# Genetic engineering as a moral duty

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#### Abstract

The following thesis aims to support the idea that genetic engineering should be considered a moral duty. To achieve this, I am presenting two of my arguments that rely on a broader position of transhumanist authors, mainly Julian Savulescu and his *Principle of procreative beneficence*. The first argument presents the case that there is a moral duty to achieve the best state of well-being possible even through the use of biological procedures on the child's DNA material. Furthermore, the goal of this argument is also to justify the ability of parents to choose disabilities for their future child based on the contextualist account of health. This is offered as one of the solutions for the limitations that liberal eugenics face. The second part of this thesis focuses on an argument that genetic engineering should also be perceived as a moral duty based on the assumption that due to the current crisis with climate change and resource depletion the quality of human life will be severely downgraded and genetic engineering might be the only option to avoid the catastrophe and ensure the survival of human species.

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# 1. Introduction

If you have ever stepped foot in any biology classroom, seen a leaflet about a science fair, or a poster for a talk on the futuristic science it is more than likely that you came across an image of the double-stranded helix with letters A, C, G, T surrounding it in a different order. The thing being presented there is DNA, an organic chemical that contains genetic information which is constituting a living organism.<sup>1</sup> With its different recombination of four acids, each of us possesses a part of the genetic code that's shared among a specific species and the rest of the combinations are creating a DNA trait specific only to each individual. DNA is the main constitutive element of human bodies and the structure of its sequences can impact the quality of human lives in an immense manner. Due to this, it is understandable that ethical questions surrounding genetic engineering technologies spark debates in the scientific and philosophical community. One group of positions can be summed up under "bio conservatives"<sup>2</sup> who believe that genetic engineering is inherently wrong since it can be perceived as humans playing God, displaying a will to control all aspects of life, or simply as playing with nature that can cause serious irreversible damages to the environment and human species as we know it. On the other hand, "transhumanists"<sup>3</sup> take an irreconcilable position that there is nothing inherently wrong with genetic engineering and that there should be no limitations

https://www.britannica.com/science/DNA. Accessed 29 May 2022.

**CEU eTD Collection** 

<sup>&</sup>lt;sup>1</sup> DNA | Definition, Discovery, Function, Bases, Facts, & Structure | Britannica.

<sup>&</sup>lt;sup>2</sup> Bostrom, Nick, and Julian Savulescu. Human Enhancement Ethics: The State of the Debate. Oxford University Press, 2009, pp. 1–22.

<sup>&</sup>lt;sup>3</sup> Ibid pp. 1.

on what characteristics a person can choose to edit on their genes or the genes of their offspring.

Concerns about genetic engineering have taken up significantly in the late 80s and 90s. Bioethicists and a broader group of people involved with the problems of the scientific community posed questions on the permissibility of cloning (as in the groundbreaking case of Dolly the sheep<sup>4</sup>), the importance of personal and impersonal harm, and have raised concerns with futuristic cases where certain groups would have access to genetic engineering whilst others would not and how it affects their relationships. Today many of those questions are still relevant and the narrative about the permissibility of genetic engineering focuses on the issues such as the extent of freedom that parents have in making decisions that affect their offspring, can we engineer human DNA only to achieve a statistically normal state or can these techniques be used also to create a certain disability or enhanced state and so on.

In this thesis, I will aim to prove that the genetic engineering of humans should be perceived as a moral duty. To achieve that my main focus will be on the defense of the principle of procreative beneficence in combination with instrumental justification as to why as a human species proceeding with the implementation of genetic interventions will raise the overall benefit but also potentially secure the very existence of human species.

<sup>&</sup>lt;sup>4</sup> Read more: Dolly | Cloned Sheep | Britannica. <u>https://www.britannica.com/topic/Dolly-cloned-sheep. Accessed</u> <u>17 May 2022</u>.

It is important to emphasize that the focus of this thesis is on the genetic engineering of characteristics associated with the *physiological aspects* of an organism. Therefore, the debate about the permissibility of genetically engineering mental traits such as intelligence, empathy, aggression, or any emotions will be set aside for now. Instead of that, the focus here is the permissibility of engineering future children's DNA for the sake of elimination/production of a certain disability and enhancement purposes.

Additionally, it is also important to point out that the focus of this thesis is on genetic engineering rather than on genetic selection (also known as "embryo selection"<sup>5</sup>). Genetic selection occurs in cases of artificial fertilization, where more than one embryo is created. Upon creation, the embryos are screened for certain genetic diseases and based on the presented results parents make a decision on which embryo to select which will develop into their future child. As for the cases of genetic engineering, there is one existing embryo whose characteristics parents can choose to keep or alter. These differences raise different sets of ethical questions. For instance, in the case of embryo selection, the question can be raised on why is a particular embryo being chosen, what is the determining characteristic it possesses so that it has more advantages as compared to the others, and can a future child claim that some harm has been done to it by that particular decision. Moreover, the selection cases are extensively analyzed through Parfitt's "non-identity problem"<sup>6</sup> which does not apply to the same extent in cases of

<sup>&</sup>lt;sup>5</sup> "Embryo Selection." Oxford Reference, https://doi.org/10.1093/oi/authority.20110803095749333. Accessed 29 May 2022.

<sup>&</sup>lt;sup>6</sup> Parfit, Derek. Reasons and Persons. Oxford University Press, 1986. University Press Scholarship, <u>https://doi.org/10.1093/019824908X.001.0001</u>.

genetic engineering. The motivation for focusing this thesis on cases of genetic engineering is the development of a "gene-editing technique called CRISPR-cas9"<sup>7</sup> that is both promising to be able to edit different characteristics of DNA whilst being cheaper and more easily accessible than previous techniques.

As previously mentioned, there is a significant amount of literature dealing with the ethics of genetic engineering. The arguments presented in this thesis rely on the transhumanist position toward the ethical status of genetic engineering. The aim of this thesis is to fill in the gap on why genetic engineering needs to be accepted as a duty and it is an attempt to make a compromise between aspirations of new liberal eugenics and the rights of people with disabilities.

To achieve this, I will present an overview of, principles of harm, and procreative beneficence whilst also presenting a case for my arguments through an analysis of liberal eugenics, positions of disability activists, and a contextualist account of health. Additionally, my second argument will strive to show genetic engineering as potentially the only tool that could preserve the existence of humanity with aspects of dignity and quality of life that we know and try to achieve nowadays. In times of irreversible crises with depleted resources, the potential arrival of new pathogens, and climate change,

<sup>&</sup>lt;sup>7</sup> "What Is CRISPR-Cas9?" Yourgenome, https://www.yourgenome.org/facts/what-is-crispr-cas9. Accessed 29 May 2022.

genetic engineering of our DNA might be the only solution for adapting human life to the living conditions of the new environment on our planet.

# 2. Can we eat the fruit without the worm?

As the title of this thesis says I believe that genetic engineering should be morally permissible and accessible to adult individuals but also as a service that parents can choose for their children in the case that they reasonably think that the brought about changes from these interventions can benefit and raise the wellbeing of affected persons. In order to do this in this chapter, I will present the argument that parents' duties to ensure the well-being of their children should also extend to duties to secure that well-being through genetic interventions. This position raises a lot of questions on the consequences of practical implications of this view as well as the ethical question of why parents even need to have a duty to ensure wellbeing to the maximum extent. When taking a critical stance towards this view we could ask why is well-being taken as the guiding principle, how can we be sure that certain biological characteristics will influence the well-being status, and if we formulate this into duty is it possible to avoid slipping into authoritative eugenics?

In the following chapter, I will attempt to make a case for my argument that genetic engineering can be perceived as a moral duty without it regressing the new liberal eugenics into the pathways of the old ones that were witnessed through the 20<sup>th</sup> century. Julian Savulescu has once said that the challenge with the arrival of new technologies is how to avoid misuse of it, or as he phrased it "is it possible to eat the fruit without the

worm?"<sup>8</sup> Genetic engineering technologies are promising a solution to the majority of medical conditions that by this point were deemed incurable and unpreventable, opening up a potential to have a genetically disease-free future. However, "the worm" represents certain skeptical considerations that have been raised on issues if genetic engineering could be used as a biological weapon, if it will create a new form of class division, and if genetic engineering will be a tool by which society will actually self-destruct. I have chosen to name this chapter after Savulescu's question since in the following lines I will reconstruct different transhumanist arguments and offer a potential solution to the challenge of the liberal new eugenics. In other words, my first argument will show that we can advocate for the permissibility of genetic engineering without regressing to discriminatory rhetoric and policies that could harm the position of people with disabilities. It just might be possible to eat the fruit without the worm.

