The Maastricht Journal of Liberal Arts
2025, Volume Sixteen 5-21

DISEASES, DISABILITIES, DESIGNER BABIES

When Does Gene Editing Go Too Far?

Authors: Charlotte Heuser, Leonhard Cuzmin & Bas Crousen

Abstract CRISPR-Cas9 has undergone significant developments, becoming the most widely used gene editing technique. While this tool has enhanced the feasibility of gene editing, it has also sparked controversies, particularly concerning its application in human embryos. Naturally, many questions arise, such as for what purposes the implementation of gene editing using CRISPR-Cas9 in human embryos is justified. We aim to answer this question by presenting biomedical background information, discussing arguments, and providing evaluations of these arguments. Finally, we conclude that CRISPR-Cas9 is an ambiguous piece of technology that is generally justifiable to implement for disease prevention, less so for disability prevention, and not justifiable for non-therapeutic purposes.

Keywords: gene editing, designer babies, CRISPR-Cas9, bioethics

1. Introduction

The gene editing mechanism CRISPR-Cas9 has been causing turbulence in the medical community ever since its discovery. CRISPR stands for 'Clustered Regularly Interspaced Short Palindromic Repeats' and Cas9 denotes the derived gene editing tool 'CRISPR-associated protein 9'. This mechanism allows for the editing of DNA by cutting and altering targeted sequences of genetic material (Huang et al., 2021). Praised as a "revolutionary genome editing tool" (Munshi, 2016, p. 777), it has become the subject of extensive research with the goal of curing currently incurable diseases (Gostimskaya, 2022). Recently, in 2023, the United Kingdom was the first country to approve CRISPR-Cas9 as a tool in therapy treatment, marking a major milestone for the technology (Wong, 2023). These developments remain subject to scrutiny, especially when edits of the human germline are involved. This issue gained widespread attention in 2018 when the Chinese scientist He Jiankui deleted the genes responsible for HIV expression in two twin embryos during in-vitro fertilization (Gostimskaya, 2022; Raposo, 2019).

This incident showcased the capabilities of CRISPR-Cas9 and simultaneously caused a large controversy. Criticism came from the scientific community and the public, pointing to the risk as well as the lack of medical necessity of the procedure. Chinese authorities apprehended He because his non-essential application of gene editing was illegal (Raposo, 2019) and many called for a moratorium on human gene editing due to ethical concerns (Gostimskaya, 2022). The case of He's so-called "CRISPR-Babies" (Morrison & de Saille, 2019, p. 2) exemplifies the controversy we address.

Gene editing has grown more relevant and disputed over the past decade. The recent technological development of CRISPR-Cas9 has made gene editing relatively cheaper, safer and more effective (Khan et al., 2018). Despite the controversy surrounding CRISPR-Cas9, a trend toward acceptance for therapeutic purposes can be observed (Martin & Turkmendag, 2021). Due to the topic's relevance, we explore the following research question: For what purposes is the implementation of gene editing using CRISPR-Cas9 in human embryos justified?

The research question raises various biomedical, ethical and socio-economic concerns which we evaluate throughout four sections. The first section comprises scientific background information and presents the basics of genetics and gene editing, providing a better understanding of the topic. Based on this scientific background, we have three main discussion points, namely the application of CRISPR-Cas9 to prevent diseases, prevent disabilities and for non-therapeutic purposes. Non-therapeutic purposes mean that gene editing is employed for improving, enhancing or modifying a characteristic unrelated to health (Lorenzo et

al., 2022). A clear definition of disease and disability is also necessary, but such a thing does not exist. Throughout time, many different definitions have been used (Scully, 2004). However, for the sake of clarity, we make the following distinction: diseases involve health impairments that often exhibit progressing symptoms such as breast cancer, whereas a disability pertains to functional limitations, such as Down syndrome.

First, we argue that the implementation of gene editing in unborn children is justified for preventing diseases since the risks and benefits are balanced. Second, we argue that it is comparatively less justified to prevent disabilities since this application may exacerbate inequalities and threaten acceptance of disabilities. Finally, we argue that gene editing in unborn children is not justified for non-therapeutic purposes such as enhancing the natural abilities or looks of humans as this could cause societal, mental and physical inequalities. Hence, CRISPR-Cas9 is an ethically and socio-economically ambiguous piece of technology. The purpose for which CRISPR-Cas9 is employed determines whether the application of the tool is justified.

2. Scientific Background

Before we discuss and answer the research question, we provide a conceptual description of gene editing by outlining the biomedical background, functioning as the underpinning of the paper and its arguments. It should be noted, however, that genetics comes with many intricacies and details that exceed the scope of this paper. Therefore, only the essential information is presented.

Every organism is made up of cells that, in their nuclei, contain deoxyribonucleic acid (DNA) in which the exact instructions necessary for directing activities are contained. DNA has a double helix structure which is composed of the same four chemical units. These so-called bases are adenine (A), thymine (T), guanine (G) and cytosine (C). The first and last two form base pairs meaning they lie opposite one another in the double helix (Genetic Alliance, 2009).

