong sorts of people' could not be trusted to self-regulate their own reproduction. Due to this idea, advocates of eugenics began devising ways to ban certain people from having children. It was thought that conditions such as what was referred to as 'feeble-mindedness' was hereditary, and it benefitted not only the individual being rid of the condition, but the society as a whole, to not bring more 'unfit' people into the world. They were considered unable to contribute to society and overall a burden on their families and the state that needed to provide them with welfare benefits. In Virginia's Buck vs. Bell case, a law was passed that was challenged eventually reaching the Supreme Court. The law was upheld and claimed that for the better social good, the state should be allowed to sterilize those who they deemed unfit to reproduce (Jones 6:17-7:10). In defense of this verdict in 1927, the Supreme Court Justice Oliver Wendall Holmes said:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes....Three generations of imbeciles are enough.

As a result of this decision, many sterilization laws were passed in the 1930s. In 24 American states, eugenic sterilization had been passed in the late 1920s, and by 1933 California had subjected more to sterilization than all the other states combined. Similar laws were passed in Canada in the British Columbia and Alberta. Because people in private care were able to avoid the sterilization, the laws discriminated against poorer people and minorities and those housed as inmates of state institutions who were handicapped or mentally ill (Kevles 3). Sterilization rates had increased with the worldwide depression in 1929, which were mainly made on economic grounds. Those who did not see eugenics as a cure for degeneracy often still favored sterilization for the mentally ill so that children were not born to parents who could not raise them. There was resistance in the United States, not on principle, but for the problems in practice. The laws unfairly targeted the poor and racial minorities. Scientists criticized eugenics in the interwar years, arguing that many mental disabilities and human behaviors are not determined by or not solely determined by genetic makeup and are rather heavily influenced by environment.

Hitler drew from many of the eugenic practices implemented in the United States, but furthered the practice by committing a genocide against those he deemed undesirable. He led a mass extinction of Jews, homosexuals, the mentally ill and other racial minorities. Due to eugenics becoming associated with Hitler's genocide in the 1940s, eugenics was mainly abandoned in the United States as a matter of public policy. However, compulsory sterilization, often without the consent of the individual, still remained in the U.S. throughout the 1970s and into the 80s, targeting ethnic minorities and the poor, but nowhere near the scale of the 1930s (3-4). The history of eugenics is recent and casts a shadow over any attempts to edit genes on a mass scale today.

Some of the problems with the eugenic attempts of the 19th century were based on bad science that attributed more to genetic makeup than was known, attributing social problems to genes. Policies were also implemented in such a way that targeted racial minorities and the poor. These are some of the concerns brought up with CRISPR, such as questions regarding distribution and the unintended consequences that could be attributed to a lack in current scientific insight. Yet, there are also questions regarding the principle of the ideology itself that is driving the desire to create the technology. Gene-editing, especially in the germline, reads as a practice to conduct eugenics. It is not a reach to imagine how a technology that can select to modify genes could be interpreted as such, especially if used on a widespread scale for a multitude of causes.

Eugenics and Disability

The practices of eugenics after WWII were largely condemned due to how the ideology of 'bettering the race' promoted the supposed welfare of society above individual rights, as well as the classist and racist implementation of the policies, but especially because of how eugenics had been taken to its extreme in Hitler's genocide. However, the belief that that individuals—as well as society as a whole—would be better off without disability remains a cultural assumption. Many bioethicists, philosophers, and doctors applaud CRISPR's potential use to eliminate disability because they consider it common sense that disability is harmful and undesirable. As of today, many doctors screen for such conditions considered disabilities and some respond to the news by recommending abortion. It has actually become customary in Iceland and Denmark, for example, to abort pregnancies when Down syndrome is detected in the embryo. Iceland has eliminated Down syndrome in their population by nearly 100% (Will 3). In Denmark, a woman can abort a child detected to have Down syndrome or similar conditions up to 22 weeks after

conception (Lindeman 2). This trend does not belong to these counties alone. Kafer quotes James Watson, one of the main contributors to The Human Genome Project, “we already accept that most couples don’t want a Down child. You would have to be crazy to say you wanted one, because that child has no future” (James Watson qtd. in Kafer 3). Now while this statement is typically criticized for its crassness, the underlying belief continues to receive support. Although seemingly rude to purport this outright, the belief that children with Down syndrome are inherently worse off and do not have valuable futures rings true to many people. Estreich exemplifies the ubiquity of this belief, that it is not the underlying message that is worrisome, but the tone and delivery of comments such as these through a joke made by comedian Margaret Cho. Her joke begins with explaining her struggle to become pregnant and her worries about doing so at 43, saying she “didn’t necessarily want to have a retard” (qtd. in Estreich 62). Upon being told by host Andy Cohen that she could not say that,’ she says “You want your kid to have the best chance at life…” After public outrage at the joke emerged, Cho apologized by saying, “Know that the children of the world, especially those differently-abled kids and their brave noble parents and families, who have it hard enough to begin with, deserve much better than me and my idiotic need for approval in the form of nervous laughter” (63). Notice that Cho’s apology frames the issue with her joke as being the derogatory language used, not the underlying message behind it. In fact, she reifies the idea that a disabled child is undesirable in that it requires exceptional bravery on behalf of the parents and family members who look after them. She asserts her choice of language was insensitive, but does not question the idea that the fear that drove the joke was misguided. More importantly, this is not an individual fear; the joke presumably is funny precisely because it plays to a common worry that typically goes unquestioned. Many people fear having children with Down syndrome as they do not want a

child who they believe will suffer physically, be socially ostracized by their peers, incur expensive medical bills and costs of home-care, have a shorter than average life span, and deviate from what they consider to be a reasonable expectation for their future child's life. Based on this belief, as well as the belief that the parents have a responsibility to provide their child with the best chance for well-being, emerges the idea that it is obviously more desirable to have a child without Down syndrome. Cho's framing of Down syndrome is a product of and perpetuates the tragic narrative of disability. This is the idea that disability is always and only a tragedy and that people who are disabled are necessarily worse-off than if they were not. Many disability rights activists and disability ethicists attempt to combat this narrative.