<sup>&</sup>lt;sup>8</sup> "Q&A: The Meaning of Synthetic Life." BBC News, 20 May 2010. www.bbc.com, <u>https://www.bbc.com/news/10134341</u>.

# 2.1 Duty to ensure the well-being of future generations

Let's imagine a very common scenario. A couple has decided to have a child. Besides the mandatory regular medical procedures that need to be followed through the pregnancy, the couple has not impacted the biology and characteristics of a future child in any way. The baby is born healthy by all of the "statistical norms for its group."9 Since the parents have planned pregnancy and intentionally had this child, before its birth they have secured a safety fund for its future education, made an equipped living space for the baby, and ensured third-person care in cases they are unable to provide 24/7 care for the baby. Besides this, they have given up their previous unhealthy lifestyle and have stopped smoking and drinking to ensure that any indirect or direct harm to the child is prevented. After a few years have passed, the parents have invested their savings to enroll a child in a private school that has a reputation for providing the best education to its students. Analyzing the steps that these parents have taken it can be said that they did everything they could to ensure that their child has an elevated state of well-being. The steps that they have taken are of financial, behavioral, and educational nature. These can be perceived as forms of social enhancement since the state in which a baby is born does not possess any of the inherent mechanisms to actualize this. To simply explain why this is even considered a form of enhancement, as humans we do not have an organ or biological process that once activated creates an ability to read, instead of through

<sup>&</sup>lt;sup>9</sup> Read more: Kahane, Guy, and Julian Savulescu. "The Concept of Harm and the Significance of Normality." Journal of Applied Philosophy, vol. 29, no. 4, Nov. 2012, pp. 318–32. PubMed, <u>https://doi.org/10.1111/j.1468-5930.2012.00574.x</u>.

social rearing we rise above our biological inherent abilities and gain a new skill by which we raise the well-being.

Now let's imagine another couple who lives in times of easily accessible genetic engineering techniques. They have also decided to have a child and visit their general practitioner and gynecologist. The pregnancy is deemed safe for the child and the mother, and the parents proceed with their decisions. Whilst talking to the doctor they are introduced to the CRISPR-cas technique of genetic engineering, which can be used as a tool to create or eliminate certain characteristics that the child's DNA carries.<sup>10</sup> The amniocentesis has already shown that the child has no predispositions for disabilities or other severe genetically inherited diseases, so once born the baby will be deemed healthy by statistical norms. However, upon reflecting on their families' histories both parents notice that they have relatives who were not brought about in the same household (which means that this phenomenon does not stem from traumatic experiences that were shared amongst members) that are battling serious alcoholism problem. Once they brought this up to the doctor, he informs them that through new technology they could detect the part of a child's DNA responsible for alcoholism and eliminate it. With this intervention, the child's well-being could be greatly elevated since there will be lesser to no chances of it developing serious alcoholism that would affect him physically and mentally in the future. In this example, the parents are also guiding their decisions by following the procedures that would ensure better well-being for their child, though in this case, the intervention is

<sup>&</sup>lt;sup>10</sup> "What Is CRISPR-Cas9?" Yourgenome, <u>https://www.yourgenome.org/facts/what-is-crispr-cas9. Accessed 29 May</u> 2022.

of biological nature, unlike in the first example where the procedure was of a behavioral kind. The question is now why is there a welcoming stance on forms of social enhancement as like in the first example, and in the case of biological one people tend to be more reserved or immediately reject the permissibility of parents making this type of a decision for their future child?

When referring to the second example we could say that the parents' decision actually fits the criteria of permissibility since alcoholism can be seen as a disease that has serious consequences for the individual and their community.

However, we can also imagine the same scenario with intentional pregnancy but in this case, the couple is using the CRISPR-cas technique to alter the embryo's genes in order to make sure that their child's muscles will be developed above the average. The couple in question are both professional bodybuilders and they perceive this decision as a manner in which they can secure the child's well-being and future since they are familiar with the world of a professional sport and could help the child with a future career. Additionally, their own lifestyle is quite active and focused on muscle developing activities so this way they will be able to spend quality time by their own standards with the child. This procedure could be deemed *unnecessary* for a child's future since even without it they will be born as a healthy individual. However, with this procedure taking place the child's well-being would be raised more than it would be the state if the parents have not conducted any type of engineering of its genes. Critics could say that the same state could be achieved without biological intervention if the child would simply be enrolled in sports training which is usually seen as an unobjectionable decision that parents make

for their child. I would say that there is no objection to the biological intervention that parents choose since it might be even easier for a child to achieve the parents' end goal. An argument that it seems too controlling for parents to direct a child's future to this extent can be raised but when it comes to real-life scenarios it seems odd to raise an objection to parenting style if the child is not endangered. For instance, we can witness a lot of families with a long history of academically skilled members. It is often a case that in these scenarios the future generations are directed to pursue education at highly ranked educational institutions with an aim of having a career in academia. Would it be justified to object to them choosing a path for their future child and investing in their education?

With the previous section in mind, I want to make an argument that parents should have a moral duty to genetically engineer their children as yet another way of achieving a better state of well-being for their offspring. My personal stance is that genetic engineering services should be accessible to everybody including future children and already existing adults, but for this particular argument, the focus is on the permissibility of this type of decision that parents can make since it raises more concerns about child's autonomy and freedom.

The core guiding principle of my argument is the *Principle of Procreative Beneficence* most famously defended by Julian Savulescu. It is important to say that when the principle was first created it was focused on the genetic selection cases, as genetic engineering techniques were still being developed and have not been so

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accessible as today. This is why the original definitions are mentioning selection, and later on the principles have been adjusted to fit cases of genetic engineering too. The principle of procreative beneficence (PPB) is derived from the broader principle known as the *Perfectionist view.* As Matthew Liao notes the perfectionist view can be summed up as:

"Given a choice between selecting a being that will have the best chance of having the best life and a different being that will not have the best chance of having the best life, it is morally obligatory to select the former."<sup>11</sup>

This view has *well-being* as its central point by which a judgment should be made on what constitutes a good/better life. Liao continues to explain the scope of this principle where we can differentiate between the stronger version by which "there is an all-thingsconsidered, absolute, obligation to engage in selection if the beings selected will have the best chance of having the best life"<sup>12</sup> and a less radical version which states that there are "prima facia obligation to engage in selection if the beings selected will have the best chance of having the best life."<sup>13</sup> Savulescu's stance on the procreative beneficence principle falls under the second category as it states that there:

"*should* be an option for parents to choose characteristics that are ensuring the best possible life."<sup>14</sup>

<sup>&</sup>lt;sup>11</sup> Liao, S. Matthew. "Selecting Children: The Ethics of Reproductive Genetic Engineering." Philosophy Compass, vol.

<sup>3,</sup> no. 5, Sept. 2008, pp. 973–91. DOI.org (Crossref), https://doi.org/10.1111/j.1747-9991.2008.00174.x.

<sup>&</sup>lt;sup>12</sup> Ibid pp 975.

<sup>&</sup>lt;sup>13</sup> Ibid pp 976.

<sup>&</sup>lt;sup>14</sup> Ibid pp 976.

To support his position, he is using an example quite similar to the famous example of a young mother that Derek Parfit has introduced to explain the *non-identity problem*. In his example, Savulescu invites us to imagine a woman who is sick with rubella and in case of conception, her child will be deaf and blind. In case she waits for three months another child will be born but without any of these disabling conditions, and by following the PPB we should advise her to wait for these three months as this act would ensure that the child's well-being is in a better state.<sup>15</sup>

On the first hand, it may seem that this principle fits within the commonsensical approach to the questions regarding birth and parenting of offspring, where we want the best life possible for them. However, many concerns can be raised once we try to question what constitutes a good life? In case certain groups of people are better off due to historical inequality does that mean that we should use them as a standard to say what is the best life and choose only their characteristics for future children? For instance, men tend to have better job positions, higher salaries, and more authority over their employees in the work field. Does this mean that couples should aim to select or edit the genes of future children to ensure that they are born as biological men so that they are better well off?