The entire set of genes in an organism makes up its genome which is organized into larger structures called chromosomes. Human cells contain 23 pairs of chromosomes of which one chromosome is inherited from the mother and one from the father. Chromosomes contain genes, the specific sequences of DNA that code for a specific protein. These are indicated by the specific order of bases on one strand of the DNA (e.g. ATTCCGGA). A gene essentially acts as a 'recipe', providing instructions that different cell parts, in turn, follow (Genetic Alliance, 2009). Although genes are the functional unit of heredity, only 29% of DNA is

composed of genes. The remaining 71% consists of non-coding segments with functions such as contributing to the structural integrity of the chromosome. (Genetic Alliance, 2009).

Although humans are all 99.9% genetically identical there is still genetic diversity which explains the differences among people like blood type or hair color (Genetic Alliance, 2009). This variation is a result of various genetic phenomena. One crucial factor contributing to genetic diversity is genetic mutation – heritable changes to the DNA sequence. Heritability here refers to both somatic cell division and germline inheritance. Somatic cell division encompasses the proliferation of cells in tissues. These cells only repair and reproduce within the same body. Since they are non-reproductive cells they do not pass on any information to the offspring. This means that a mutation, also known as a variant, in a somatic cell is not passed on to the offspring. A mutation in the germline, however, is passed on to the offspring. The germline refers to a group of cells that is involved in the production of gametes, which are reproductive cells. This explains why some genetic diseases are heritable (Jackson et al., 2018).

There are different types of mutations including single nucleotide variants where a single base pair is substituted for another, insertion and deletions where a base pair is added or removed, structural variations that alter DNA structure on a larger scale and repeat variations involving repetition of specific DNA sequences. (Jackson et al., 2018). A mutation, however, is not inherently harmful. Changes in DNA may have no impact, for example when occurring in non-coding segments. Nevertheless, numerous diseases are proven to be linked to genetics, leading to the classification of variants as either pathogenic or benign. Harmful mutations can manifest in various ways, causing a range of health issues, including Down syndrome, various cancers and diseases such as hemophilia A, cystic fibrosis, and sickle-cell anemia (Jackson et al., 2018).

Genetic disorders can have a detrimental impact on a life. Although there are various therapies and treatments that help manage symptoms or slow a disease's progression, genetic disorders are practically impossible to cure as their causes lie within the DNA (Jackson et al., 2018). This is where gene editing comes in. Gene editing is a technique where specific target genes are modified. This can mean adding, deleting or replacing individual or multiple bases. With this groundbreaking technology, researchers have accomplished various remarkable achievements like improving the quality of rice (Huang et al., 2021). In the biomedical field, gene editing can be deployed in diverse ways as well, with the potential to cure or prevent numerous genetic disorders, for instance. A real-life example of this is the revolutionary treatment called exa-cel that functionally cures sickle cell disease which has recently been approved by the FDA (Reardon, 2023). But gene

editing, as aforementioned, can also be used for what Lorenzo et al. (2022) call improvement. This can range from improving adaptability to coldness to improving one's intelligence.

Over the last couple of decades, gene editing has undergone significant advancements, witnessing the emergence of numerous techniques, each building on the successes of its predecessor (Huang et al., 2021). The predominant gene editing technique currently in widespread use is CRISPR-Cas9. It has proven to be very promising, and its success can be attributed to multiple factors like its ease of adoption due to its simplicity or its relative preciseness and reliability, compared to previous genome editing tools (Khan et al., 2018).

The CRISPR-Cas9 system originated from a bacteria defense mechanism against viruses. Fragments of the viral DNA, that are injected when a virus infects a bacterium, are captured and stored by the CRISPR system as RNA guides, a copy of the original DNA. When a similar virus attacks again, the CRISPR system recognizes the viral DNA and launches a counterattack. The RNA guides the Cas9 protein to the corresponding viral DNA sequence which Cas9 in turn cleaves, functioning as molecular scissors, to neutralize it (Li et al., 2021).

In recent years, scientists have managed to repurpose this CRISPR-Cas9 system for gene editing. In a lab, scientists design a synthetic RNA guide that guides the Cas9 protein to the target DNA sequence in an organism. The Cas9 protein induces a precise double-stranded break (DSB) at the designated location. A DNA's repair mechanism will be triggered which can be either Non-Homologous End Joining (NHEJ) or Homology-Directed Repair (HDR). Through NHEJ, the DNA seeks rapid repair by rejoining the broken ends, frequently resulting in mutations that render the gene nonfunctional—a desired outcome for achieving gene knockout. HDR is a more precise process where scientists insert a DNA template into the cell with the desired modification. After the Cas9 induces a DSB, the DNA will repair itself after this template. This allows for precise changes to the DNA (Li et al., 2021).

Although CRISPR-Cas9 is a highly valuable tool, it is not perfect yet. A notable challenge is off-target effects, unintended modifications that could lead to potential health risks (Li et al., 2021). Nevertheless, CRISPR-Cas9 has proven to be very promising in the world of gene editing and biomedicine in general.

3. Preventing Diseases

With CRISPR-Cas9, genetic diseases caused by DNA mutations could be prevented, treated and potentially cured. Although this seems desirable, the question

remains whether the use of CRISPR-Cas9 to prevent diseases is justified.