One of the main principles of the disability pride movement is "nothing about us without us," which Barnes argues in *The Minority Body: A Theory of Disability*, cannot be sufficiently addressed if disabled people consistently experience testimonial injustice. Non-disabled people reliably misunderstand what it is like to be disabled, largely because they fail to listen to or believe the testimonies of disabled people themselves. Many disabled people express having levels of subjective well-being on average with the rest of the population, yet the idea that disability decreases well-being remains a pervasive idea. Elizabeth Harman argued that at least some disability-positive testimonies are the results of a "mistaken application of a form of 'I'll be glad I did it' reasoning'" (qtd. in Barnes 121). Harman argues that it makes sense for people to value and prefer being who they are, and so if someone is disabled, they value being that way. Yet, this is not an argument that supports these preferences exist beyond their own experience. Harman argues that one can value the experience of disabled people without valuing disability itself. Several disability theorists, including Rosemarie Garland-Thompson, argue that disability can provide the opportunities for valuable lessons they might not or could not otherwise have

had (20). However, these theorists also purport that they value disability for more than that as well. Disability is not only valuable in an instrumental sense; it is not akin to a bad experience that one is grateful for having had (Barnes 85). Lessons that come out of bad experiences, although people can be grateful for having had them, are generally preferred not to have had to been learned the hard way. Given that people do typically know how to distinguish between valuing the ways that something has shaped them and valuing things for their own sake, in order for Harman's argument to be true, disabled people must be consistently making a systematic mistake. Something must account for such a mistake; the most popular account is the idea of *adaptive preference*.

The adaptive preference approach details the way in which someone changes their preferences based on their abilities. Jon Elster argues that although it is considered rational to change one's preference based on a meta-desire, it is not to change it on the basis of an unconscious desire not to be disappointed or frustrated (qtd. in Barnes 125). Amartya Sen and Martha Nussbaum build off Elster's model to include that one can have a coherent set of preferences for things that are not good for you, which changes the construction to a normative one. If one *should not* prefer it, it is considered an adaptive preference. This model is used in the case of someone with Stockholm syndrome who has convinced herself, through a coping mechanism, to prefer to stay with an abuser in an *objectively bad situation*.

Barnes argues, however, that everyone's choices are limited by ability and that an overgeneralization of the adaptive preference model can reveal its weaknesses. This is not disturbing only in the abstract. Ideas supportive of the adaptive preference model have been used to silence and ridicule different marginalized groups throughout history. Similar reasoning used against disabled people now has occurred in various instances in which the group in power has

decided which bodies are suboptimal. In the Middle Ages, women used to be seen as deformed men and anyone who had pride in being a woman was seen as only believing this because women lacked rationality, thus discounting their testimonies. In the 1950s, gay people were seen as having a psychological disorder and if they did not seek 'help' and preferred not to be 'cured' this was seen as further evidence of the disorder they supposedly had (Barnes 134-136). The adaptive model can be used to justify the dismissal of testimonies of marginalized people and uphold the status quo. Who and how a situation is considered suboptimal is important to note. In the case of Stockholm syndrome, victims' self-reported testimonies can be compared to other things they experience, for example: stress, anxiety, fear, and depression. This discordance in the testimonies of disabled people usually does not exist. Many disabled people, according to their own testimonies and actions, seem to greatly value disability, actively celebrate disability by participating in disability pride marches, upholding their own art and culture. (140-141). The adaptive preference model can only be implemented in denying the testimonies of disabled people if we actually know that being disabled is *objectively suboptimal*. The cultural assumption that disability is and must always be undesirable, is so strong that we deny the testimonies of those who are likely to possess the greatest epistemic advantage in determining the value of a life with disability.

In further explaining that adaptive preference is not a persuasive case for why some people value disability, we should consider the phenomenon of Body Integrity Identity Disorder (BIID). I use this example not to argue of the origins of BIID or suggest how it should be treated, but rather to demonstrate how ingrained ableism is in our society. BIID is a condition in which someone possesses an intense desire to become relatively impaired, usually through amputation. There is disagreement over the cause of this rare condition, yet it is apparent that only certain

impairments are favored. “Invisible” or “unhealthy” disabilities are not desired. Although the cause of the desire is unknown, bioethics assumes it to be pathological in nature (Reynolds BIID 39). Chloe Jennings-White’s desire to become paraplegic became popularized with her appearance on CNNS’s “360.” Her experience reflects that of people with BIID as she explained how walking did not feel “right” and uses a wheelchair to help correct for this. She has struggled to find a surgeon who would perform a procedure to sever her spinal cord to fix her discordance between her mind and body. Anderson Cooper argued that that her desire was inappropriate given how many do not get to choose to be paraplegic. Reynolds builds off Fiona Kumari Campbell’s discussion of the topic, saying that the idea that one should want a disability is equated to the idea of desiring a constraint and this is, by society’s standards, considered repulsive. He argues:

> Implicit in Cooper’s comment and the ensuing applause is not just disbelief in the veracity of Jennings-White’s claims about her own experience, but a more thoroughgoing incredulity regarding the very *possibility* of her desire…if one can only imagine a desire as pathological, one cannot imagine that desire as authentic” (39).

