Gene Editing: How Advancements in this Technology Highlight the Need to Redefine Disability

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If you could prevent your child from being born with a disability, would you? This is a question that many parents face every year. Often, the answer is yes, resulting in many choosing to abort. However, a recent gene editing experiment on twin embryos could give people another option. In 2018, Chinese scientist He Jiankui announced to the world that he had successfully used the gene editing technique known as CRISPR (clustered regularly interspaced short palindromic repeats) to alter two embryos. He specifically targeted a couple where the husband was HIV positive and used the technology to make the twin embryos immune to HIV. The experiment led to many ethical debates, among them what conditions would be eligible to undergo gene editing? This debate directly applies to the disabled community as this technology would allow parents to edit out disabilities from their embryos in order to give birth to a "normal" child. The debate has highlighted the historical stigmatization faced by people with disabilities. Many believe that people with disabilities lead subpar lives, both health-wise and socially. However, this view has been repeatedly challenged by those with disabilities. Many within the disabled community have pushed back against the use of gene editing, as many believe that disability is valuable to themselves and to our society. Because of society's perception of what life is like for the disabled, many people would choose to eliminate disabilities from our genome if given the opportunity. However, an analysis of the He Jiankui CRISPR case highlights the uncertainty surrounding which conditions should be eligible for gene-editing, particularly relating to disabilities. When with the beliefs of the disabled community are taken into account, it is apparent that there is no firm consensus about what constitutes a disability and which traits are desirable.

CRISPR is just one approach to gene editing that has been developed and is currently the preferred method. Gene editing is the process of using technology to alter someone's DNA. This process allows for "genetic material to be added, removed, or altered at particular locations in the genome" (*What Are Genome Editing and CRISPR-Cas9?*). Although this technology could be used for

a multitude of reasons, it is most often used to prevent and treat diseases. For example, scientists are exploring the use of this technology as a treatment for cancer, heart disease, cystic fibrosis, hemophilia, etc. Many believe that gene editing should be used in embryos to prevent disability.

Legally, disability may be defined as any impediment on "normal" function or health. In the book *Disability, Health, Law, and Bioethics* (2019), I. Glenn Cohen, a professor of law at Harvard University specializing in the law and policy of biotechnology, defines disability as anything that could inhibit someone from having good health. He explains that "health is the absence of pathology. Pathology is a negative departure from normal function. And negative departures from normal function are departures from species, age, and sex-typical function that reduce the ability to survive and/or reproduce" (Cohen, I. G. et al. 2019, p. 8). This is a generally accepted definition of health. Cohen argues that in order to be in good health, there must not be a presence of any injury or disease that would affect someone's normal function. As Cohen explains, "normal function" means meeting average lifespan and reproduction rates for one's age, gender, and species. Therefore, Cohen argues that in order to be in good health, one must meet the above requirements. People with disabilities would not meet this definition of good health, as the cause of disability is disease or injury which alters the way that they function. However, the extent to which this deviation from "normal" health would be negative is arguable. Thus, society's current definition of what is good health must be reexamined.

Many argue that gene editing should be used on embryos deemed to have a disability because it is believed that people with disabilities will generally be in worse health than their "normal" counterparts. In her article "CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability" (2016), Shawna Benston, an expert on the ethical and policy implications of gene editing technologies, explains why many hold this viewpoint. She states, "the majority of people might affirm that, where a choice of outcomes exist, babies have the right to be born healthy, both mentally and physically" (p. 8). People believe that we have a duty to

our children and future generations to ensure that they are born healthy. Because of this duty, if given a choice to guarantee their health, they argue that we must take it. Furthermore, many would consider disabilities to be an unmet medical need. Thus, they argue that gene editing technology is nothing more than a medical procedure to prevent children from being born with an impairment. By preventing them from having a disability, we would be able to optimize the health of future generations.