Gene editing embryos can help prevent lifelong illnesses and infant deaths caused or exacerbated by genetic abnormalities. Wojcik et al. (2019) describe a significant correlation between infant deaths and genetic disorders and argue that the application of genetic testing and gene therapy before birth should be explored. De Melo-Martin (2022) asserts that such gene editing would also be more effective at guaranteeing that carriers of genetic diseases can have healthy and genetically related children. Current technologies are based on testing in-vitro fertilized embryos before implantation. Under certain circumstances, however, it is impossible to prevent an abnormal combination of genes (de Melo-Martin, 2022). In such cases, the only method of having a healthy child is adoption, which Severijns et al. (2021) describe as unpopular. They believe the lack of genetic relation and the associated bureaucratic processes to be the main factors of this (Severijns et al., 2021). Gene editing could provide more couples with the possibility of having genetically related and healthy children, irrespective of their own genetic disorders.

Aside from infant mortality and reproductive fears, genetic diseases are also a financial burden. Sedrak and Kondamudi (2023) found that annually, approximately 300,000 infants in the USA are born with sickle cell disease (SCD). SCD is calculated to produce a lifetime burden of medical costs of around $1.65 million on average before reaching senior age, according to Johnson et al. (2023). Additionally, insured individuals must pay $44,000, leading to a significant financial burden. Similarly, Duchenne muscular dystrophy is estimated to be present in 0.02% of the US population, according to Venugopal and Pavlakis (2023). It produces approximately $54,270 direct costs and $120,910 total burden per year in the USA, according to Landfeldt et al. (2014). Especially in the second case, a gene edit might be cheaper than the accumulated medical and intangible costs of living with a genetic disease.

However, the potential medical and social benefits of preventing diseases using gene editing come with difficulties. One of the main issues identified with this medical procedure is that unborn children, such as embryos, cannot consent to it. This poses the issue of informed consent (Shinwari et al., 2018). Both Rodriguez (2016) and Biberman (2023) argue for informed consent by the individual, which is impossible to achieve with gene editing in unborn children. Genetic interference can change the human nature of an individual, the genome. Thus, a common point of criticism is that such interference contradicts the fundamental right to freedom of choice (Joseph et al., 2022).

Furthermore, there is a risk of unintended side effects, also known as off-target effects, with CRISPR-Cas9. This is because some DNA sequences in individuals

are identical (Rodriguez, 2016). For instance, the so-called CCR5 gene is connected to HIV as well as brain functions. If the gene connected to HIV is being targeted, the gene editing could impact and alter both areas (Raposo, 2019). Hence, there could be unintended alterations of genes and, thus, unintended side effects. These changes can cause mutations and lead to cell transformation or even cell death (Rodriguez, 2016). Total accuracy is therefore not possible to achieve. Lorenzo et al. (2022) argue that scientists must explore the genetic and epigenetic effects of gene editing further before pursuing such applications due to the associated risks.

The arguments show a reasonable balance between risks and benefits. Risks include producing mutations, while benefits include a high degree of accuracy, simple construction, and more sensible costs than lifelong treatment (Rodriguez, 2016). Since the potential and benefits outweigh the concerns and risks, using CRISPR-Cas9 to prevent diseases in human embryos is justifiable from an ethical and socio-economic standpoint. The justifiability is, however, more complex to determine for preventing disabilities using CRISPR-Cas9.

4. Preventing Disabilities

The second way gene editing can be employed is for the prevention of disabilities. By targeting the genetic mutations that often cause disabilities, CRISPR-Cas9 could prevent and treat disabilities early on. Also, here the question arises whether this implementation would be justified or not.

Medical professionals could use gene editing to prevent congenital disabilities by altering the responsible gene abnormalities. Especially the burden caused by hereditary developmental disabilities could be alleviated. Ilyas et al. (2020) report a world prevalence of at least 1% for developmental disabilities and a strong interrelatedness with genetic factors. The hereditary genetic factor Fragile X syndrome is a known cause for a variety of disabilities, such as autism disorder or Down syndrome (Cleveland Clinic, 2021). Such disorders generate a significant financial burden on families and society. A study conducted by Genereaux et al. (2015) identified a median cost of CA$44,570 for parents of children with developmental disabilities and a societal cost of CA$27,428 excluding medicare per year in Canada. Similarly, Lindgren et al. (2021) found that in the USA, the annual expenses for emergency care and hospitalization were doubled for children with developmental disabilities. In addition to financial issues, developmental disorders also impact the quality of life of affected individuals. Kyrkou (2018) asserts that having a disabled child challenges the overall physical and mental health of family

members. Often, at least one parent gives up work to care for their child, a physically and mentally strenuous task (Kyrkou, 2018). Gene editing could provide a significant social and economic benefit by alleviating the burdens individuals with genetic disabilities and their families encounter.

However, viewing disabilities as a purely negative thing can be seen as problematic. Goering (2015) argues that many perspectives on disabilities and being disabled exist, often differing strongly between disabled and non-disabled people. She attributes this mainly to a lack of relatability by non-disabled people, who often overlook important, potentially positive aspects of living with a disability (Goering, 2015). Similarly, Schramme (2013) quotes a paralysis patient and a psychiatric patient who both acknowledge and emphasize the positive aspects their impairments have had. He also asserts that the plurality of perspectives, factors of evaluation, and individual experiences make a generalized judgment impossible (Schramme, 2013). Accordingly, Shakespeare (2015) asserts that many disabled people do not report a lower quality of life. Therefore, a categorically negative view on disabilities, especially by able-bodied people, is a misconception and ignores the positive accounts of people living with disabilities. These factors make it difficult to achieve an adequate judgment on whether disabilities should be genetically prevented.