Reynolds notes that around of the time of this publication, there was plenty of media coverage on famous transgender people, as well as the infamous case of Rachel Dolezal, who claimed to feel as though she was a difference race. Debate ensued about the social acceptance of people wanting to alter their identity by changing their gender, race, or ability. On examination of Dolezal’s case, it appears as though transgender and claiming to be ‘transracial’ are importantly different and likely not equally legitimate, the basis of which I will not defend in this paper. Neither do I care to argue for Jennings-White’s desire to get the surgery as grounds for a surgeon to sever her spinal cord. Instead, I introduce the Jennings-White case due to the distinctive rhetoric used to oppose their claims.

Dolezal received backlash for many reasons, her deceit and the profit she made from being a leader in the NAACP being two of the main ones, however, her claims of being transracial were not seen as illegitimate because it was not *conceivable* for her to want to be Black. Perhaps a minority of arguments against her were based on a lack of understanding why she would want to be read as part of a racial group that is so heavily discriminated against. Still, the thought that she should want to be perceived as being part of the Black community—a community that has a rich culture and history in which many Black people take pride—was not questioned on the basis of desirability. The criticisms against her were mainly that her claim to Blackness was illegitimate because the desire to belong to a race is not the basis upon which race is determined. Some of these claims are relevant in opposing Jennings-White's claim as well, for example a *desire* to be paraplegic may not merit one the right to become one. However, the claims made against Jennings-White were distinct in that they argued against the legitimacy of anyone desiring to become paraplegic. This is based not on a failure to believe *her*, per se, but on the idea that there could be anything desirable about disability in general. It is the failure to believe and accept her on the grounds that disability is *objectively suboptimal* and that she must be mentally ill in order to desire this. Thus the solution to this unacceptable desire must be 'fixing' her mind, not correcting the discrepancy between what she feels and the nature of her body. This rhetoric raises red flags primarily on its similarities to historical examples in which minorities have been pathologized for deviating from dominant cultural norms, such as those previously discussed.

We see similar disbelief that disability can be a preference in public responses to the case of a deaf lesbian couple. CRISPR attracts praise in part for its potential to end genetic disabilities, and many already use prenatal screening to check if their child is predicted to be

disabled. However, some deaf parents want their children to share their culture and would prefer to have a deaf child, such was the case for one couple whose decision sparked controversy for a different reason than the case of Jennings-White. The case referenced is one that inspired controversy because the couple sought a sperm donor with a family history of deafness in the hopes of having a deaf child. Initially, the couple attempted to find a deaf sperm donor, but were told that congenital deafness usually disqualifies potential donors. They decided then, to ask a deaf friend of theirs who comes from a family with five generations of deafness. The couple say they would love their baby regardless of its hearing ability, but because they do not see deafness as a disability, but rather a cultural identity. Their deafness and the community it brought about for them was a positive experience in their lives and they wanted to share that connection with their children. Reynolds argues that negative attitudes towards the couple were not based on the couple being "pathological," but rather the relative harm caused due to the disability this would cause in an ableist society. They understood that a deaf child would experience a harder time navigating a world that was not made for them, yet they see choosing to have a deaf child as no different than a Black couple wanting their child to be Black as well. Although Black people, like deaf people, are discriminated against, it is still understandable why a Black couple would want a child who looked like them and was able to share a stronger connection to their culture. The couple argued that the public would not tell a Black couple in their position that they were harming their child by choosing a Black donor.

Although deaf people may experience some disadvantages in our society, the couple asserted that it also carries with it its own valuable culture. Gauvin, their child, was confirmed to be deaf—but there was a chance at restoring his hearing through the use of a hearing aid. Their doctor suggested they should use one for him as soon as possible so he could have an easier time

learning spoken language. The couple, however, opposed it, saying that if he wants a hearing aid when he gets older, he can have one. Some deaf parents expressed they shared the desire to have a deaf child, but had not taken the steps to increase their likelihood of having one. Yet, for them, it seems more a question of accessibility rather than opposition to choosing a deaf donor due to a fear it might make their children worse off. Because deafness is a condition used to screen out potential sperm donors, it is difficult to go about having a deaf child, even if a couple did prefer to have one. Nancy Rarus of the National Association of the Deaf, however, says she does not understand why someone would want to purposefully bring an impaired person into the world when it limits so many of their opportunities (Spriggs 283). Many people spoke out against the idea of them attempting to have a deaf child, even from within the deaf community, because of the idea that it would limit their child's potential. However, Kafer addresses the idea that many consider deaf people as distinct from disabled people, which she says is an issue that further marginalizes members of the disabled community. Nonetheless, some perceive deaf people as akin to a distinct linguistic and cultural minority more so than to people in wheelchairs or who are blind (Kafer 77). For example, Spanish speakers are not seen as disabled simply because they cannot communicate in English without the aid of an interpreter. And although such a person would 'miss out' on some of the beauty of the English language, one would not say this necessarily makes the Spanish speaker worse off. This is especially true because that person benefits from fluency in Spanish. To think that deaf people do not find similar cultural enjoyments from sign language or being deaf, is to be shortsighted.

Barnes explains that disability is typically seen by non-disabled people as lacking the ability to do something or experience something. She agrees that sometimes disability does inhibit people from certain experiences. Nonetheless, to say that it *only* causes a lack fails to

recognize how disability can bring with it elements of other cultural experiences. One of these examples is the way deaf people can share musical experiences by feeling the vibrations of soundwaves (Barnes 57). Rachel Kolb, explains during a Hastings Center sponsored conference, "Belonging: On Disability, Technology, and Community," how, although at times uses a cochlear implant to hear, she still often removes it in order to enjoy the value of deaf culture and to relieve herself of the burden of constantly hearing. She praises the ability to communicate through the use of sign language in a noisy restaurant. She also appreciates being able to remove the implant when she is ready to go to sleep, jokingly expressing her failure to understand how non-deaf people are able to fall asleep.