It is important to say that Savulescu's principle does not define which characteristic should be selected as parents should make a decision based on what they believe will

<sup>&</sup>lt;sup>15</sup> Ibid pp 976.

create "the best life possible."<sup>16</sup> This way both parents who choose to eliminate or introduce certain disabilities could still be following the principle of procreative beneficence. Additionally, his definition of a principle states that parents should choose the child with the best life possible, however, the question is how does this should turn into a duty? I believe the answer to this can be seen easily once applied to an example. Let's imagine a woman who did the genetic screening of an embryo that she plants to implement through IVF. Once the data has been received, the doctor informs her that the child has a genetic predisposition for obesity. Upon reflecting on the implications of this condition she realizes that life without obesity would be a better one for her child. If she has access to services that could eliminate the condition that is making future life worse off and refuses to implement them on the embryo it can be said that she made a neglectful decision for the future person. The situation would not be morally unobjectionable if the woman knew this information but did not have access to services as the potential harm would not be intentional and made solely on her behalf. As the permissibility of geneediting techniques is commonly defended by comparison to the other non-biological means of achieving a better state of well-being another scenario can be imagined. Let's say that there is a woman who went outside for a walk with her baby. Suddenly it starts raining but the woman has an umbrella. Nonetheless, she chooses not to open it and protect her child. There won't be any significant harm done to the child (it won't get distressed, get a cold...) but still wouldn't it be reasonable to criticize the mother's action

<sup>&</sup>lt;sup>16</sup> Herissone-Kelly, P. "Procreative Beneficence and the Prospective Parent." Journal of Medical Ethics, vol. 32, no. 3, Mar. 2006, pp. 166–69. PubMed Central, <u>https://doi.org/10.1136/jme.2005.012369</u>.

and say that she indeed had a duty to raise the well-being of the child by using the accessible means for that?

Moreover, since PPB is also underlined by "principles of *reproductive freedom*"<sup>17</sup> which extend to parents' rights concerning having freedom of decisions for their children, how can we say that the best possible life from parents' perspective is not in collision with societal standards? For instance, let us imagine a couple who have psychopathic tendencies and enjoy seeing people suffer, but due to fear of criminal punishment, they do not act on their desires. They instead choose to have a child and genetically modify it to have zero empathy and enhanced aggressive traits so that it could carry out these violent acts instead of them. We can say that the actions of this future child are absolutely morally impermissible but can we say the same for the intentions and actions that parents underwent? We might assume that by PPB, they should be free to make decisions like this as by their standards this is the best life and characteristics that they value. However, as these principles are tackling practical ethical life problems the PPB should not be seen one-dimensionally as it is usually grounding its argumentation in combination with the *harm principle*.

<sup>&</sup>lt;sup>17</sup> Erdman, J. N., and R. J. Cook. "Reproductive Rights." International Encyclopedia of Public Health, edited by Harald Kristian (Kris) Heggenhougen, Academic Press, 2008, pp. 532–38. ScienceDirect, <u>https://doi.org/10.1016/B978-012373960-5.00478-0</u>.

### 2.2 The harm principle

The principle's origin is in John Stuart Mills' libertarian thought, which states that "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."<sup>18</sup> With this combination in mind principle of procreative beneficence manages to ensure the freedom that parents desire in choosing the characteristics of their future children whilst assuring that no harm is brought about on the larger scale.

Since the focus of my arguments are on the physiological interventions, and the principle of procreative beneficence is advocating for pursuing the best state possible, at the first glance it can be thought that this implies that only decisions that aim at the elimination of diseases are the ones that parents can choose for their child. I would state that this is the biggest challenge to advocates of genetic engineering since the freedom of choice that is the central point of their view has certain underlying biases that are prejudiced and limiting towards people who do not fit the current medical standard of a healthy individual<sup>19</sup> even though their states are not limiting them in being autonomous free persons. In order to see how my argument is avoiding this issue, it is first necessary to examine the position of new liberal eugenics and the concerns raised by disability activists.

<sup>&</sup>lt;sup>18</sup> Mill, John Stuart, et al. On Liberty. Yale University Press, 2003. pp. 13.

<sup>&</sup>lt;sup>19</sup> In the later part of this thesis the contextualist approach to health is defined in detail. However, it is worthwhile emphasizing already at this point that medical standards for health and diseases are in constant development, what was ones seen as a disease does not necessarily fit the same criteria today.

## 2.3 Liberal eugenics and disability rights

If somebody not familiar with the main topics of ethics of genetic engineering heard that people are writing papers that endorse liberal eugenics, they would probably be shocked. This is a common reaction since the word eugenics is typically associated with the atrocities committed by Nazi Germany, the forced sterilizations of minorities, and people with mental health difficulties that were happening in Sweden, the USA, and Canada to name a few. Under these different policies, people were sterilized based on potential hereditary criminality, the so-called impurity of genes, and to prevent prolongation of "degeneracy" by future offspring inheriting these characteristics from their parents who were seen as unfit and undesirable for the ideal society. What is important to notice as a common trait in these examples is that all of these conducted procedures were state-ordered and the affected individuals could not refuse to undergo them. Even though these policies were just practical implications of racial, nationalistic, and gender discrimination we could imagine that some of the non-affected citizens of these countries thought that these are not immoral discriminatory acts but a way to achieve a better future for society.

This plays a big role in skepticism towards eugenics in the 21<sup>st</sup> century as one can wonder is there new prejudice hiding under the promising veil of salvation and the success of genetic engineering? Today the term "*liberal eugenics*" <sup>20</sup> is used to differentiate itself from the old authoritative eugenics and to promote the idea that humans should be

<sup>&</sup>lt;sup>20</sup> Agar, Nicholas. Liberal Eugenics: In Defence of Human Enhancement. Blackwell Pub, 2005.

enhanced through the use of genetic engineering. Additionally, the decision needs to be made freely by parents and adult individuals without state-imposed restrictions on which characteristics should be kept or introduced. As a society we have debunked the racial and gender stereotypes that were constituting the ideology of authoritative stateproclaimed eugenics, however, the moral status of new liberal eugenics is still questioned as the proponents of them are accused of perpetuating discriminatory stances against people affected by different forms of disabilities. Since genetic engineering is an ethical issue that directly refers to the very notion of life there are several points of divergence even within the liberal eugenics movement.

Nicholas Agar, one of the most notable authors on liberal eugenics, tries to support his position on freedom of choice for genetic engineering based on the principle of *reproductive freedom* which is seen as one of the human rights by which we usually determine the extent of freedom of a certain society. He proposes that genetic engineering needs to be accessible to parents as part of their reproductive freedom just as the state's involvement in decisions regarding the reproductive and private lives of its citizens cannot be justified in other examples, so it should not impose rigid regulations in this particular case.<sup>21</sup>

The general argumentation for liberal eugenics is best presented through the works of John Rawls and Ronald Dworkin on this matter. Rawls states in his work *"Theory of Justice"* that it is in the interest of all members of society to have "better natural assets."<sup>22</sup>

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<sup>&</sup>lt;sup>21</sup> Note. Regulating Eugenics. https://harvardlawreview.org/2008/04/regulating-eugenics/. Accessed 5 May 2022.

<sup>&</sup>lt;sup>22</sup> Rawls, John. A Theory of Justice. Rev. ed, Belknap Press of Harvard University Press, 1999. pp 91.

Both authors believe that a "rational agent should strive to enhance their offspring's characteristics as it is one mode of improving their lifepath and overall well-being if by doing this we are not endangering anybody's liberty or making somebody worse off."<sup>23</sup> It is important to try to ensure a successful life for future generations and it is up to individuals to curate their vision of success and values that will be appreciated. This seems like a view that many could accept. You are free to make decisions concerning you and your children's future as long as they are not maleficent. Here we can notice the harm principle is the core of an argument and the example of psychopathic parents can be recalled.

On the other hand, liberal eugenics accommodates a variety of arguments that claim that we have a duty to implement genetic engineering on our offspring, both in cases of what is (for now) seen as a pure enhancement (unnecessary medical procedure) but it also needs to be obligatory to prevent disabilities. Authors like Allen Buchanan, Dan W. Brock, and Norman Daniels who support this view are trying to distance themselves from the accusations of discrimination by stating that "it is the disability that is unwanted and not the people who possess them."<sup>24</sup> This however seems dangerously close to the notions of old eugenics as they are following one set of standards to what constitutes a disability and the character of it as being only a debilitating state. Moreover, if we perceive biological traits only as one part of identity that is not the core defining aspect and possession or lack of them does not play into the ethical debate, then their justification

 <sup>&</sup>lt;sup>23</sup> Note. Regulating Eugenics. https://harvardlawreview.org/2008/04/regulating-eugenics/. Accessed 5 May 2022.
pp. 1583.

<sup>&</sup>lt;sup>24</sup> Ibid pp 1583.

might work. However, since they are advocating the removal of these traits, we can assume that they see them as constitutive of one's identity and the state of life associated with it. Therefore, it is challenging to see how their position is not discriminatory. To clarify their position, a person who is born blind is not seen as an individual with neutral or good value to their life that lacks a certain sensory impairment. Blindness is seen as a disease, and automatically the affected individual's life is seen as one of lesser quality than compared to the persons who are not blind. As a parallel, in their example, we can change disability with race and say that it is not a person that is not desired but their race, with which we can directly see how new eugenics could just be a veil for the old eugenics' ideology.