Further complications to this judgment come from considering the social model of disability. Goering (2015) asserts that the social environment is what makes impaired people 'different' and 'disabled'. Accordingly, Courtright-Lim (2022) argues that this social component of disability must be examined as a safer, cheaper, and, in most cases, more effective way of dealing with disabilities. She exemplifies this with dyslexia, a common learning impairment that rarely receives recognition for its correlation with improved visual-spatial abilities (Courtright-Lim, 2022). The discourse on disability is centered around a non-disabled perspective, which causes an inaccurate perception and unrealistic judgment of impairments. Consequently, an approach to disability that focuses on the social environment rather than the impaired individual could achieve better results without medical risks and costs.

Concerns about diversity and recognition further question whether gene editing to prevent disabilities can be justified. Sufian and Garland-Thomson (2021) assert that disabled people contribute to a diverse society by enriching it with their perspectives and ideas. According to Sufian (2021), the sentiment of preventing disabilities threatens this fruitful diversity. This sentiment might also threaten the general acceptance of disabilities, as Sufian and Garland-Thomson (2021) assert that aspirations for a future without disabilities question the status of current disabled people. The influence of such ambitions and the overall

negative view on disabilities may influence the decisions parents make with regard to their children. Addressing the reproductive application of gene editing, Niemiec and Howard (2020) express concern about a parental perspective that considers certain traits to be undesirable. Such a perspective questions the usual parent-child relationship and could further disenfranchise those living with disabilities (Niemiec & Howard, 2020). Sufian (2021) further argues that it is not possible to embrace disabilities and see them as undesirable at the same time. Fully accepting disabilities as a component of a diverse society cannot coexist with the ambition to prevent them. Therefore, the pursuit of this objective threatens the further disenfranchisement of disabled people. Additional consequences may jeopardize the parent-child relationship and the diversity of society. These implications contradict the ethical report issued by the Nuffield Council on Bioethics (2019), which states that gene editing must not increase inequalities or disenfranchisement.

In addition to all these implications stands the issue of informed consent. For genetic disease prevention, the problem is that an embryo cannot consent. Regarding genetic disability prevention, however, the parents' free choice is endangered as well. While some parents favor gene editing as a viable tool, there is also significant opposition. Elliott et al. (2022) describe a prevalence of conflicted views among parents of children with chromosomal disabilities. A slight majority expressed reluctance or opposition to germline gene editing because they see disabilities either as part of their child's identity or personal development (Elliott et al., 2022). Similarly, Kelly (2009) found that after having one genetically impaired child, most parents either decided against further children or refused prenatal diagnosis, actively declining the option to abort their pregnancy should their child again be impaired. Such choices, however, would become much more difficult should gene editing become a tool for disability prevention. In that case, parents could find themselves under social pressure and confronted with the knowledge that life with a disability will be more difficult due to lower acceptance. Under these circumstances, parents could be compelled to take a decision they disagree with. Any discourse about implementing gene editing as a tool to prevent disabilities must consider that the present issues pose significant social and moral risks to society and its members.

Preventing disabilities is more difficult to justify than preventing diseases. On the one hand, preventing disabilities could improve the lives of humans who would otherwise be born socially, physically, and cognitively disadvantaged. On the other hand, such efforts carry severe negative implications for people currently living with disabilities. For one, future prevention disincentivises present accessibility investments and treating diabilities as undesirable harms acceptance. Next

to discrimination concerns, future diversity would decrease, resulting in the loss of many enriching perspectives for society. Additionally, difficulties come from informed consent and the risk of unintended side effects. Furthermore, there is a wide spectrum of disabilities, some of which are more harmful than others. For instance, down syndrome tends to be physically and mentally impairing to the individual (Antonarakis et al., 2020). Despite the social downsides that autism can have, it can also lead to increased cognitive abilities (Tordjman, 2015). Both Albert Einstein and Charles Darwin were believed to have autism disorder (Cascio et al., 2014). Hence, this disability can also lead to great discoveries, for instance in the natural sciences, and its benefits should not be completely disregarded. This leads to the question of which disabilities should be eradicated.

Due to this illustrated uncertainty and complexity, the prevention of disabilities using CRISPR-Cas9 is comparatively less justified than preventing diseases. This is an ambiguous case, in which the risks and benefits are not balanced, and it seems that the concerns outweigh. There is one more application of CRISPR-Cas9, which is arguably less ambiguous and more problematic.

5. Non-therapeutic Gene Editing

The final way CRISPR-Cas9 can be implemented is for non-therapeutic gene editing, which is arguably the most controversial application. Every human trait is determined by the DNA, and certain traits can be modified or enhanced by targeting and altering certain DNA sequences. Through CRISPR-Cas9, humans could modify their offspring to their own liking. This naturally raises the question of whether the application of CRISPR-Cas9 for non-therapeutic purposes is justified.