In respect to the case of the couple's decision, even if the argument can be made that not being able to hear would cause more harm than good socially—although this would be a difficult argument to make—would these same people condemn a deaf heterosexual couple for having children, even though they might risk limiting their child's potential? (Kafer 77) It strikes Kafer that it would seem inappropriate at the least, for someone to suggest they not conceive a child due to the risk their child might be deaf. It is understandable for people to argue that the child's opportunities might be limited, but this problem should rest on social institutions to become more accommodating, not on the right of a couple to have a child.

This case, however, also illustrates the potential dangers of being able to select the genetic traits of one's children prior to them being born. In response to the case, Queer author Jeanette Winterson said, "You take a chance with love; you take a chance with nature, but it is those chances and the unexpected possibilities they bring, that give life beauty " (Kafer 77). Winterson suggests that being a parent or a proper parent, means accepting one's child, however

it happens to be born. A couple of points are important to make in response to this sentiment. The first, is that the idea of a 'natural conception' must be brought into question considering this is a same-sex couple. In the case of IVF, the couple would be *choosing* a donor regardless of whether said donor was deaf or not. Secondly, chance is still present in their scenario; a deaf donor does not guarantee a deaf child. Furthermore, it seems that Winterson is only concerned with the parents choosing the *deaf* donor, as it doesn't concern her that screening out deaf donors from sperm banks also removes the 'chance of unexpected possibilities.' CRISPR differs from IVF because if the tool worked perfectly it would eliminate chance. While some might agree with Winterson's point that parents should not select their children's' genes, this is typically more troubling for people when selecting for rather than against disabilities.

When we genuinely encounter the testimonies of people who find value in their own disabilities, people who are disabled and would prefer their child to be as well, and the existence of people who are not disabled but desire an impairment, a conflict arises in the image of the potentially perfect, disability free future that inspires many advocates of CRISPR. In responding to James Watson's comments about children with Down syndrome, Kafer explains the assumptions he, and supposedly many, agree with:

> The first is that disability is seen as the sign of no future, or at least no good future. The second, and related, assumption is that we all agree; not only do we accept that couples don't want a child with Down syndrome, we know that anyone who feels otherwise is 'crazy.' To want a disabled child, to desire or even to accept disability in this way, is to be disordered, unbalanced, sick. 'We' all know this, and there is no room for 'you' to think differently (Kafer 3).

A future free of disability is assumed to be desired by all, and when confronted with instances in which people oppose that intuition, this evidence is ignored and those presenting their testimonies are rather seen as sick, cruel, and crazy. It appears unfathomable for disability to be

accepted under this intuition. Disability is assumed undesirable by the non-disabled, but this is phenomenological understanding non-disabled people cannot assume to know. Reynolds draws from the philosopher Maurice Merleau-Ponty in explaining the phenomenological difference between someone wearing a blindfold and someone who is blind (Reynolds "Merleau-Ponty" 422). At a surface level, it may make sense to someone who is not blind to think that one could gain useful information about the experience of a blind person by masking one's perception and going about one's day with the use of a blindfold. Yet, the embodied experience of a blind person, that person's sense of perception, spatial reasoning, and socialized treatment, cannot be gained through such an exercise. This phenomenological difference is important to note, as Kafer explains, because it contributes to the denial of testimony. If we think we *can* know 'what it's like' to have a disability, then we think we know what's best for disabled ppl. 'We' know 'what it's like,' and we know that disabled people are missing out on "x" and thus we know what's better for them. This here is at the core of what is troubling about the pseudo-utopian vision created by CRISPR, it is assumed to be desired by all for all. Because it is considered common sense that everyone should want this, it is taken for granted that choosing to change a gene likely to cause a disability in an embryo can only be a positive change. It is seen as freeing that soon-to-be child from the inherent limits that disability brings, not as robbing the child of any experience they might have acquired due to that disability. Building off the assumption that limiting a child in such a way that a disability will definitely worsen their well-being is thus sufficient justification for desiring a disability free world, a world that CRISPR will aid in creating.

Conceptions of Disability Ethics

The previous section demonstrates common attitudes and beliefs that help us to understand the dangers of CRISPR; we can now examine alternative ways of conceptualizing disability as not simply a lack or disadvantage. This section will examine how disability can be defined in different ways that challenge the interventions that CRISPR sees as beneficial. If we can understand disability as not only disadvantage, we can problematize the way that CRISPR construes disability as something to be eradicated. Long before the introduction of CRISPR, activists and scholars in disability studies had made distinctions between different models of disability in order to exemplify the true experience of disabled people and reveal the societal prejudice against them.

Disability studies, as described by Reynolds in **"**The Extended Body: *On Aging, Disability, and Well-being,***"** is that which examines human experience through the lens of disability using empirical, data-driven science as well as reflective and critical inquiry. He explains that it is typically thought to have begun as a counter to the *medical model* of disability. The medical model of disability links disability to the condition of the individual's physical body. While it emerged from the bio-medical perspective, it is that which pervades most of society and drives some of the practices seen as expressions of eugenics. The *social model* of disability contrasts "impairment" from "disability;" "impairment" refers to the bodily condition that causes the body to be considered disabled, whereas "disability" is defined by the way society treats bodies with impairments. This model was proposed and adopted by many disability ethicists and disability rights activists in order to combat the negative attitudes towards disabled people that the medical model perpetuated. The social model shaped understanding of disability leading to the passing of

the Americans with Disability Act of 1990 and the acts passed at the United Nation's 2006 Convention on the Rights of People with Disabilities (Reynolds "Extended Body" 2). However, noticing the limitations of the social model have led scholars to new theories in a category Reynolds refers to as critical models of disability. Barnes creates the Value Neutral Model of disability, Kafer develops the Political/Relational Model of disability, but as Reynolds explains, what these critical models of disability have in common is that they emphasize the social discrimination aspect of disability while continuing to acknowledge the ways in which disabled bodies themselves can present challenges that would exist even in a society free of ableism.