However, the He Jiankui case casts doubt about what qualifies as a medical need and thus which embryos should undergo gene editing. In his article "The untold story of the 'circle of trust': behind the world's first gene-edited babies," Jon Cohen (2019) discusses the ethical debates that arose after news of He's experiment was released. One expert who contributed to the discussion was Craig Mello, a Nobel Laureate of Physiology or Medicine, who gave his thoughts on whether the use of the CRISPR technology was medically necessary. Cohen writes in his article on the He case, "Mello, who had co-discovered the gene-silencing process called RNA interference, thought that modifying *CCR5* did not address 'a true unmet medical need' and warned He that the experiment was 'risking the health of the child you are editing'" (Cohen, J. 2019). Mello believed that there was no medical reason to use gene-editing on these embryos. Furthermore, because of how new the technology was and how little was known about it, Mello feared that its use could actually put the children at more risk. Mainly, he argued that the technology could accidentally edit other parts of the genes which could have unintended consequences on their health. Mello worried that this could inhibit their ability to function. When He decided to use the CRISPR technology, he did so out of a belief that it would be beneficial to the children medically. However, Mello's contradictory view on this issue shows that there is no consensus on what constitutes a medical need and how subjective this issue can be. This subjectiveness can be seen in the disabled community, as there is no clear answer about whether disability truly constitutes an unmet medical need.

Despite common negative perceptions of the health of people with disabilities, many disabled people are able to live relatively long, healthy lives, thus further highlighting the ambiguity of the definition of good health and whether disability classifies as an unmet medical need. In 2019, a study was published comparing the lifespans of those with disabilities and those without. The study titled "The Life Expectancy Gap between Registered Disabled and Non-Disabled People in Korea from 2004 to 2017" (2019) was led by Jinwook Bahk, a researcher at Keimyung University specializing in life expectancy and inequality. The study found that, although there were variations depending on the severity of the disability, in general, the average lifespan has increased greatly since 2004. On average, the life expectancy for people with disabilities increased by 9.1 years in men and 8.3 years in women, a little more than double the increase in the non-disabled population. Furthermore, the gap in life expectancy between disabled and non-disabled individuals has become much slimmer since 2004, with those with less severe disabilities currently having shorter lifespans by only 5 years (Bahk et al. 2019). It is important to consider that variations exist between different disabilities, with those with severe disabilities having a considerably shorter lifespan than the general population. However, the lifespan of individuals with disabilities, regardless of severity, has been steadily increasing in recent years, and it is projected that this trend will continue. This is primarily due to increased access to health care and better social services for people with disabilities. In South Korea, many people with disabilities have a lifespan comparable to those without a disability (Bahk et al. 2019). Similar trends can be seen in other countries, as the care and services provided to people with disabilities has greatly improved. A similar study led by Dr. Eileen Crimmins looks at the life expectancy of disabled people in North America from 1970 to 2010. In her study she states, "Over the 40 years, life with disability in the community was the category in which the increase in life expectancy at birth was largest," and she explains that this trend is expected to continue (Crimmins et al. 2016). Being diagnosed with a disability is no longer a death sentence. Today, people with disabilities are able to live long lives and generally be in good health.

Therefore, it is hard to say that these disabilities constitute a true unmet medical need. As stated earlier, many classify disabilities as unmet medical needs because of a belief that people with disabilities are in worse health, but this belief is based on outdated knowledge. Thus, given how subjective the definition of unmet medical need is, and current trends in the health of disabled people, it is hard to determine whether gene editing should be used solely based on their health outcomes.

Beyond medical need, some argue that people with disabilities have a worse quality of life, particularly in more social settings. Thus, they would use gene editing in order to ensure that their children could lead "normal" lives. In his book, *The Social Psychology of Disability*, Dr. Dana Dunn, a professor of psychology at Moravian College, explains the findings of a test he administered to non-disabled people known as the Scale of Attitudes Toward Disabled Persons. This test asks participants to rank different statements relating to the quality of life of people with disabilities (PWDs) from "strongly disagree" to "strongly agree." This test has been used since the 1980s to quantify the societal stigma toward people with disabilities. When summarizing his findings, Dunn writes, "nondisabled people routinely predict that PWDs will report experiencing a lower quality of life" (Dunn 2015, p. 77). In general, the test results showed that most people have a generally negative view of the lives people with disabilities are able to live. Particularly, they believe that people with disabilities will not be fulfilled by their lives and that they will be unable to partake in regular social activities, such as having a job or being able to maintain relationships. Because there is such a fear about the quality of life that people with disabilities are perceived to have, many wish to prevent their children from having what they would consider a worse life. If given the choice, many would turn to gene editing so that their children would be able to live a life that society finds acceptable.

This perception of the quality of life of disabled people is reflected in the He CRISPR case, as the couple involved were motivated by a want to protect their children from discrimination. In his

article, Jon Cohen (2019) explains that He only involved couples where the husband had HIV. Cohen writes, “He sought couples who had endured HIV-related stigma and discrimination and wanted to spare their children that fate by dramatically reducing their risk of ever becoming infected.” Cohen explains that the parents of the gene-edited babies had been subjected to harassment because of the father’s HIV status. Therefore, they were motivated to ensure that their children would never have to face the same thing they did. By ensuring this, they believed they would be able to provide their children with a better quality of life.