Much more than for preventing disabilities, the non-therapeutic application of gene editing threatens to increase social division and inequality. As argued by Sufian (2021) on the issue of disabilities, the wish to prevent a trait from occurring necessitates a negative perception of that trait. Consequently, the desire to attain a certain trait necessitates viewing it as superior. As shown in the previous section, these perspectives already endanger social diversity and acceptance of disabilities. Unlike with disabilities, where a majority sees them as negative (Schramme, 2013), society lacks consensus about non-health-related traits. Hair color preference, for example, is distributed unequally, according to Wortham et al. (2018). This lack of consensus might exacerbate the formation of grievances that exceed the dimensions of those related to disabilities. Additionally, Wortham et al. (2018) found that the relative preferences of different population groups closely resem-

ble the relative prevalence of hair colors in these groups. Members of a group will therefore generally gravitate toward their most familiar variation. Therefore, it is possible that conflicts about 'superior' and 'inferior' traits arise, promoting intolerance and group division. Furthermore, Pougnet et al. (2023) bring up the possibility that genetically enhanced children might also face discrimination for the way they were conceived. Because genetic enhancement and the expression of preferences are inseparable, the application of gene editing for non-therapeutic purposes bears significant potential for discrimination and conflict.

There are various examples that emphasize the inequalities and issues deriving from the genetic enhancement of natural looks or abilities. For one, these alterations can lead to socio-economic disparities (Pougnet et al., 2023). Increased physical capacities can have wide-ranging effects. For instance, they could lead to an increased ability to perform labor in craftsmanship or in office work. Consequently, longer concentration spans and more physical strength would advantage gene-edited individuals and enable them to outperform their coworkers. A second example is the ability to outperform fellow humans in sports. Tamburrini (2007) asserts that, especially in competitive sports, genetic privileges would lead to inequalities, unfairness and dispute, while Camporesi and Maugeri (2011) argue that there are too many pre-existing inequalities in sports based on medicine and drugs. Gene editing would exacerbate these problems competitive athletes have to face thus far (Camporesi & Maugeri, 2011).

Both examples are based on one individual being genetically privileged over another. This genetic privilege is not inherent but cultivated through gene editing. The same accounts for changes in the genome which increase cognitive abilities (Stern & Alberini, 2018). Improved cognitive functioning is associated with better concentration and better memory formation (Stern & Alberini, 2018). Improving cognition poses ethical concerns because it can change thought processes and the overall intelligence of a person (Kostick-Quenet et al., 2022). With gene editing in individuals, it would therefore be difficult to decipher which cognitive achievements are attributable toward the individual and which toward gene editing.

Aside from generating further social divide, implementing gene editing for non-therapeutic purposes could lead to eugenic practices. Eugenics is defined as "the practice […] of controlled selective breeding of human populations […] to improve the populations' genetic composition" (Reese, 2023, tackling eugenics section, para. 1). They are important concerning the topic at hand because the CRISPR technology can enhance desired traits (Shinwari et al., 2018). Based on this possibility to increase and enhance physical and cognitive abilities, a lot of criticism has been raised. This section focuses on two aspects of this criticism.

First, the fear of the introduction of a societally advantaged masterclass, such

as that of the 'Aryan race' during Adolf Hitler's National Socialist regime, arises again (Biberman, 2023). Such attempts in history to create a superior class of people led to societal divide and psychological destruction. Second, genetically engineered humans with enhanced capacities and abilities could have unpredictable consequences for society. Like Shinwari et al. (2018), Rodriguez (2016) acknowledges that with CRISPR-Cas9, the ability to enhance and cultivate specific traits in individuals is growing. This poses a socio-economic issue through which some individuals or groups, such as the financially advantaged, could become genetically superior in terms of physical and intellectual capacities (Rodriguez, 2016).

Some argue that medical enterprises have an obligation to improve the human body if the means to do so are available (Lorenzo et al., 2022). This would align with the argument that the goal of biomedical advancement lies in improving the human condition (Joseph et al., 2022). More, however, argue that the use of genetics to improve non-pathological features is unacceptable as it could lead to deepened inequalities and the practice of eugenics (Lorenzo et al., 2022). It is neither ethically nor socio-economically justifiable to use gene editing to advantage an individual over another. Hence, the answer is that using CRISPR-Cas9 for non-therapeutic purposes of enhancement of natural looks or abilities is not by any means justified.

6. Conclusion

CRISPR-Cas9 is a powerful tool that has made the prospect of therapeutic and non-therapeutic gene editing feasible. These capabilities, however, come with significant social implications, especially when edits of an embryo are involved. Therefore, different use cases and all relevant arguments must be carefully considered to decide when such a gene edit is justified.

Preventing presently incurable genetic diseases has the potential to alleviate massive financial burdens on affected individuals and society. Additionally, parents that carry genetic diseases could, under all circumstances, guarantee a genetically healthy child using gene editing. However, genetic procedures do carry some medical risk that could potentially cause unforeseen harm to children. Some criticism also comes from the lack of informed consent, as an embryo is unable to choose or decline genetic edits. Overall, the expected benefits seem to outweigh the risks. These risks, however, must be acknowledged and individually reevaluated.