In *Feminist, Queer, Crip*, Kafer discloses she also takes a "friendly departure" from the social model because it fails to acknowledge the challenges that arise due to the way disability affects disabled people's bodies. She does not find the distinction between impairment and disability useful. Although she agrees that we need to attend to the social aspect of disability, asserting a sharp divide between "impairment" and "disability" fails to recognize that they are both socially constructed. She worries about the dangers of relying solely on the social factors of disability, arguing that "in its well-intentioned focus on the disabling effects of society, it overlooks the often-disabling effects of our bodies" (Kafer 7). It is important to acknowledge that some disabled people do experience extreme pain and some seek cures. A theory of disability should include those people as well, instead of further marginalizing them and denying them a community in which to express their complex feelings towards their disability. Finally, dividing impairment from disability tends to make it challenging to understand how compulsory able-bodiedness affects everyone. Kafer uses a political/relational model of disability in order to

push back against the de-politicization of disability and to recognize how disability does not exist in isolation but is created in relation to others.

Barnes' work illustrates the complexity of forming any model of disability. In *The Minority Body: A Theory of Disability*, she devotes an entire chapter dedicated to defining what disability is. She attempts to develop one that encompasses the following criteria: (i) it delivers a correct verdict for paradigm cases, (ii) it doesn't prejudge normative issues, (iii) it is unifying or explanatory, and (iv) it is not circular (Barnes 10-13). This means that some ambiguity in borderline cases of disability may not disqualify the theory, but a case that people clearly identify to be a disability should be considered so under this definition. It also should not define disability as inherently bad or good. The definition should be unifying between different disabilities and it should not appeal to something it being attempted to explain in the definition itself. Barnes suggests a moderate social constructionism that argues disability is socially constructed but that places a greater importance on objective features of bodies rather than how those bodies are treated (40). She then develops a Value-Neutral Model of disability that supports that the main source of suffering for disabled people stems from how their society treats them. However, she also finds it important to acknowledge that even in a society that carries no stigma against the disabled, disabled people would still experience some of the negative outcomes that come with the physical conditions of their bodies.

The disability theory put forth by Barnes is particularly helpful in revealing that the often-unchecked intuition that disability is intrinsically and overall harmful to any individual is misguided, which is one of the guiding attitudes of CRSIPR development. In constructing her Value-Neutral Model, she asserts that disability is mere-difference, rather than bad-difference,

which is not to say that there cannot be some downsides to one's disability. Mere-difference is usually associated with the idea that:

> (a) disability is analogous to race, gender, sexuality, and ethnicity, (b) disability is not a defect or departure from 'normal functioning,' (c) disability is a valuable part of human diversity that should be celebrated and preserved, (d) a principal source of the bad effects of disability is society's treatment of disabled people, rather than disability itself (70-71).

Barnes goes on to argue that there are some difficulties in accepting the default or common-sense view is the bad-difference view. She says that non-disabled people are notably poor at determining accurately the well-being of someone disabled, which is an empirical problem. She also says that seeing this as the default view could be an instinct rather than the result of a logical argument, in which it is a philosophical problem.

In responding to a possible counter-argument, Barnes asserts that causing disability to someone without that person's permission is not wrong per se because disability is bad, but because we don't believe people should have the authority to interfere in making substantial changes without justification in other people's lives. Additionally, there is a difference between *being* and *becoming* disabled. Even if one is able to adjust to the acquisition of a disability, there can be high transition costs in adapting to a disability, which can be a very difficult and painful process (147-149). One can ascribe to the idea that it is wrong for someone to inflict this painful process on another without that person's permission, and still believe in a mere-difference theory of disability.

Barnes asserts that the mere-difference view of disability is correct and that it is compatible with the idea that disability can bring with it negative effects, some that would still exist even if there were no social prejudice against the disabled. She explains that the Value-Neutral Model she proposes aims to show that disability is a neutral feature that is compatible with the idea that in some ways it can be negative for someone in some aspects of life, just as it

can also be positive in some aspects of life. One can value disability on the whole while still acknowledging the bad effects and not reducing them. In elaborating upon the difference between a good thing with some harmful aspects or vice versa, Barnes distinguishes between global bads and local bads. A global bad is something that is ‘on the whole’ or ‘all things considered’ bad for someone. Whereas a local bad is something that has a negative effect on someone’s well-being with respect to some feature or for some time (80-81). She claims this aspect of disability is comparable to other social categories such as sex and sexual orientation that, even in a world without prejudice, would have their downsides.

I highlight a useful distinction between something being good or bad ‘simplicter’ as opposed to something being overall good or bad. Something ‘good simpliciter’ is something that enriches one’s life and without it, one would be missing something. Things that are ‘bad simpliciter’ detract from one’s life and one is worse off due to its presence. Although there can be things that always or almost always cause a net positive or net negative effect on well-being, it is not the case that something that affects the net effect on well-being is necessarily bad or good simpliciter. This is because something that is in itself bad can have an overall or all-things considered positive effect on well-being and something that is in itself good can have an overall negative effect on well-being (Barnes 85). She uses this framing in order to reject the idea that disabled people have simply acquired an adaptive preference to their disabilities. It is one thing to acknowledge that although an experience was horrible, they are now glad to have had it happen because it allowed them to arrive at a happier place overall. The horrible event would be ‘bad simpliciter’ even if as a result, their net positivity increased. This is not what disabled people mean when they say they value their disability. It is possible that some parts of their

disability they consider to be ‘bad simpliciter’ but that does not mean that *disability* is in itself ‘bad simpliciter’ and that people would be better off without it.