However, despite the societal belief that people with disabilities are less likely to have a fulfilling life, many disabled people report that they are generally satisfied with their lives. In his book, Dunn argues that society has misconstrued notions of what life is like for people with disabilities. He cites many surveys that asses their satisfaction with their lives. He states:

> Various studies demonstrate that many PWDs display relatively high levels of subjective well-being (SWB) or positive, evaluative emotions and thoughts about their lives. SWB consists of happiness as well as life satisfaction, fulfillment, and a sense of peace … PWDs report being generally happy and find pleasure in work, recreation, social interactions with family members and friends, and simple daily living. (Dunn, 2016, p. 87)

These studies show that people with disabilities report being satisfied with their lives and generally find that they are happy and fulfilled. They draw their fulfillment from the same places that non-disabled people do, mainly through their careers and relationships. This disproves the idea that people with disabilities are necessarily unable to have what society considers a “good life.” Due to their different views on health and social issues, there would appear to be a discrepancy between the views of society at large and the disabled community as to the definition of disability.

Many people with disabilities would not characterize their condition as a disability at all. In her article, Benston discusses how people with certain disabilities do not consider themselves impaired. In particular, she focuses on the deaf community and those with achondroplasia. She

states, “Both deafness and achondroplastic short stature have been viewed as cultural traits, rather than disabilities, by many affected individuals and disability rights activists” (10). Deaf people and those with achondroplasia do not see themselves as disabled and do not believe that their so-called disability is actually an impediment to their lives. Other disability cohorts would agree with the communities listed above as they do not consider their condition a disability. Although society may label their condition as a disability, many fight against the label. The views of these groups further show how subjective and unclear the definition of a disability is.

Not only do some people with disabilities not view themselves as being impaired, but many would not wish to give up their disability as they see it as a vital part of who they are. In the book, *The Ethics of Inheritable Genetic Modification: A Dividing Line?*, Jackie Leach Scully, a professor of bioethics at the University of New South Wales, discusses the findings of a survey she conducted where she asked people with disabilities how they view the impact their disability has had on their lives. In this survey she focuses only on four disabilities: cystic fibrosis, multiple sclerosis, achondroplasia, and hearing impairment. She writes, “the empirical data from our study … suggest that *at least some* disabled people consider their impairment to be a strong, and strongly positive, part of their identity” (Scully 2001, p. 185). This belief was held predominantly by the achondroplasia and deaf participants, with the majority of these participants agreeing with the statement that their disability was a positive influence on their life (Scully et al. 2003, p. 634). Experiences shape who we are, and for people with disabilities, their impediment has had a significant influence on their experiences and ultimately their lives and identities. As Scully’s research shows, many believe that their disability has had an overwhelmingly positive impact on themselves. Those who hold this belief are primarily individuals with impairments who view their disability as a cultural trait and feel that they belong to a community solely based on their disability. Thus, Scully suggests that there is a strong correlation between disability being seen as a community and the perception of the impacts of disability on one’s life. Because of the positive way

in which disabilities have shaped their lives and their identities, many would not change being born with a disability. This suggest that at least some people would consider their disability a desirable trait. This contradicts the popular assumption that disabilities as undesirable.

Because some view it as desirable, some people with disabilities wish to pass on their disability to their children. Benston discusses the use of the test known as preimplantation genetic diagnosis (PGD) by potential parents with disabilities. PGD is a reproductive technology that is generally used by couples undergoing IVF treatments to determine which embryos have genetic diseases and to help select the best embryos to achieve pregnancy. Benston writes, "Some IVF clinics have reported potential parents requesting the use of PGD to select for either deafness or achondroplasia so that their children may better fit into the parents' communities, and some clinics have provided such a service" (10). Some people with disabilities purposefully attempt to have children with disabilities. Because their disability had such a positive influence on themselves, and because they wish to raise their children in the same community that they grew up in, some potential parents will go to great lengths to do so. However, the number of people with disabilities who request this service is small, with only about 3% of IVF clinics in the US reporting having been asked to provide this service and complying (Baruch 2008, p. 255). Despite the small number, this suggests that at least some people would consider disabilities desirable traits. This differs greatly from what society perceives as desirable, as, generally, non-disabled people believe that disabilities should be avoided. There is a discrepancy between societal views and the views of those with disabilities, which further complicates the debate on what traits should be edited out and which are desirable enough to be left in our genome.