The use of gene editing to prevent congenital disabilities promises similar benefits but comes with a much larger number of drawbacks. Many scholars take

issue with the general assumption that disabilities inherently detract from life, viewing them to be part of a person's identity. As the wish to avoid disabilities necessitates a negative view, it threatens to further disenfranchise disabled people and detract from diversity. Furthermore, parents might feel pressured to engage in gene editing against their will, should society become less accepting of disabilities, threatening their agency. For these reasons, the use of gene editing to prevent disabilities is much more problematic and necessitates medical professionals to carefully weigh the risks and benefits of every individual case.

Less ambiguous is the use of gene editing for non-therapeutic purposes or genetic enhancement. The lack of consensus about 'good' and 'bad' physical traits could make them an even more divisive issue than disabilities. This threatens to cause group grievances and could develop into eugenic practices. Additionally, physical or mental enhancement could lead to a rise in inequality as the enhanced people would be genetically privileged. The significant issues and lack of specific benefits non-therapeutic genetic enhancement bears make it infeasible for application. George Daley, a leader in stem cell science and cancer biology at Harvard Medical School, drew a similar conclusion: "There are stark distinctions between editing genes in an embryo to prevent a baby from being born with sickle cell anaemia and editing genes to alter the appearance or intelligence of future generations." (Bergman, 2019, para. 23). While CRISPR-Cas9 does have the potential to cure diseases and positively impact medical enterprises, its usage must be regulated, which poses a significant challenge.

Technological advancements cannot be stopped; however, their development trajectory can be influenced and shaped (Biberman, 2023). This requires strong regulations for the use of CRISPR-Cas9 and rules for its implementation that respect the medical, socio-economic, and ethical implications and consequences it can have. Wer conducted such an evaluation and concluded that all uses of gene editing in embryos carry considerable risks, which are only outweighed in specific cases of disease and perhaps disability prevention and never for non-therapeutic purposes.

References

Antonarakis, S. E., Skotko, B. G., Rafii, M. S., Strydom, A., Pape, S. E., Bianchi, D. W., Sherman, S. L., & Reeves, R. H. (2020). Down syndrome. *Nature Reviews Disease Primers, 6*(1), Article 9. https://doi.org/10.1038/s41572-019-0143-7

Bergman, M. T. (2019, January 9). Harvard researchers share views on future, ethics of gene editing. *Harvard Gazette*. https://news.harvard.edu/gazette/story/2019/01/perspectives-on-gene-editing/

Biberman, Y. (2023, June 26). The ethics and security challenge of gene editing. *Georgetown Journal of International Affairs*. https://gjia.georgetown.edu/2023/06/26/the-ethics-and-security-challenge-of-gene-editing/

Camporesi, S., & Maugeri, P. (2011). Genetic enhancement in sports: The role of reason and private rationalities in the public arena. *Cambridge Quarterly of Healthcare Ethics, 20*(2), 248–257. https://doi.org/10.1017/S0963180110000897

Cascio, C. J., Foss-Feig, J. H., Heacock, J., Schauder, K. B., Loring, W. A., Rogers, B. P., Pryweller, J. R., Newsom, C. R., Cockhren, J., Cao, A., & Bolton, S. (2014). Affective neural response to restricted interests in autism spectrum disorders. *Journal of Child Psychology and Psychiatry, 55*(2), 162–171. https://doi.org/10.1111/jcpp.12147

Cleveland Clinic. (2021, May 18). *Fragile X Syndrome: Diagnosis, Symptoms & Treatment*. Retrieved January 29, 2024, from https://my.clevelandclinic.org/health/diseases/5476-fragile-x-syndrome

Courtright-Lim, A. (2022). "CRISPR for disabilities: How to self-regulate" or something? *Journal of Bioethical Inquiry, 19*(1), 151–161. https://doi.org/10.1007/s11673-021-10162-8

De Melo-Martín, I. (2022). Reproductive embryo editing: Attending to justice. *Hastings Center Report, 52*(4), 26–33. https://doi.org/10.1002/hast.1406

Elliott, K., Ahlawat, N., Beckman, E. S., & Ormond, K. E. (2022). "I wouldn't want anything that would change who he is." The relationship between perceptions of identity and attitudes towards hypothetical gene-editing in parents of children with autosomal aneuploidies. *SSM - Qualitative Research in Health, 2*, Article 100151. https://doi.org/10.1016/j.ssmqr.2022.100151

Genereaux, D., van Karnebeek, C. D., & Birch, P. H. (2015). Costs of caring for children with an intellectual developmental disorder. *Disability and Health Journal, 8*(4), 646–651. https://doi.org/10.1016/j.dhjo.2015.03.011

Genetic Alliance. (2009). Chapter 1: Genetics 101. In S. F. Terry & S. B. Haga (Eds.), *Understanding Genetics* (pp. 5-9). Washington, DC: Genetic Alliance. https://www.ncbi.nlm.nih.gov/books/NBK115568/

Goering, S. (2015). Rethinking disability: The social model of disability and chronic disease. *Current Reviews in Musculoskeletal Medicine, 8*(2), 134–138. https://doi.org/10.1007/s12178-015-9273-z