Barnes implements a useful analogy between disability and LGBTQ identities. With the use of this example, I do not presume society is currently anywhere near being completely accepting of gay or trans people, but it is helpful to compare ableism to homophobia and transphobia because it would have been unthinkable only decades ago for most people to imagine the progress made on LGBTQ+ acceptance thus far. She begins with arguing that one is neither better off nor worse off because one is gay. There are aspects of being gay that are unique and valuable to someone’s experience which mean very much to them and enrich their life, yet it can also have some negative effects. Some of these are socially created, such as anti-gay discrimination. Some of these are not socially created, such as the inability for two cis-lesbians to conceive a biological child. Depending on their desire to do this, it could be a very strong negative effect and in this way being gay is ‘bad for’ them, but this does not mean being gay is bad. She explains how this analogy could extend to being male. Being male is not bad in itself, but for some transwomen who despise their masculine traits, being male could be bad for them (88-90). Barnes introduces the testimonies of Fyodor Dostoevsky, Sarah Eyre, and Neil Marcus to explain what they enjoy and value about their disabilities. Dostoevsky, for example, valued the feeling of ecstasy he felt prior to an attack of epilepsy. Barnes emphasizes that she is not pushing for an ‘X-Men view’ of disability in which the local bads are compensated for with special enhanced abilities, only that disability can offer unique and valuable experiences without producing extra abilities. Barnes urges us to view disability as a difference that can bring with it both positive and negatives for an individual, and that does not *necessarily* make one worse-off.

When we implement the idea that 'we' can know what is better for someone and what is better for everyone, we inherently exclude 'us' from 'them'. The dominant group asserts the standard of desirability, instead of listening to the testimonies of others and accepting that there is a wide range of ways to live well. CRISPR promotes this underlying belief that it is possible for some to determine what is best for all people and that they should have the ability to veer the future of humanity onto that path.

One of the concerns about CRISPR discussed earlier is the possibility of reducing diversity, this is especially relevant when it risks wiping out not only genetic diversity but ways of life and cultures based upon these. Yet, Schermer suggests: not all diversity is worth preserving (qtd. in Barnes 219). There is a good case to be made on the idea that diversity should not be preserved when it significantly reduces well-being. However, Barnes for one, argues that determining whose lives are examples of flourishing is not obvious to the dominant group. This is seen through historical examples of race, sexual orientation, and disability. Kafer quotes Susan Wendell in *Feminist Queer Crip,* "people with disabilities have experiences, by virtue of their disabilities, which non-disabled do not have, and which are [or can be] sources of knowledge that is not directly accessible to non-disabled people" (83). However, these can only be discovered if people are willing first to entertain the possibility that disability could be valuable to society, and subjectively desirably to some. If we introduce CRISPR into a society that already devalues disabled bodies, we will further decrease diversity.

The Focus on Controlling Genes & Parental Choice

The idea that people can determine what is best for others, returns us to the link between CRISPR and eugenics. Underlying eugenics, are the beliefs that only some people are useful to and belong in society, and that it is more important to create a productive society than to protect

individuals' right to live and to have children. Widespread germline gene-editing will likely create a not sense of liberation due to the availability of a new tool, but personal dilemmas caused by a responsibility to make genetic choices about future children. Managing the life of a child is priced highly in evaluating the care of parents towards their children. A good parent is usually seen as one that plans out their child's schedule so they acquire skills that will prepare them for the future. If gene-editing was promoted as yet another way to secure a good future for children, this could become the next element of child's life that parents should plan; as previously discussed, only some categories of people are believed to be capable of having a good life.

Stemming from the belief that we know what is best, is the idea that having more options to choose from is necessarily better. It is assumed by most to associate freedom with human rights, autonomy, and self-determination (Iyengar and Kumon 100). Yet, several studies in social psychology show that the availability of too many choices can cause people to become paralyzed in choice, unable or afraid to make a decision for fear of making the wrong one. It has also shown that upon making a choice amongst so many options—more than about twelve—can lead to lower levels of satisfaction and more feelings of doubt and regret in the choice they made (102). We can theorize about how this might translate to the realm of gene-editing, in which a parent may wonder whether they selected the best genetic options for their child as they develop.

Some of the most interesting studies on choice exemplify the impact of ordering and framing a decision. People tend to choose an option near the top or bottom of a list, likely due being overwhelmed by the options available. The way a question is framed can play into people's existing cognitive biases to lean them towards a particular choice, even if the information presented is identical to one that is framed differently. People's preferences also appear to be

relatively malleable, and thus susceptible to nudging. While nudging can be beneficial if it nudges people towards a better choice, acknowledging this power also brings into question whom we would allow to possess this power to arrange the architecture of this choice. One might rightly declare that we are all nudged in one way, either by "consciously curated choice architecture or the accidental form in which our choosing experience unfolds in any given context" (108). This is to say, choosing not to influence someone's decision in what one might deem 'a better direction' is still a choice, and a choice that could lead to people choosing the more harmful option when presented with various selections. While this may be true, there is harm in prematurely assuming that any one person or institution, or even majority of people, can know what is best for every individual. Leaving the choice to an institution that is heavily influenced by social context and likely also driven by its own source of income, could be an insidious decision.

