

# The Legality of Genetic Engineering

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The meteoric advancements made in genetic engineering have completely revolutionized human health, offering the potential to eradicate harmful hereditary diseases by directly altering the human genome. However, the possible benefits gained through genetic engineering must be evaluated carefully along with the legal and ethical challenges that it creates regarding bodily autonomy. The infamous Supreme Court decision made in *Buck v. Bell* (1927) once penalized those regarded as “feeble-minded” and legalized forced sterilizations under the guise of public safety. While the rise of genetic engineering marks a significant step taken in the scientific world, the lack of legal regulation related to modern eugenics could introduce social and ethical risks that were once sanctioned by *Buck v. Bell*. The individual right to reproduce is now protected in several aspects, but the lack of a comprehensive legal framework regarding modern eugenics leaves room for the mistakes echoed in *Buck v. Bell* to repeat. Technologies like CRISPR and gene drives are developing faster than the legal system can adapt, and it is imperative that laws are established in order to protect individual freedoms.

The concept of eugenics first emerged in the late 1800s and gained traction throughout the early 20th century. The eugenics movement promoted the scientifically inaccurate idea of improving society through selective reproduction and the elimination of undesirable genes. As a result, the United States implemented state sterilization laws, including Virginia’s Sterilization Act of 1924. Essentially, it legalized the forced sexual sterilization of individuals with intellectual disabilities or mental illness. It aimed to limit the procreation of individuals who were disabled or “feeble-minded”. The discriminatory nature of these laws was concealed under the guise of public welfare. The landmark case *Buck v. Bell* upheld these discriminatory practices

when the Supreme Court ruled that Carrie Buck, a young, “feeble-minded” woman admitted to a state mental institution, should be forcefully sterilized. Carrie Buck was placed in a Virginia asylum at the age of 18 for having both epilepsy and a low IQ; both of which were considered characteristics of a “feeble-minded” individual. Her condition had been present in the family for 3 generations, and Justice Oliver Wendell Holmes harshly stated that “three generations of imbeciles are enough”. In reality, Carrie Buck’s condition was based on a flawed understanding of mental health at the time. However, Justice Holmes argued that forced sterilization was an integral measure for public safety. Eugenics laws began to be repealed gradually, as the public began to recognize the ethical and scientific flaws in the eugenics movement. Particularly, scientific advancements made in the mid-20th century undermined the idea that mental disabilities were solely hereditary. However, the legacy of eugenics laws emphasizes the need for robust legal protections surrounding modern genetic engineering to be in place to ensure that past mistakes aren’t repeated.

Modern genetic engineering has rapidly developed in the last century, with technologies such as CRISPR and gene drives revolutionizing the future of human health. CRISPR is a prominent gene-editing tool that offers the potential to cure hereditary diseases by allowing scientists to make precise edits to the human genome; it can treat a variety of diseases such as sickle-cell anemia, AIDS, and transfusion-dependent beta-thalassemia. However, the possibility of gene-drive failure exists and can create disastrous consequences. Genetic engineering could present risks to the human gene pool by enabling genetic modifications to spread uncontrollably throughout a population. This would result in unforeseen consequences to the human species due to the lack of research on the complex interactions that take place between genes. Genetic engineering not only raises health concerns, but ethical concerns when exploited. If genetic

engineering were to become more available to the public as it develops, wealthy individuals who can afford it could exploit it to create “designer babies”. Designer babies are children that have had their genes edited to resist diseases and obtain desirable qualities. By the selection of specific, genetic traits, designer babies have the chance to acquire “genetically superior” physical appearance, intelligence, and health. Superficially, it may seem like offspring with edited genes would have the potential to drastically improve society due to their genetic advantage. However, the ability to design children based on socially desirable traits could inadvertently create new forms of discrimination and social divide by constructing a genetically superior social class. Individuals who do not have access to gene editing could face possible marginalization. Furthermore, the creation of designer babies raises the question of the extent to which parents have the right to alter their child’s genetics. Beyond that, how much control would the federal government have over micro-managing these designer babies? Currently, the Genetic Information Nondiscrimination Act (GINA) is in place to prevent genetic discrimination in employment and health insurance, but it does not completely protect individuals from genetic discrimination in other areas, such as life and disability insurance. The federal government also prohibits the usage of federal funding for research on genetically modified embryos, but this does not prevent the use of private funding. Regulations from the NIH do provide some oversight for gene therapy, but a massive grey area still exists due to limited legislation to govern the ethical concerns of gene editing. As genetic engineering evolves, it is important to implement regulations that will protect individual rights and prevent the abuse of this powerful tool.

Current legislation surrounding genetic engineering and eugenics is insufficient to properly address and regulate it. The Genetic Information Nondiscrimination Act (GINA) provides protection against genetic discrimination in both employment and health insurance.

However, GINA is flawed because it does not extend to other forms of insurance. Additionally, the NIH regulates gene therapy, but its oversight is limited to certain forms of genetic engineering. For instance, the NIH does provide guidelines for research protocols related to gene editing. The NIH also does not directly fund any research related to human embryo gene editing. Many argue that the NIH does not have enough guidelines in place to address the unintended consequences that gene editing may have, especially on health. A significant issue with current related legislation is the lack of a clear, federal definition of what constitutes eugenics in modern genetic engineering. However, *Buck v. Bell* serves as a reminder of the dangers that state and federal involvement can have on personal reproductive decisions. Yet, without clear legal guidelines, modern genetic technologies have the massive potential to be misused. The decision made in *Buck v. Bell* emphasizes the need for comprehensive laws to be introduced that will protect individual rights. It is essential to have a clear definition of the guidelines surrounding genetic engineering in order to prevent its possible consequences and misappropriation.

The international approach towards the regulation of genetic engineering differs significantly. Among the most strict regulatory frameworks is the Oviedo Convention in the European Union; it establishes clear guidelines surrounding the ethics behind genetic modification. It places strict limits on germline editing and ensures that the intentions behind genetic engineering don't align with the sick ideology behind eugenics. In China, a scientist by the name of He Jiankui produced the first genetically modified embryos using CRISPR technology to prevent the risk of HIV in these babies. However, this experiment was carried out in secret, thus without both transparency and ethical approval. This experiment faced global backlash and highlighted the need for directives against unregulated experimentation of genetic engineering. As aforementioned, in the United States, both the NIH and the federal government

refuse to provide funding to research similar to the type conducted by He Jiankui. However, this does not limit the use of private funding. This leads to another gap in federal legislation due to the lack of oversight related to private research on eugenics.

The rapid growth of genetic engineering presents both extraordinary scientific progress and serious ethical concerns that require clear regulation. The history of eugenics, as exemplified in *Buck v. Bell*, showcases the dangers of government interference with personal freedom, such as reproduction. However, as technologies such as CRISPR develop, it is imperative to institute legislation that will prevent the misuse of this scientific innovation. Current legal frameworks created by GINA and the NIH are not enough to fully address all of the ethical concerns that genetic engineering creates. Mirroring the clear guidelines set by the Oviedo Convention in the European Union is a viable option to prevent the dangers of eugenics and establish a strict divide between life-changing genetic engineering and harmful genetic modification. It is essential for lawmakers to set clear guidelines to protect both individual rights and the responsible use of these powerful technologies.

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