Gostimskaya, I. (2022). CRISPR–Cas9: A history of its discovery and ethical considerations of its use in genome editing. *Biochemistry (Moscow), 87*(8), 777–788. https://doi.org/10.1134/S0006297922080090

Huang, S., Yan, Y., Su, F., Huang, X., Xia, D., Jiang, X., Dong, Y., Lv, P., Chen, F., & Lv, Y. (2021). Research progress in gene editing technology. *Frontiers in Bioscience-Landmark 26*(10), 916-927. https://www.imrpress.com/journal/FBL/26/10/10.52586/4997

Ilyas, M., Mir, A., Efthymiou, S., & Houlden, H. (2020). The genetics of intellectual disability: Advancing technology and gene editing. *F1000Research, 9*, Article 22. https://doi.org/10.12688/f1000research.16315.1

Jackson, M., Marks, L., May, G. H. W., & Wilson, J. B. (2018). The genetic basis of disease. *Essays in Biochemistry, 62*(5), 643–723. https://doi.org/10.1042/EBC20170053

Johnson, K. M., Jiao, B., Ramsey, S. D., Bender, M. A., Devine, B., & Basu, A. (2023). Lifetime medical costs attributable to sickle cell disease among nonelderly individuals with commercial insurance. *Blood Advances, 7*(3), 365–374. https://doi.org/10.1182/bloodadvances.2021006281

Joseph, A. M., Karas, M., Ramadan, Y., Joubran, E., & Jacobs, R. J. (2022). Ethical perspectives of therapeutic human genome editing from multiple and diverse viewpoints: A scoping review. *Cureus, 14*(11). https://doi.org/10.7759/cureus.31927

Kelly, S. E. (2009). Choosing not to choose: Reproductive responses of parents of children with genetic conditions or impairments. *Sociology of Health & Illness, 31*(1), 81–97. https://doi.org/10.1111/j.1467-9566.2008.01110.x

Khan, S., Mahmood, M. S., Rahman, S. U., Zafar, H., Habibullah, S., Khan, Z., & Ahmad, A. (2018). CRISPR/Cas9: The Jedi against the dark empire of diseases. *Journal of Biomedical Science, 25*(1), Article 29. https://doi.org/10.1186/s12929-018-0425-5

Kostick-Quenet, K., Kalwani, L., Koenig, B., Torgerson, L., Sanchez, C., Munoz, K., Hsu, R. L., Sierra-Mercado, D., Robinson, J. O., Outram, S., Pereira, S., McGuire, A., Zuk, P., & Lazaro-Munoz, G. (2022). Researchers' ethical concerns about using adaptive deep brain stimulation for enhancement. *Frontiers in Human Neuroscience, 16*. https://doi.org/10.3389/fnhum.2022.813922

Kyrkou, M. R. (2018). Health-related family quality of life when a child or young person has a disability. *International Journal of Child, Youth and Family Studies, 9*(4), 49-74. https://doi.org/10.18357/ijcyfs94201818640

Landfeldt, E., Lindgren, P., Bell, C. F., Schmitt, C., Guglieri, M., Straub, V., Lochmüller, H., & Bushby, K. (2014). The burden of Duchenne muscular dystrophy: An international, cross-sectional study. *Neurology, 83*(6), 529–536. https://doi.org/10.1212/WNL.0000000000000669

Li, C., Brant, E., Budak, H., & Zhang, B. (2021). CRISPR/Cas: a Nobel Prize award-winning precise genome editing technology for gene therapy and crop improvement. *Journal of Zhejiang University. Science. B, 22*(4), 253–284. https://doi.org/10.1631/jzus.B2100009

Lindgren, S., Lauer, E., Momany, E., Cope, T., Royer, J., Cogan, L., McDermott, S., & Armour, B. S. (2021). Disability, hospital care, and cost: Utilization of emergency and inpatient care by a cohort of children with intellectual and developmental disabilities. *The Journal of Pediatrics, 229*, 259–266. https://doi.org/10.1016/j.jpeds.2020.08.084

Lorenzo, D., Esquerda, M., Palau, F., Cambra, F. J., & Bioética, G. I. E. (2022). Ethics and genomic editing using the Crispr-Cas9 technique: Challenges and conflicts. *NanoEthics, 16*(3), 313–321. https://doi.org/10.1007/s11569-022-00425-y

Martin, P. A., & Turkmendag, I. (2021). Thinking the unthinkable: How did human germline genome editing become ethically acceptable? *New Genetics and Society, 40*(4), 384–405. https://doi.org/10.1080/14699915.2021.1932451

Morrison, M., & de Saille, S. (2019). CRISPR in context: Towards a socially responsible debate on embryo editing. *Palgrave Communications, 5*(1), Article 110. https://doi.org/10.1057/s41599-019-0319-5

Munshi, N. V. (2016). CRISPR (Clustered Regularly Interspaced Palindromic Repeat)/Cas9 system: A revolutionary disease-modifying technology. *Circulation, 134*(11), 777–779. https://doi.org/10.1161/CIRCULATIONAHA.116.024007

Niemiec, E., & Howard, H. C. (2020). Ethical issues related to research on genome editing in human embryos. *Computational and Structural Biotechnology Journal, 18*, 887–896. https://doi.org/10.1016/j.csbj.2020.03.014