Currently, the choices involved regarding a pregnancy with Down syndrome are already heavily influenced by medical professionals. In denying that Denmark's abortion policies supported a eugenic practice aimed at eradicating people with Down syndrome, the Danish ambassador, Carsten Sondergaard, argued that "it is [the medical professional's] duty to provide the pregnant woman with the best possible basis for her to make her own decision about her pregnancy" (qtd. in Lindeman 2). However, because screening for Downs has become such a routine procedure, some Danish women came forward expressing they felt as though they were not allowed to keep the baby. Estreich expresses concerns about this in regards to several prenatal screening services such as Natera noninvasive prenatal testing (NIPT). He argues that online ads for NIPT appear to be open and informative, yet are covertly persuasive in highlighting the risks of not screening and implying reassurance if someone does screen the child

(Estreich 83).The advertisements put forth by these services instill a sense of responsibility on the part of the mother to screen (and likely abort) her child in order for her to be considered a good parent, rather than opening up the conversation for the mother to articulate what she wants.

As most of these ethicists do, I veer away from debating the individual choices ppl make to screen their children or to use CRISPR or to desire a cure. I want to highlight the systematic ways in which individuals are, unknowingly influenced into making these choices. In framing social change, it is important to keep in mind the broader perspective of the issue rather than individually condemning each person's choices. At the moment, questions of access, finances, and discrimination may have a heavy hand in guiding parents in the choices they make. Yet, these must be recognized as socially produced fears of disability rather than signifiers that disabled people are inherently worse-off. Even with discrimination, limited access, and financial distress, disabled people are revealed to have average levels of well-being. I invite you to think of how this argument would be made in respect to other ideas that value convenience over diversity.

Building off ideas Barnes addresses in her book, what would we say to hypothetical situations involving gay people instead of disabled people? Much of the ideology against gay conversion therapy is based on the idea that it does not work, and in trying to change one's sexual orientation to fit a societal norm, one inflicts traumatic experiences upon a person that do nothing but make them suffer. However, say that there was something that *did* work, and did not have any traumatic side effects? Would making this pill available but not given forcibly be wrong? We must consider the effects of such a technology being introduced into an already anti-gay society and how it would affect people who valued their sexual identity and did not want to change simply to fit in with most of society. This is only possible if we do find value in diversity.

If we view the deaf community as akin to belonging to a cultural linguistic minority, to what extent to we value the preservation of that culture? This is a question that is becoming increasingly important as we develop into a more globalized economy and become more reliant on languages more commonly spoken. We should hesitate when making arguments that everyone would be better off if we all spoke the same language. We continue to see convenience taking precedence over diversity of experience, in so doing, choosing whose experience is valued and should become the norm, and marginalizing those who currently do not fit this projected norm of the future.

The case of Ashley X is a disturbing example worth examining to recognize how the search for medical procedures as cures for disabled people value convenience over the experience and dignity of a person. Ashley was born in 1997 with static encephalopathy and was thought not to grow cognitively past age six. Her parents fought for her to get a hysterectomy, a bilateral mastectomy, and an appendectomy. After her surgeries she was put on high doses of estrogen for over two years (Kafer 49). Although she was unable to consent to the hysterectomy, attorney, Larry Jones, claimed that the procedure did not violate sterilization laws because the sterilization was only a byproduct of surgery aimed at different medical needs. This is despite the fact that the hospital's ethics committee originally argued it was necessary to have her case reviewed. Her mother assured the public that her sterilization did not harm Ashley since she would never have children anyway. Doctors were hesitant to perform the double mastectomy. However, the parents argued that it would prevent her breasts from developing and causing her back pain, prevent her from developing breast cancer that runs in the family, and would protect her from being sexualized (52). Kafer argues that her parents attempted to restore a normal sense of time to her body because society does not make room for difference. They wanted her to

remain in a body of a child to match her ‘childlike’ cognition. Because of her disability they had already ruled out the possibility of her experiencing sexual pleasure or having children. They didn’t see her having this in her future anyway, therefore radically changing her body without her consent did not matter. Another reason they opted for the surgeries was to keep her small. Her parents insisted that keeping her small would maintain their ability to bring her to gatherings so she could stay part of their family, they claimed this would allow them to keep them to keep her from being institutionalized.

While managing care is a concern, changing her body in such a way shows the prioritization of her being convenient to them over her own autonomy and possible experiences. She was projected to not grow cognitively past age six, but there are plenty of cases in which disabled people have greatly surpassed the original expectations from their doctors. Even so, her body was changed to be less sexual so that other people would not be uncomfortable. These changes are set forth by the parents as protecting her, as though if she were to get assaulted it would be because of her body. The parents frame the changes made to her body as unproblematic because she would never have sex or have children anyway, yet even if this were true, they rule out the possibility of her own sexuality or her own body being valuable not in sex with a partner or for reproduction but for herself. What’s more, once this case became public, several parents of children with disabilities asked their doctors to give their children the “Ashley Treatment,” and many became upset when doctors refused to perform it on their children due to their conditions not being considered severe enough. This case raises not only the question of whom we value and under what conditions, but who gets to make decisions on the behalf of others.