This is where advocates for disability rights step into the debate and also this is a point where the *liberal* part of the new eugenics is being challenged the most. Often when proponents of liberal eugenics give examples to justify their insistence on the permissibility of genetic engineering and obligations to eliminate certain DNA sequences that are causing disadvantages to a future child, they use medical states such as the child being born deaf, blind, with genetic diseases like cystic fibrosis, Down syndrome and similar. They base their view on the notion that these are all examples of diseases that are causing the well-being of an affected person to be endangered. Simply they see the lives with these conditions as worse off automatically compared to the statistically medically "normal" people. Advocates for the rights of disabled persons are stating that liberal eugenics is directly violating disabled persons' right to exist since they are deeming fetuses with these conditions as unwanted and parental desires as immoral.

However, this argument is taken into the account and the previous critique is reformulated to accompany genetic engineering cases as well (as the above criticism was mostly aimed at the genetic selection cases). This new version states that genetic engineering proponents are sending a harmful message that the lives of already born people with these targeted disabilities are not worth living at all or that they have a lesser value compared to the people born without them. As Christopher Gyngell asserts "expressing a negative judgment about disabled people is impermissible because it harms those about whom the negative evaluation is made."<sup>25</sup> However, we can also

<sup>&</sup>lt;sup>25</sup> Gyngell, Christopher, and Thomas Douglas. "Selecting Against Disability: The Liberal Eugenic Challenge and the Argument From Cognitive Diversity." Journal of Applied Philosophy, vol. 35, no. 2, 2018, pp. 319–40. PhilPapers, https://doi.org/10.1111/japp.12199.

guestion what types of harm the state has a right to intervene in and formulate regulations around. There are certainly harms in our society recognized as that by the state, in which case the state proposes regulations for the prevention and punishment of those acts. For example, crimes can be understood as this type of harm caused to people or their property. However, people can also be harmed by certain actions but in which cases the state does not have a right to interfere or if it did it would be seen as authoritative and in need of total control of the lives of its citizens. Gyngell gives an example of infidelity that "causes harm to the third party but it would be odd if there were state regulations on this issue."<sup>26</sup> The question is is genetic engineering freedom of parents something that should be completely free as with Nozick's vision of a "supermarket of genes"<sup>27</sup>, or should there be state regulations on what procedures are permissible and which are not. In other words, should parents be free to engineer a child's gene to produce a disability, or enhance certain features or will the state create different policies which give permission only for certain procedures to be done, for instance only allowing genetic engineering for the sake of removing genes that cause disabilities? Additionally, if we understand genetic engineering as a duty, with which means will that be ensured and controlled, as at first glance it may seem that this would fall under the scope of states' policies which again brings us to the authoritative forms of eugenics.

People affected with conditions usually used as examples of diseases that we are obliged to remove from the DNA, state that they are not unwell individuals who are

<sup>&</sup>lt;sup>26</sup> Ibid pp. 4.

<sup>&</sup>lt;sup>27</sup> Nozick, Robert. Anarchy, State, and Utopia. New York: Basic Books, 1974.

carrying genetic diseases, instead, they are just having a different genetic structure and are living a life in an alternative state compared to the rest of the people who do not carry these particular genes. This position is one of the aspects of a *social model of disability*.<sup>28</sup> This model creates a distinction between "impairment and disabilities"<sup>29</sup>, where the disadvantages of their lives that are pointed out by liberal eugenics are showing the social obstacles that these people are facing due to discriminatory social policies that are not taking their needs into account. These disadvantages cannot be taken as a strong argument that there is something inherently wrong with being born blind, deaf, or some other disease rather it is showing the societal inequality.

The permissibility of genetic engineering here gets another set of raised concerns. In case we accept that genetic engineering should be permissible in cases of treatment of diseases, and in cases of enhancement the question is does new genetic reproductive freedom of parents also imply the permissibility of parents to choose to have a child with disabilities? In other words, could disabilities be seen as something that is contributing to a better well-being. Liberal eugenics proponents who have a more rigid version of this view (that there is a moral obligation to remove disabilities) think that parents' freedom cannot go to the extent of deciding not to treat a child for a disease or to actively produce a disability which was not in the embryo genetically. They justify their view by stating that these disabilities are lowering the well-being of a future person, and by that, it can be

 <sup>&</sup>lt;sup>28</sup> Kahane, Guy, and Julian Savulescu. "The Concept of Harm and the Significance of Normality." Journal of Applied Philosophy, vol. 29, no. 4, Nov. 2012, pp. 318–32. PubMed, <u>https://doi.org/10.1111/j.1468-5930.2012.00574.x</u>.
<sup>29</sup> Goering, Sara. "Rethinking Disability: The Social Model of Disability and Chronic Disease." Current Reviews in Musculoskeletal Medicine, vol. 8, no. 2, Apr. 2015, pp. 134–38. PubMed Central, <u>https://doi.org/10.1007/s12178-015-9273-z</u>.

considered as *intentional harm* done to a person which is not permissible. As previously mentioned, this position in practicality entails that there should be state regulations that will impose rules on future parents on which children they can or cannot have, and the new eugenics are losing the liberal crucial part of it. There have been different approaches to this issue. Some which are erasing the difference between disease and a healthy state of the human organism, the view that disability rights advocates are making their claims as a form of coping mechanism to accept their disadvantaged position, and those who think that we need to keep or modify for certain disabilities in order to keep up the cognitive diversity.<sup>30</sup>

My proposal is to focus on potential answers that a contextualist account of health might give to us. In synthesis with the principle of harm, it may offer a solution that will satisfy the transhumanist desires for improvement while accompanying the rights and respect of the disability rights groups. Before transitioning to the contextualist account of health, it is important to explain why is there even a need to define certain disabilities as states that are not necessarily perceived as diseases. By examining this position there is an opportunity for parents with disabilities to have justification for their decision to produce a disability for their future child. Currently, in medical practice, there isn't a unified position on the permissibility of selecting/engineering a disability. Usually, the state of the debate on genetic engineering is focused on treating disabilities as a form of therapy, raising capacities above the average as a form of enhancement, or introduction

<sup>&</sup>lt;sup>30</sup> Gyngell, Christopher, and Thomas Douglas. "Selecting Against Disability: The Liberal Eugenic Challenge and the Argument From Cognitive Diversity." Journal of Applied Philosophy, vol. 35, no. 2, 2018, pp. 319–40. PhilPapers, https://doi.org/10.1111/japp.12199. pp 1.

of certain biological traits that are keeping the capacities at a normal level but are making a change to the "original" state of an organism (for example genetic engineering for cosmetic purposes). The cases of choosing disabilities are usually dismissed as they are seen as harmful procedures for the future child. Though this might seem like an unlikely scenario, there have been attempts to do this. However, the couples are often stigmatized for their choices and limited by policies around reproductive health that are excluding the needs of disability-affected groups. One of the most first examples of choosing a disability is the case of deaf parents who wanted to select an embryo that had genetic predispositions for deafness. At the time genetic engineering technologies were not that advanced, so the couple aimed to achieve this goal by selecting sperm from a deaf donor, however, this was not possible as people with disabilities are excluded from participating in donations for fertility clinics.<sup>31</sup>

<sup>&</sup>lt;sup>31</sup> Spriggs, M. "Lesbian Couple Create a Child Who Is Deaf like Them." Journal of Medical Ethics, vol. 28, no. 5, Oct. 2002, pp. 283–283. jme.bmj.com, <u>https://doi.org/10.1136/jme.28.5.283</u>.

# 2.4 Contextualist approach to health

Genetic engineering is promising to advance humans as a whole species with the potential to remove all of the traits that are seen as constitutional aspects of our lives now: growing old, having diseases, being born into the genetic lottery without any choice, and so on. Since the engineered traits can also be inherited by future offspring, the scientific and ethical community is approaching this manner with a vast precaution as the procedures could have unknown consequences for the affected people but also their environment. The debate is no longer about imaginary scenarios to which extent these gene-editing techniques can go as the technology already exists and human trials are ongoing (though it is worth saying that some of the human trials have been approved and some not as was the case with Chinese CRISPR-cas twins<sup>32</sup>). The case of CRISPR-cas twins shows us the urgency of formulating a proper bioethical policy on the permissibility of different types of genetic engineering. In this case, the Chinese scientist He Jiankui has edited the genetic material of two girls so that they have lesser chances of contracting the HIV virus later in life<sup>33</sup>. Their biological father has HIV whilst the mother was negative, however, there was no real medical concern about them inheriting HIV directly from their father and the procedure is rather focused on preventing that from happening later in life.<sup>34</sup> This case has shocked the scientific and ethical community. The first raised concerns were about the necessity of this intervention if there are other ways to prevent

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<sup>&</sup>lt;sup>32</sup> Read more: CRISPR Bombshell: Chinese Researcher Claims to Have Created Gene-Edited Twins.

https://www.science.org/content/article/crispr-bombshell-chinese-researcher-claims-have-created-gene-edited-twins. Accessed 10 May 2022

<sup>33</sup> Ibid

<sup>&</sup>lt;sup>34</sup> Ibid

the contraction of this virus. Moreover, the crucial element for objection to this procedure was that it was done in the early stages of discovering CRISPR-cas technology without known consequences of editing human genes with this technique, and even worse it was a germline type of engineering where the edited traits are inherited by the next generation of offspring as well. Without a doubt, this type of experiment is concerning, especially since the scientists involved have kept this research secret without following typical procedures and ethical guidelines concerning human trials. However, we can put this example in the context of the argument that I have presented at the beginning of this chapter and pose the question of whether this procedure would be inherently impermissible if both parents expressed a desire to edit this part of the gene and if we had a strong level of reassurance that the technique is safe and effective without any unpredictable consequences for the health of a future person?