Nuffield Council on Bioethics. (2019). Genome editing and human reproduction. *Jahrbuch für Wissenschaft und Ethik, 24*(1), 255–322. https://doi.org/10.1515/jwiet-2019-0012

Pougnet, R., Derbez, B., & Troadec, M.-B. (2023). Mapping the 'ethical' controversy of human heritable genome editing: A multidisciplinary approach. *Asian Bioethics Review, 15*(2), 189–204. https://doi.org/10.1007/s41649-022-00234-1

Raposo, V. L. (2019). The first Chinese edited babies: A leap of faith in science. *JBRA Assisted Reproduction, 23*(3), 197–199. https://doi.org/10.5935/1518-0557.20190042

Reardon, S. (2023, December 8). FDA approves first CRISPR gene editing treatment for sickle cell disease. *Scientific American*. https://www.scientificamerican.com/article/fda-approves-first-crispr-gene-editing-treatment-for-sickle-cell-disease/

Reese, A. (2023, May 10). Addressing scientific racism and eugenics in the classroom. *American Society for Microbiology*. https://asm.org:443/Articles/2023/May/Addressing-Scientific-Racism-and-Eugenics-in-the-C

Rodriguez, E. (2016). Ethical issues in genome editing using Crispr/Cas9 system. *Journal of Clinical Research & Bioethics, 7*(2). https://doi.org/10.4172/2155-9627.1000266

Schramme, T. (2013). Disability (not) as a harmful condition: The received view challenged. In J. E. Bickenbach, F. Felder, & B. Schmitz (Eds.), *Disability and the Good Human Life* (pp. 72–92). Cambridge: Cambridge University Press.

Scully J. L. (2004). What is a disease? *EMBO reports, 5*(7), 650–653. https://doi.org/10.1038/sj.embor.7400195

Sedrak, A., & Kondamudi, N. P. (2023). Sickle Cell Disease (Archived). In *StatPearls*. StatPearls Publishing.

Severijns, Y., de Die-Smulders, C. E. M., Gültzow, T., de Vries, H., & van Osch, L. A. D. M. (2021). Hereditary diseases and child wish: exploring motives, considerations, and the (joint) decision-making process of genetically at-risk couples. *the Journal of Community Genetics, 12*(3), 325–335. https://doi.org/10.1007/s12687-021-00510-x

Shakespeare, T. (2015). Gene editing: Heed disability views. *Nature, 527*, 446. https://doi.org/10.1038/527446a

Shinwari, Z. K., Tanveer, F., & Khalil, A. T. (2018). Ethical issues regarding CRISPR mediated genome editing. *Current Issues in Molecular Biology, 26*, 103–110. https://doi.org/10.21775/cimb.026.103

Stern, S. A., & Alberini, C. M. (2013). Mechanisms of memory enhancement. *WIREs Systems Biology and Medicine, 5*(1), 37–53. https://doi.org/10.1002/wsbm.1196

Sufian, S. (2021, March 15). The threat that CRISPR poses to disabled people. *BRINK – Conversations and Insights on Global Business*. https://www.brinknews.com/the-threat-that-crispr-poses-to-the-disabled/

Sufian, S. & Garland-Thomson, R. (2021, February 16). The dark side of CRISPR. *Scientific American*. https://www.scientificamerican.com/article/the-dark-side-of-crispr/

Tamburrini, C. M. (2007). What's wrong with genetic inequality? The impact of genetic technology on elite sports and society. *Sport, Ethics and Philosophy, 1*(2), 229–238. https://doi.org/10.1080/17511320701425249

Tordjman, S., Davlantis, K. S., Georgieff, N., Geoffray, M.-M., Speranza, M., Anderson, G. M., Xavier, J., Botbol, M., Oriol, C., Bellissant, E., Vernay-Leconte, J., Fougerou, C., Hespel, A., Tavenard, A., Cohen, D., Kermarrec, S., Coulon, N., Bonnot, O., & Dawson, G. (2015). Autism as a disorder of biological and behavioral rhythms: Toward new therapeutic perspectives. *Frontiers in Pediatrics, 3*. https://doi.org/10.3389/fped.2015.00001

Venugopal, V., & Pavlakis, S. (2023). Duchenne Muscular Dystrophy. In *StatPearls*. StatPearls Publishing.

Wojcik, M. H., Schwartz, T. S., Thiele, K. E., Paterson, H., Stadelmaier, R., Mullen, T. E., VanNoy, G. E., Genetti, C. A., Madden, J. A., Gubbels, C. S., Yu, T. W., Tan, W.-H., & Agrawal, P. B. (2019). Infant mortality: The contribution of genetic disorders. *Journal of Perinatology, 39*(12), 1611–1619. https://doi.org/10.1038/s41372-019-0451-5

Wong, C. (2023, November 16). UK first to approve CRISPR treatment for diseases: What you need to know. *Nature*. https://www.nature.com/articles/d41586-023-03590-6#

Wortham, J., Miller, A., & Delvescovo, D. (2018). Male and female hair color preferences: Influences of familiarity, geographic region of origin, and environment on mate attraction in University of Tampa students. *Florida Scientist, 81*(1), 33–54. https://www.jstor.org/stable/26477962