The principle of controlling the genetic turnout of future generations is one that many have argued seems inconsistent with flourishing. Rosemarie Garland-Thomson explains that people should grow rather than be made (Garland-Thomson 23). Growing is conducive to flourishing in that it maintains the joint effort between the individual and those who help it develop; whereas a subject *makes* an individual by bringing it into being as its sole creator. The Western perspective tends to value domination of the environment over an idea of harmony within one's environment. Drawing from Daoist beliefs of acceptance, we can reconceptualize flourishing not as gaining perfect control but as valuing acceptance and adaptation. Two of the essential aspects of Daoism are the heavenly perspective and the virtue of spontaneity (78). In tandem, they remind humans to keep in mind that there is a bigger picture of the universe that humans do not understand and that we should not pre-eminently judge something we encounter. Something initially perceived as bad could be revealed later on to be good, and vice versa. This implies a hubris in humans assuming they know what is best, and that they should be able to select for it in people's genetics denies that there are various ways to live good lives. One of the problems with CRISPR mentioned previously is the unintended consequences that could ensue, even with massive amounts of research done beforehand. In being willing to risk the possibility that gene-editing could affect humans in ways we cannot predict, rather than approach problems with acceptance and willingness to accommodate, reveals how deeply ableism is embedded in our cultural values.

Ableist driven fears driven by medical professionals, advertisements or long-held cultural assumptions influence parents to choose to screen or abort children with disabilities; the introduction of CRISPR is likely to amplify the effects of ableism on disabled people. The question of who will get to choose in which situations CRISPR should be used will be muddied

by medical influence. However, In the case of Ashley X, it was the parents pushing against reluctant doctors for most of her procedures to be performed. Many parents of disabled children like Ashley resent the idea that those who are not parents of disabled children should have the right to propose limits on how they choose to care for their children. Nonetheless, many disabled activists know how the ideology behind parental choices made for disabled people pervade society, making it both a private and public issue. There are care-based ways to manage the worries Ashley's parents claim to possess, but if we continue to attempt to standardize people rather than accept the differences in people, we will not look for those solutions.

Is it *worth it* to continue research on CRISPR?

After discussing the underlying beliefs behind CRISPR, I want to return to the question of its promise and consider whether it is 'worth it' to have CRISPR progress. Firstly, I want to clarify that CRISPR is in its beginning stages and is unlikely to fulfill the sci-fi dream that its emergence has promulgated. Much of this dream, as noted both by Reynolds and Estreich, is manufactured in order to incentivize funding for research. CRISPR, like many new pre-natal screening and genetic technologies, are characterized as revolutionary in order to attract venture capitalists to invest in their research. Secondly, the tool in itself has the potential to be of great use in developing therapies for some very rare genetic conditions. Reynolds suggests it may do wonders for people with Phenylketonuria (PKU), which can cause serious health problems due to a defect in the gene that helps the enzyme needed to break down phenylalanine ("Personal Interview"). Gene-editing shows promise in conditions like PKU because it is caused by a single gene, is very rare, can create intense health problems, and currently has no alternative cure. He also advocates against the use of germline editing altogether, the risks are numerous and it would be nearly impossible to show evidence of its safety. Even in gene drives, in which, a gene is

modified in a species in order to decrease the probability of a certain trait developing in its offspring, the consequences are wildly unpredictable. The first engineered gene-drive was to reduce malaria cases by decreasing the mosquito population through a gene drive (Scudellari 2). While the desire to eliminate this deadly disease is commendable, it is incredibly difficult to predict with accuracy how this could affect the ecosystem. A single change in a gene could have a dramatic effect on the natural environment. Moreover, there already exists an effective way to prevent malaria. The Against Malaria Foundation works to donate mosquito nets to people in the regions most affected by malaria. A long-lasting insecticidal net LLIN costs $2.00, lasts 3-4 years and protects, on average, two people—and without subjecting the environment to the possibility of unpredictable danger. There are solutions to radically improve health for those most in need, but they are not glamorous and do not generate transhumanist sci-fi realities, so they receive less attention and are not funded with as much excitement. In this example, I intend to highlight how our attitude towards the problem and a re-examination of values, can help us find attainable and much more cost-effective social solutions to many health problems, alongside progressing the potential of CRISPR to solve problems it is best equipped to do. It may be a useful tool in very specific cases, but it does not possess the power to eliminate disease and decelerate aging. It will not be able to eradicate disability, nor should this be something we unequivocally desire.

Conclusion

CRISPR is a technological innovation made to look like a solution for all human imperfection. Although there are definitely some beneficial uses for CRISPR such as curing rare and very harmful conditions, it is unable to fulfill the promise it is proposed to be. Yet, its progress and projected success are widely overblown, mostly for the purpose of attracting

potential funders. Gene-editing remains in extremely early phases of use, is currently very unreliable, and its use surges various set of ethical dilemmas. Moreover, were it to work perfectly, it would not be able to eradicate disability. Disability is largely socially created and the barriers that people currently face due to more commonly known disabilities would be replaced with new and elevated notions of what the standard of normalcy would be. Most people, if they live long enough, will become disabled. A project that would most improve the health of those most at risk would be one invested in the root of many health issues. With the promise of perfection that surrounds CRISPR, we are looking to science to solve a social issue (Reynolds "Personal Interview"). So many people globally, but in the United States as well, do not have access to basic healthcare. Some of the worthwhile projects to aid in improving basic health could include making sure every person in the U.S. lives within two hours of a hospital, electing politicians committed to universal healthcare, providing secure housing for the homeless, and funding free meal programs for people who need them. CRISPR's existence will not create a better future for everyone, partially because we already have much of the technology that could create a better future for many people and plenty of marginalized people are denied access to them. Listening to disabled people and centering accessibility will better help them than funding CRISPR research. Many want tools to help them cope with some of the bodily harms of disability they experience, as well as gain access to public spaces and conversation, this does not mean they desire a medical cure for their disability. Provided that we can listen to the testimonies of disabled people, perhaps we can guide society towards an attitude of valuing difference and being willing to accommodate to people's needs, rather than trying to invent new ways to change people to better conform to a standard of normalcy.

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