The general focus of the bioethical community is now on the question can access to these services be available only to the people who are aiming to cure diseases/completely remove the DNA part that would cause it in a child, or can they also be allowed for enhancement purposes, where a person can function properly without the intervention and the gene-editing would raise their targeted capabilities to a higher degree than the statistical norm.

I will argue that we should strive to accept the position that there is no difference in the moral status of procedures that are aimed at therapy and those that would be used

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for enhancement cases. The distinction between therapy and enhancements automatically raises the question of what constitutes a healthy state so that we could say that the implemented procedure is an enhancement, and when does a state of an organism become a disease so that the procedure is seen as treatment. Clarifying this will help solve the issue of the permissibility of genetic engineering while accompanying disability rights group preferences to choose for a disease which will resolve the challenge of liberal eugenics.

A common approach in medicine is to view a disease from an *objectivist point*. Under this position "a person is sick, ill, or unhealthy in virtue of the fact that, first, their biology is in some sense malfunctioning and, second, that this malfunction makes their life go worse than it otherwise would."<sup>35</sup> This view is based on the biological examination of a state of an organism and its comparison to the statistical norm that is constituted of people who are of the same age and gender as an examined individual. Parker Crutchfield in his work "*Moral enhancement and public good*" develops an argument for the *contextualist approach to health*. First, he questions the statistical normality approach to health, by imagining a scenario where a significant portion of the population is born with a malfunctioning organ. As he says:

"Suppose a condition that from a malfunctioning organ is highly prevalent amongst a population. For a theory that grounds disease in function, that condition will count as a disease. Interventions upon that condition may then count as treatments. But for a theory that grounds disease in

<sup>&</sup>lt;sup>35</sup> "Moral Enhancement and the Public Good." Routledge & CRC Press, <u>https://www.routledge.com/Moral-</u> Enhancement-and-the-Public-Good/Crutchfield/p/book/9781032018850. Accessed 2 May 2022. pp 10.

statistical normalcy, that same condition will count as not a disease. Interventions upon that condition may then count as an enhancement. If there is a morally relevant difference between treatment and enhancement, then different accounts of health and disease will imply morally relevant differences in which interventions are permissible or obligatory."<sup>36</sup>

This section of his work is already showing us that distinction between disease and a healthy state is not so easily defined and the permissibility of therapy versus enhancement is not solvable just by stating that we should aim for approval of treatments as they are bringing an individual to a healthy "normal" level. Medicine should not focus only on bringing individuals to a normal state and processes of curing, as we can witness that some of the crucial medical interventions are actually preventative measures where the disease does not yet exist, as in the case with vaccines<sup>37</sup>. With this in mind, we are one step closer to approving genetic engineering as a medical tool that prevents a certain state from endangering the well-being of a person.

Crutchfield sees the objectivist approach to health in the value-neutral health definition developed by Christopher Boorse. This approach says that health is defined by statistical norms, and a certain condition is a disease regardless of whether the affected individual wants it, or even has some benefits from it.<sup>38</sup> By this account, a person with Down syndrome could not state that they are just existing alternatively but their state

<sup>&</sup>lt;sup>36</sup> Ibid pp 12.

<sup>&</sup>lt;sup>37</sup> Ibid pp 12.

<sup>&</sup>lt;sup>38</sup> Ibid pp 15.

should be understood as that of a disease-affected individual. In opposition to this contextualist approach to health and disease is developed. To explain this view, we are introduced to the example of Rob and his dad:

"Rob's dad is in a critical care unit being treated for complications related to end-stage heart failure, a result of decades of smoking cigarettes. Rob's big toe is broken, and he's in a walking boot. But he's well-fed, fit, moving around easily, and looks well-rested. When the critical care physician comes in to check on Rob's dad's ventilator settings, he looks at Rob and says, "Don't smoke, you'll stay healthy." The physician has attributed health to Rob, and this attribution seems true. But suppose that, conveniently, Rob has an appointment in the same hospital that same day with his orthopedic surgeon. As Rob enters the waiting room, he bangs his boot against the door frame hard. The physician sees him do this and says, "Be careful, Rob, or you'll never be healthy." This attribution of health also seems true. What changed was the conversational context of the attributor. In critical care, the context of one in which the patients are old and often near death; in orthopedic surgery, they typically are not."<sup>39</sup>

In the section above, we can see how the notion of health changes in different contexts and how the practical effect on the individual plays a significant role. In the comparative analysis of Rob's dad's situation, we can say that Rob is a healthy individual since he lacks any of the conditions that are threatening his life in contrast to his dad. However, from a point of a specialist, Rob's broken foot is a sign of an ill-bodied person that needs to be treated.

<sup>&</sup>lt;sup>39</sup> Ibid pp 21.

In the contextualist approach, health is defined by the functioning but also practical interests of the affected person. This is important for the permissibility of genetic engineering as a certain procedure can be viewed differently based on the fact if the persons consider themselves healthy or diseased. As Crutchfield claims "unless one defines the morally objectionable contexts, if shifting contexts changes whether an intervention is a treatment or enhancement, the purported treatment/ enhancement distinction cannot ground a moral objection to enhancements."<sup>40</sup>

If we keep in mind the principle of procreative beneficence, and contextualist analysis of health and we advocate for the no difference in the moral status of therapy and enhancement we are on the pathway to open transhumanist ideals also for disability rights advocates. By fitting in certain disabilities outside of the framework of disease, the disable parents are no longer outcasted, and their decision can fit under the form of enhancement since they will introduce a trait that was not there and is raising the wellbeing. To understand the position of this argument, I will again introduce an example of parents who are faced with the option of genetically engineering their future child.

In this example, a deaf couple has decided to have a child. Upon all of the medical exams, the baby is deemed healthy and its genetic screening has shown no DNA traces for deafness. However, the parents are aware of the extent of possibilities that CRISPR-cas technology has and ask the doctor if it would be possible to introduce the deafness

<sup>&</sup>lt;sup>40</sup> Ibid pp 26.

gene to the embryo so that the child is born deaf. If this doctor supports the position of previously mentioned authors like Buchanan, Brock, and Daniels he would say that this type of intervention is impermissible since the child's wellbeing will be worse off than if no intervention was done. However, the parents insist on this and defend their decision by stating first that their deafness is not a debilitating state and is yet another form of how humans can exist. Additionally, they state that their child's well-being will be better off in case it is born deaf since both parents have been deaf since birth so they will be able to create a better bond with a child since they will know exactly what are its needs and how to communicate and act on them. The parents' decision can be understood from the point of principle of procreative beneficence in combination with the contextualist approach to health. The main goal of their decision is to have a child whose state of well-being will be the best possible. To ensure this they are aware that they need to be able to provide necessary good living conditions (shelter, food, safety) but the main element is the connection with a child. Understanding that their condition will make it difficult for them to bond and even raise a hearing child they believe this is the best decision. Moreover, if we apply the principle of harm, it is not clear if the doctor should not fulfill the parent's wish. If we follow the contextualist approach to health being deaf in this case would not be an unhealthy state of the organism so no harm is brought about. However, even if we observe deafness by the objectivist account of health the question remains if a parent's failure of ability to connect with their hearing child can be perceived as greater harm than not possessing a certain biological trait?