However, the belief that disabilities are desirable traits is only held by some disability groups, with others wishing that they did not have any form of impediment. Scully acknowledges that she received mixed answers on her study on the importance of disability in one's life and explains that opinions vary depending on the type of disability. She writes:

> The fact that disabled experience cannot be reduced to a singular phenomenon was also pointed up by the variations between patient groups here. Some patients, especially those with MS, perceived the condition as a disruption of their "real" identity and always described it as unwanted, negative, and not part of the self. (Scully 2001, p. 182)

These findings show that the opinions of people with disabilities regarding this topic are not unanimous. While some groups of disabilities would describe their experiences as largely positive, there are a significant number who would disagree. In fact, they would go so far as to say that their disability has strongly negatively impacted their lives. Not only are we unable to reach a consensus on what constitutes a disability, but there is also disagreement regarding the desirability of traits. Even within the disabled community, people are not able to agree on how they view the influence their disability has had on their lives. Because of this, they have not been able to reach an agreement about which traits are most desirable and should be left in our genome, further complicating the issue of eligibility as it pertains to gene editing.

Not only does the He CRISPR case cast doubt on the determination of eligibility for gene editing, but also cautions against the use of this technology as it could lead to the exacerbation of disability. After He presented his findings from his experiment at a summit on gene editing, many were concerned about issues of equity that would arise from the use of CRISPR. Particularly, people were concerned because of how new the technology was and how little was known about its potential use and effects. Jon Cohen (2019) states in his article:

> Scientists in the audience—and more than 1 million people watching a live webcast—strained to analyze He's data slides showing that the gene edits had taken place in one baby and been on target. The other girl, He noted, did not have the edit in both parental genes and thus would not be protected from HIV.

He did not manage to successfully disable the CCR5 protein in both embryos. This protein is the one directly linked to HIV immunization. Because He was unable to disable this protein in both

embryos, one baby is now effectively healthier than the other. Through his experiment, He created an inequality between the two children. The baby who was not protected from HIV could now be considered at a disadvantage to her sister. This case shows that if not used carefully, gene-editing technology could create more inequalities in our society, thus effectively contradicting the perceived purpose of the technology.

Many wish to eliminate disability entirely from our genome, however the use of gene editing technology could potentially lead to more disability in our society. Scully discusses the potential unintended consequences that gene editing could have, particularly by creating a new, more extensive type of disability. Specifically, she examines the inability to edit out all disabilities and the issues of equity that would arise from the use of this technology. She writes, "If germ-line or somatic interventions aimed at enhancement are permitted, the result could be the creation of a new category of disabled people" (Scully 2001, p. 187). The use of this technology could be dangerous as it could lead to unintended consequences. Not only could there be negative effects to our genes, but it could also lead to new groups of disability. Scully explains that the novelty of this technology combined with society's inexperience with its use could lead to its being used incorrectly or ineffectively (Scully 2001, p. 187). The technology could be used incorrectly and cause off-target edits in one's genes, which could ultimately cause them to have an impairment and impact their ability to function. In addition, the lack of experience with the use of this technology could lead to it being ineffective and having no effect on one's DNA, as was the case with one of the embryos in the He case. Those who had been successfully gene-edited would have a significant advantage over those who were negatively affected or unaffected by the use of the technology. Therefore, a new group of disability based on inequality in the enhancement of one's health could be created. Furthermore, it is important to consider that there are disabilities that are not caused genetically that would still exist. No matter how hard we try to edit out all disabilities from our genome, we will never successfully be able to do so. The concerns related to the use of this

technology and the implications it could have on our society are important to consider. If by using gene editing to edit out disabilities from our genome could potentially create more disability in our society, should we use the technology for this purpose at all?

The conversation surrounding the difficult topic of gene editing and the eligibility of diseases is not as straightforward as many think. This is especially made more difficult after considering the lack of consensus on what defines a disability and which traits are desirable. The concerns raised by some within the disabled community must be considered when attempting to reach a decision on eligibility for gene editing. This is not to say that gene editing should not be employed in any circumstance but rather that all voices need to be considered before putting strict guidelines in place. Throughout history, the voice of the disabled community has often been ignored. However, we cannot let this continue to happen, especially regarding a topic that could potentially have drastic effects on that community. It is clear that those establishing guidelines and regulations for gene editing as well as society as a whole need to think more thoughtfully about how we employ this technology moving forward.

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