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The argument can be understood as two-dimensional, with a subjectivist point of parents as an *instigator* of a procedure and an objectivist point of the broader medical community that serves as a *regulator* which ensures that the harm principle is satisfied. The subjectivist point of view concerns parents and their freedom of choice on which children they will have and the scope of health by their own contextualist approach. Additionally, the traits that are perceived as valuable for the well-being of a child are determined by their subjective points of view on what constitutes a good life. In the above example, the couple had their reproductive rights fulfilled to a certain extent. As rights concerning reproductive health, they are consisted of "three broad categories of rights: (1) rights to reproductive self-determination, (2) rights to sexual and reproductive health services, information, and education, and (3) rights to equality and nondiscrimination."41 The parents made a free decision when to conceive a child, and they had access to medical services and informational appointments with their doctor. However, we can say that their right to nondiscrimination is not met as the characteristic that they possess and want their child to carry is disfavored. At this point, the objectivist element is included in decision-making. By following the societal standard and perception of certain states as diseases the parents' wish is deemed impermissible.

I am not arguing for the exclusion of the objectivist element in the approval of decisions concerning the genetic engineering of offspring. Rather I believe that the objectivist regulator should be guided by the harm principle and contextualist account of health. The contextualist approach to health broadens the scope of desired traits as it also supports

<sup>&</sup>lt;sup>41</sup> Erdman, J. N., and R. J. Cook. "Reproductive Rights." International Encyclopedia of Public Health, edited by Harald Kristian (Kris) Heggenhougen, Academic Press, 2008, pp. 532–38. ScienceDirect, <u>https://doi.org/10.1016/B978-012373960-5.00478-0</u>.

the view that disabilities are not necessarily harm introducing conditions. Moreover, the harm principle is ensuring that the child will still have autonomy and freedom and that there are significant factors indicating that the well-being will be raised. In this, more liberal approach to genetic engineering parents would be free to choose any characteristics for their future child as long as it won't cause a state where a child needs constant paternalistic care or its life expectancy will be significantly lower. For example, parents should be free to choose to introduce "sensory disabilities" or Down syndrome if they possess these traits and have rational reasons to believe their child will be better off this way. However, it should not be permissible for them to introduce or not cure diseases like Cystic fibrosis<sup>42</sup> or Tay-Sachs disease.<sup>43</sup> This is because these types of diseases are limiting the freedom and autonomy of an individual whilst also creating a state of constant pain which is seen as one of the key aspects that is degrading the well-being of an individual. On the other hand, people with sensory disabilities or Down syndrome can still be capable of living autonomous lives without paternalistic care with many of them being able to care for themselves, secure jobs, and partners, and to achieve similar aspects of everyday life. I have also stated that in cases where parents are proactively choosing a disability it should be permissible in the cases where they are impacted with the same conditions in order to prevent misuse of these interventions for cases like Munchausen syndrome where a person is deliberately causing somebody symptoms for which they need care and assistance.44

<sup>&</sup>lt;sup>42</sup> Read more: "Cystic Fibrosis - Symptoms and Causes." Mayo Clinic, https://www.mayoclinic.org/diseasesconditions/cystic-fibrosis/symptoms-causes/syc-20353700. Accessed 23 May 2022.

<sup>&</sup>lt;sup>43</sup> Read more: "Tay-Sachs Disease - Symptoms and Causes." Mayo Clinic, https://www.mayoclinic.org/diseasesconditions/tay-sachs-disease/symptoms-causes/syc-20378190. Accessed 23 May 2022.

<sup>&</sup>lt;sup>44</sup> "Overview - Munchausen's Syndrome." Nhs.Uk, 16 Feb. 2021, <u>https://www.nhs.uk/mental-health/conditions/munchausens-syndrome/overview/</u>.

#### 2.5 Relationship between parents and an engineered child

With previous sections in mind, it seems that there is a place to say that liberal eugenics can support the rights and desires of disability rights advocates. However, the question still remains why should parents take these procedures into consideration, and should the scope of their reproductive freedom go to the extent of editing the biology of a future child.

Beyond the discussions of differences between medically needed and unnecessary interventions, the common criticism for the permissibility of genetic engineering is the fact that it will create an unbalanced relationship between parents and an engineered child. One of the most prominent critics who fits under this position is Michael Sandel. In his work "*A case against perfection*" he is objecting to the possibility of parents having the freedom to choose the characteristics of their children since it is "*demystifying the mystery of life*."<sup>45</sup> As for this argument, Sandel believes that the very intention of parents to have such significant power over their child's biology is morally wrong. He states:

"The problem lies in the hubris of the designing parents, in their drive to master the mystery of birth. Even if this disposition did not make parents tyrants to their children, it would disfigure the

<sup>&</sup>lt;sup>45</sup> Sandel, Michael J. The Case against Perfection: Ethics in the Age of Genetic Engineering. Harvard University Press, 2007. JSTOR, <u>https://doi.org/10.2307/j.ctvjz80mc</u>.

relation between parent and child, and deprive the parent of the humility and enlarged human sympathies that an openness to the unbidden can cultivate.<sup>346</sup>

I believe that this argument is not a strong enough objection to the permissibility of parents making a decision to genetically engineer a child for the sake of better well-being. The current medical practice already contains a lot of procedures that are morally unobjectionable and are usually recommended to parents which could be understood as deconstructing the mystery of birth. For instance, an amniocentesis test is commonly recommended in the early stages of pregnancy to check if the embryo has any concerning genetic conditions. This type of test has helped many parents to decide if they will abort the embryo, or continue the pregnancy but with the knowledge that the child will need special care. Knowing this information beforehand can certainly be perceived as more beneficial for them as they have time to adjust to the situation and prepare the necessary care for the child with genetic conditions. To say that there is something of an essential value in not knowing anything about the future child seems to be naïve and even irresponsible to a certain extent.

Another form of criticism in the line of reasoning about the disparate relationship between parents and genetically edited children comes from Anca Gheaus. She believes that there "should be a difference in the moral evaluation of shaping children through social means and doing that through genetic engineering."<sup>47</sup> What makes her argument

<sup>&</sup>lt;sup>46</sup> Ibid pp. 80.

<sup>&</sup>lt;sup>47</sup> Gheaus, Anca. "Parental Genetic Shaping and Parental Environmental Shaping." The Philosophical Quarterly, Oct. 2016, p. pqw064. DOI.org (Crossref), <u>https://doi.org/10.1093/pq/pqw064</u>. pp. 264.

interesting is the fact that she sees "parental genetic engineering as morally objectionable"<sup>48</sup> but states that it is not necessarily making it impermissible. By choosing to genetically engineer a child the parents are limiting the autonomy of that future individual by imposing their desired characteristics on it and this creates an unbalanced "objectionable relationship."<sup>49</sup> It is worth noting that she understands the utilitarian stance on the permissibility of genetic engineering as that way parents' desires are fulfilled and the child has a better relationship with their parents so the overall well-being is raised for all participating agents.<sup>50</sup> The focus of her objection is on the creation of an imbalanced relationship and the potential problem if the affected children will question the parent's love. First, it is important to note the difference that Gheaus makes between "mere procreators"<sup>51</sup> as in persons who bring a child into existence but do not raise it, and parents as "procreators and child rearers"<sup>52</sup> who bring a child into existence and spend time upbringing it. The focus of her argument is on the second group. What creates an unbalanced relationship between parents and a child is that the child "enters the relationship involuntary."53 Simply said the child does not have an option to choose to be born or not. Since these relationships are unequal from the start why does the implementation of genetic engineering make a significant moral difference? For Gheause genetic engineering is problematic since it's bringing in another dimension of inequality. According to her, it is important to bring equality in these already disproportionate

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<sup>&</sup>lt;sup>48</sup> Ibid pp. 265.

<sup>&</sup>lt;sup>49</sup> Ibid pp. 269.

<sup>&</sup>lt;sup>50</sup> Ibid pp. 277.

<sup>&</sup>lt;sup>51</sup> Ibid pp. 269.

<sup>&</sup>lt;sup>52</sup> Ibid pp. 269.

<sup>&</sup>lt;sup>53</sup> Ibid pp. 274.

associations, and editing a child's features is "avoidable inequality."<sup>54</sup> As previously mentioned, Gheause is aware of parents being inclined to choose a child's biological characteristics for the sake of elevating well-being. However, she raises a concern that the children might hold a grudge against parents for being "edited" and not unconditionally accepted.<sup>55</sup>

I believe that possibility of a child raising these concerns is not making a strong enough case not to allow these types of procedures. First of all, it is hard to define what would even be the appropriate elements to ensure the authenticity and sincerity of parents' love for their child. Additionally, she also recalls Malmqvist's argument that "environmental shaping happens over time"<sup>56</sup> so it is easier to see if the taken actions are contributing to the well-being of the child. And, the child is a participant in this process so they can affect its course. I believe that this objection wrongly sees genetic engineering as a shortcut that parents take to achieve a certain characteristic of a child with it being the end of the parenting process. Parents indeed perceive certain characteristics as crucial for elevating well-being, however, this does not mean that there are no further interrelations between parents and a child where the latter can express their attitude and (dis)pleasure as in the permissible cases of environmental shaping. Simply, the engineered physiological trait is yet another means to ensure well-being. Let's recall the bodybuilding family from the beginning. They are choosing that their child's muscles are more prone to bulking up so that they can include the child in their lifestyle to form a better

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<sup>&</sup>lt;sup>54</sup> Ibid pp. 277.

<sup>&</sup>lt;sup>55</sup> Ibid pp. 279.

<sup>&</sup>lt;sup>56</sup> Ibid pp. 278.

relationship. The child is born, and with low impact movements, its muscles are strong as in individuals who do high impact exercises. The parents are still interacting with a child through different activities that are catered to raise its well-being. Even in these cases, the child has an option to "opt out" if the activities and interaction with parents is not actually beneficial for its well-being. It is important to acknowledge that the child might not be able to reverse the artificial genetic traits of its muscles but there is still space to practice autonomy by objecting to the parents' decision and directing these physiological traits to other means. It is important to keep in mind that Gheause does not state to which extent these procedures are objectionable. Potential cases of genetic engineering effectively find the akin examples within social "behavioral engineering" and it is not easy to see what difference they have so that they are considered impermissible procedures and objectionable. Again, when it comes to the cases where a child could make a claim against parents for being subjected to the genetic engineering, the same concern could be raised in the cases of parents who had the "unedited" child, since the child could perceive their action as being neglectful and disregardful towards ensuring better wellbeing for them.

### 3. Genetic engineering as means of avoiding catastrophe

The purpose of the previous parts of the thesis was to present a case for genetic engineering as a moral duty. Incorporating contextualist analysis of health broadens the scope of liberal eugenics so that it also fits the narrative of disability rights advocates. The arguments are claiming that there is a duty to implement genetic engineering whenever there are strong reasons for parents to believe that certain introduced traits will raise the well-being of future children. However, there is still a place for doubting the benefits of genetic engineering in this context and skeptics can still not view genetic engineering as something that should be considered a duty. In this chapter, I will claim that due to the overall crisis that is endangering the well-being of future persons as well as already existing one's genetic engineering might represent the only means by which the human species can preserve the satisfying levels of well-being and dignity and therefore it should be considered as a moral duty taken into account by everybody.

### 3.1. Preventing catastrophe through the use of genetic engineering

Intergovernmental Panel on Climate Change<sup>57</sup> (IPCC) is an assembly within United Nations that has a role in analyzing issues connected to climate change.<sup>58</sup> Every few years the IPCC issues an extensive report on the current state of climate change

<sup>&</sup>lt;sup>57</sup> IPCC — Intergovernmental Panel on Climate Change. https://www.ipcc.ch/. Accessed 30 May 2022.

<sup>58</sup> Ibid

(temperature rise, estimated carbon emissions from big polluters, predictions about environmental conditions, and so on) and unfortunately, each new report paints a pessimistic picture of our future. While the previous reports have warned of *potential* dangers that may be caused if we recklessly proceed with managing resources and continue depending on fossil fuels, today those dangers became a part of the reality and irreversible damage has been done already. The newest report from 2022. sends a warning message that the temperature rises above the level of 1.5 Celsius could be devastating for the environment and humanity.<sup>59</sup> Since government officials and "big polluters"<sup>60</sup> have ignored the previous warnings, it is fair to assume that there will be drastic environmental changes in the upcoming years. This presents a catastrophe for humans. Besides the obvious harm of short span impacts of climate change like floods, hurricanes, forest fires, and similar occurrences the other aspect of catastrophe are more long-term damages to the environment and at the same time to humans.

The following scenario can be imagined: your house is destroyed in a sudden flood that happened due to unexpected excessive rainfall. You have private financial resources and you have received adequate support from your local government to move to a new home in an unimpacted part of the town. Here it can be observed that the affected community has responded to the environmental crises through *social means*. In this case, the well-being of affected individuals was reestablished through social modes. Now let's

<sup>&</sup>lt;sup>59</sup> Climate Change 2022: Impacts, Adaptation and Vulnerability. https://www.ipcc.ch/report/ar6/wg2/. Accessed 17 May 2022. SPM-13.

<sup>&</sup>lt;sup>60</sup> Read more: Vanessa. "Which Countries Are the World's Biggest Carbon Polluters?" ClimateTrade, 17 May 2021, <u>https://climatetrade.com/which-countries-are-the-worlds-biggest-carbon-polluters/</u>.

imagine a scenario where carbon emissions have not been regulated and downsized which causes the temperature to severely rise. The human body can function properly in temperatures below 35 degree Celsius.<sup>61</sup> High temperatures above 35 degrees Celsius are becoming a frequent occurrence due to global warming. If there are no social means to aid in relieving the impact of climate change, should we look for solutions in changing our biology? I am inclined to support this idea. The concept of adjusting human biology through genetic engineering to tackle climate change-related issues was first developed by Matthew Liao. Liao believes that "human engineering"<sup>62</sup> should be seen as a more efficient way of handling climate change impacts. As he states there have been several attempts and proposals on how to adapt to the new environment, which is mostly focused on behavioral changes and the creation of policies.<sup>63</sup> These proposals have turned out to not be so promising as there is usually an unwillingness to change behavior on an individual level and countries often do not follow up on the agreements set by a certain policy.<sup>64</sup> Liao proposes that genetic engineering should be implemented in order to make "people smaller, intolerant to meat, and more empathetic."<sup>65</sup> Additionally, he proposes "lowering birth rates through cognitive enhancement."<sup>66</sup> I believe that Liao's proposal to tackle climate change through biological interventions is ingenious. However, the specific steps that he proposes seem to be responding to the crisis in a circuitous manner. I will set aside the arguments aimed at enhancing empathy and cognitive skills, as so far, the

<sup>62</sup> Liao, Matthew. "Tackling Climate Change Through Human Engineering." OpenMind, https://www.bbvaopenmind.com/en/articles/articletackling-climate-change-through-human-engineering/. Accessed 23 May 2022.

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<sup>&</sup>lt;sup>61</sup> published, Tyler Santora. "What's the Hottest Temperature the Human Body Can Endure?" Livescience.Com, 31 July 2021, https://www.livescience.com/hottest-temperature-people-can-tolerate.html.

<sup>63</sup> Ibid

<sup>64</sup> Ibid

<sup>65</sup> Ibid

<sup>66</sup> Ibid

focus of this thesis was on direct physiological changes. For instance, he proposes creating "meat intolerance"<sup>67</sup> with the goal of people eating less red meat, which will lower the demand for excessive livestock breeding. Besides the question of ethics of eating meat, livestock production is problematic for climate change as animals produce large quantities of methane.<sup>68</sup> As his position fits within the liberal stance on genetic engineering where these procedures are only taken up willing fully, wouldn't it be more effective if we propose undergoing genetic engineering so that the human body can stand high temperatures above the current average? If meat intolerance is only created within a certain number of volunteers this implies that there will still be meat consumers who will create a demand for livestock and there will still be a significant methane production that will add up to the global warming. Not to be mistaken, I am supportive of Liao's proposal to adapt our bodies through genetic engineering, it is just the case that I disagree with the effectiveness of particular proposed solutions.

The big question arises from supporting the view of adapting our biology as a means of not just tackling but actually surviving climate change impacts. The question is testing out the potential imposed obligations from dealing with climate change in this way. In other words, if avoiding climate change impacts and the onset of catastrophes that go with it are seen as a duty, how do we not infringe on the rights of people who are against genetic engineering? It can be recalled from the previous chapter, that only permissible

<sup>67</sup> Ibid

<sup>&</sup>lt;sup>68</sup> Read more: "Methane Emissions Are Driving Climate Change. Here's How to Reduce Them." UNEP, 20 Aug. 2021, <u>http://www.unep.org/news-and-stories/story/methane-emissions-are-driving-climate-change-heres-how-reduce-them</u>.

forms of genetic engineering are the ones where individuals have decided for themselves or their offspring to undergo these interventions. Making these procedures state-ordered is again bringing the concerns about old eugenics.

Dealing with the new harsh environment through changes in our bodies might not sound appealing to a lot of people. However not going through any interventions or behaviors that could preserve our well-being seems contra-intuitive with the general attitude towards preserving human life with all of the qualities that are commonly appreciated. As mentioned previously this proposal cannot be imposed on people though, there are other means by which genetic engineering can still be seen as a duty and presented as a suggestion. The potential solution is to formulate it into a health recommendation. By formulating moral duty to preserve well-being into a health recommendation we are avoiding slipping into coercive measures that would impact the individual's autonomy. When discussing the ways in which public health policies take place Fabrizio Turoldo distinct between three versions: "highly coercive, soft coercive and non-coercive interventions."<sup>69</sup> The example that can be helpful for the case of genetic engineering is the example of warnings put on cigarette packs. The cigarette packs are labeled with warnings like "smoking kills" even though the medical community knows that cigarettes don't impose this type of direct harm, but are contributing to other complications that may lead to death.<sup>70</sup> Health recommendations for genetic engineering may be

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<sup>&</sup>lt;sup>69</sup> Turoldo, Fabrizio. "Responsibility as an Ethical Framework for Public Health Interventions." American Journal of Public Health, vol. 99, no. 7, July 2009, pp. 1197–202. PubMed Central, <u>https://doi.org/10.2105/AJPH.2007.127514</u>.

<sup>70</sup> Ibid

formulated in a similar form. A poster may be seen in the medical practice office that says "Not undergoing genetic engineering kills", this statement might seem a bit drastic but due to the environment becoming more and more uninhabitable for humans it can be concluded that not doing this will create more complications for an individual whose body is not adapted which will eventually lead to death. Just like with cigarettes, there is a duty to warn about dangers but an individual is free to continue smoking or take the risks into an account and change their behavior. In the case of genetic engineering, a person can ignore the warnings or decide to change their biology. It is important to say that the CRISPR-cas technique of genetic engineering can be done both on adults and embryos, which makes this type of decision a realistic option.

### 3.2. Genetic engineering as a mitigation tool for the scientific community

The previous argument's focus was on the issues concerning direct environmental harm brought about by climate change. In this section, I will present yet another argument why genetic engineering should be seen as a moral duty because it could have mitigating and redeeming effects on the *indirect harms* caused by new environmental changes.

The direct harm of climate change can be witnessed through the examples of frequent natural disasters like hurricanes, floods, droughts, and similar. However drastic and rapid changes to the environment are also causing another set of problems for the human population. One of the biggest threats to human health is "zoonotic pathogens."<sup>71</sup>

<sup>&</sup>lt;sup>71</sup> Zoonoses. <u>https://www.who.int/news-room/fact-sheets/detail/zoonoses.</u> Accessed 28 May 2022.

These types of pathogens are transmitted from animals to humans. With urbanization, the destruction of wildlife habitats, and meat consumption human population increases the risk of getting in contact with these types of pathogens.<sup>72</sup> The majority secluded animal species carry pathogens whose impact on humans has not been researched enough due to the low risk of infections from animals to humans. However, due to climate change, there are migrations into previously uninhabited areas both by animals and humans. Within these migratory routes species interact and transmission of pathogens occurs. It is important to say that climate change is also contributing to the return of old pathogens that were deemed extinct due to medical progress. The concern over climate change impacts has been raised with the "anthrax outbreak in 2016."73 In this particular case, climate change has influenced temperature rising in Siberia which has led to the melting of the permafrost.<sup>74</sup> It is believed that the permafrost contained remains of previously infected animals, and with the ice layer melting away the contagious spores were free. This is yet another strong message about the dangers that climate change causes. However, the focus of my argument is on the arrival of novel pathogens.

The outbreak of the coronavirus<sup>75</sup> in 2020. has shed light on the frailty of medical infrastructures and the general incompetence to provide rapid proper treatment for the pathogen that has not been extensively researched. The practical implication of this was

 <sup>&</sup>lt;sup>72</sup> Baker, Rachel E., et al. "Infectious Disease in an Era of Global Change." Nature Reviews Microbiology, vol. 20, no.
4, Apr. 2022, pp. 193–205. www.nature.com, <u>https://doi.org/10.1038/s41579-021-00639-z</u>.

 <sup>&</sup>lt;sup>73</sup> Stella, Elisa, et al. "Permafrost Dynamics and the Risk of Anthrax Transmission: A Modelling Study." Scientific Reports, vol. 10, no. 1, Oct. 2020, p. 16460. www.nature.com, <u>https://doi.org/10.1038/s41598-020-72440-6</u>.
<sup>74</sup> Ibid

<sup>&</sup>lt;sup>75</sup> Read more: About the Virus. https://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/novel-coronavirus-2019-ncov. Accessed 28 May 2022.

the alarming state in which the scientific (mostly medical) community found itself. While the research on this virus was in its first stages there have already been thousands of patients in need of medical care and treatment. This created a significant burden on the scientists conducting research and medical teams who were dealing with rising numbers of patients. Besides patients impacted by the coronavirus, the arrival of a new pathogen had calamitous consequences for yet another group of patients: patients with chronic diseases. Chronic diseases affect individuals for long periods, meaning they are in more frequent need of medical care and treatment in comparison to people with acute diseases. Usually, the symptoms of diseases can be relieved through various procedures and medicaments but not eradicated. Due to the coronavirus pandemic, the accessibility of medical care became difficult to obtain. With relocations of specialists to corona-infected cases, there has been a significant decline in the number of available appointments for general checkups, access to community support, and general medical attention.<sup>76</sup> On the other hand, chronic patients that had access to medical care were limiting the hospital capacities for newly infected cases.

What can climate change impact on the arrival of pathogens and coronavirus crises tell us about the need to make genetic engineering a moral duty? With scientific predictions about the dangers of the arrival of new pathogens, we can be quite certain that we could expect a new crisis similar to the corona one. Additionally, the coronavirus

<sup>&</sup>lt;sup>76</sup> Fekadu, Ginenus, et al. "Impact of COVID-19 Pandemic on Chronic Diseases Care Follow-up and Current Perspectives in Low Resource Settings: A Narrative Review." International Journal of Physiology, Pathophysiology and Pharmacology, vol. 13, no. 3, June 2021, pp. 86–93. PubMed Central, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8310882/.

crisis has shown us the need for the scientific community to act fast in response to new emerging diseases and how this is a colossal challenge. Genetic engineering, more specifically CRISPR-cas has the potential to cure and eliminate many of the common chronic diseases that have been researched for years and treated through other medical means (surgeries, medication, lifestyle changes...). Currently, there are several trials where CRISPR-cas is tested as a cure for chronic issues like blindness, cancer, heart diseases,<sup>77</sup> and similar long-term conditions. In order to prevent the collapse of the medical system and to lower the burden on the scientific community, there should be a duty to implement genetic engineering for the treatment of well-researched diseases. This means that in case CRISPR-cas proves to be successful in curing chronic issues both in vitro and in vivo there should again be a health recommendation to undergo these procedures. This will potentially generate relief in the medical community as there will be a lower number of patients in need of general medical appointments, places in hospitals, and a lesser number of people who need consistent medical observations. With the threat of new pathogens, it can be anticipated that the medical community will have to focus on new diseases, and a lesser number of chronically ill patients will give enough space for the medical community to focus on newly infected cases whilst not endangering the wellbeing of other patients.

<sup>&</sup>lt;sup>77</sup> Read more: Wu, Shao-Shuai, et al. "Advances in CRISPR/Cas-Based Gene Therapy in Human Genetic Diseases." Theranostics, vol. 10, no. 10, Mar. 2020, pp. 4374–82. PubMed Central, <u>https://doi.org/10.7150/thno.43360</u>.

# 4. Conclusion

Genetic engineering of humans has proven to be one of the biggest challenges for bioethics. The concerns regarding the implementation of these techniques are making us question the consequences of genetic engineering for humanity, for the affected individual, but are also turning us to introspection as often it is quite convoluted why we feel like certain procedures are (un)objectionable. In this thesis, I have made an attempt to present different arguments on why genetic engineering should be perceived as a duty. Additionally, an argument was presented on how liberal eugenics can truly ensure freedom of choice for all the parents regardless of their health conditions, and how a broader group of biological characteristics can fit under the scope of permissible genetic interventions.

New genetic engineering techniques are already making a revolution in the scientific community, but this is only their first stage of creating a significant impact on humanity as we know it. Since this is a such complex bioethical problem, this thesis was an attempt to fill in some of the gaps within the concepts that are composing the debate on the permissibility of engineering humans. Besides the general concerns regarding these techniques, more questions remain unanswered and give space for further research. For instance, it would be fruitful for the discussion to see how far back in the past can children make claims against parent's decisions and if the engineering of embryos is something that could be objected to from that point. Moreover, it can be questioned what would be

the impact of complete freedom of decision on genetic engineering in the context of the presented climate crisis? Will the extend of personal freedom clash with general social standards? What we can be sure of is that this problem will keep emerging within bioethics with each new technological development. Certainly, it will be interesting to revisit and review different philosophical positions and their arguments within this debate once the "designer babies" present their experience with being altered before birth.

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