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BEYOND CORRECTION: RECONCILING GENE EDITING WITH THE RIGHTS OF PERSONS WITH DISABILITIES IN INDIA'S RIGHTS-BASED FRAMEWORK

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ABSTRACT

The accelerated progression of gene-editing tools provides incredible opportunities to put an end to hereditary diseases, yet it raises extremely serious fears of discrimination, commodification, and the loss of human diversity at the same time. These dangers are even more crucial for India where the country's constitution and legislative measures committed to the dignity, autonomy, and inclusiveness, particularly of persons with disabilities, are in a kind of conflict with the genetic intervention correctional paradigms.

This article dissects gene-editing scientific and moral grounds, India's regime for disability rights, as well as the country's fragmented regulatory landscape, while also making use of comparative insights from such jurisdictions as the United Kingdom, the United States, and China. It is pointing out the most critical issues like the lack of binding legislation, the failure to draw the line between therapy and enhancement, and the complete disregard for disability rights perspectives. The study is supporting the introduction of a powerful law framework that ensures the protection of rights through the inclusion of the clear prohibition of genetic discrimination, the strengthening of data privacy, and the adoption of a rights-based approach that is anchored on the Constitution and the Rights of Persons with Disabilities Act as the primary sources of authority.

If India makes use of these normative foundations, not only can it meet its regulatory obligations but also become a world leader in balancing scientific progress with the needs of human dignity, inclusion, and diversity.

Keywords: CRISPR, Eugenics, Gene Editing, Persons with Disabilities, Rights of Persons with Disabilities

INTRODUCTION

CRISPR-Cas9 gene editing experienced a complete change of perspective with the arrival of CRISPR-Cas9 in 2012, a discovery that led to the award of the 2020 Nobel Prize in Chemistry. This mechanism provides the possibility of treating hereditary diseases like thalassemia, sickle cell anemia, and cystic fibrosis in a way that components of one living organism can be replaced with precise ones of the same or different organism. As well, the company behind the technology projects a reduction in the number of chronic diseases with an associated reduction of human suffering in the future- which is supposed to be the social benefit of it- but, at the same time, its drawbacks are the following: the threat of genetic discrimination, the commercializing of life, and the return of neo-eugenics, from which diversity may be destroyed and inequality deepened at the same time, because of all these risks.

In India, these questions have some similarities with the constitutional and legal provisions for people with disabilities. The Rights of Persons with Disabilities Act, 2016[1], based on the UNCRPD, is a law that provides for dignity, equality, and full participation through a social model of disability that does not recognize it as a defect. This is quite different from gene editing paradigm, which is a risk that respect for diversity may gradually disappear. Despite that, the reaction of India is still not one of the whole country regulatory and policy divided. Current regulations, like the ICMR guidelines (2019)[2], and the New Drugs and Clinical Trials Rules (2019)[3], provide ethical guidance but are insufficient in terms of comprehensive statutory clarity. The present paper intends to close those voids in a way that it introduces a rights-based framework that considers scientific advancement as well as the constitutional values of dignity, inclusion, and equality.

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[1] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).

[2] Indian Council of Med. Research, National Ethical Guidelines for Biomedical and Health Research Involving Human Participants (2007), https://ethics.icmr.org.in/index.php/ICMR_Ethical_Guidelines_2007.pdf

[3] Ministry of Health & Family Welfare, New Drugs and Clinical Trial Rules, Gazette of India, G.S.R. 227(E) (Mar. 19, 2019), https://cdsco.gov.in/opencms/resources/UploadCDSCOWeb/2018/UploadGazetteNotificationFiles/NewDrugsClinicalTrialsRules2019.pdf

GENE EDITING: SCIENTIFIC AND ETHICAL FOUNDATIONS

Gene editing has been completely revolutionized over time through its primary stages. Just to mention some of the earliest examples, "zinc finger nucleases (ZFNs)" and "transcription activator-like effector nucleases (TALENs)" in the 1990s and 2000s were the initial methods to open the door for gene editing[4]. These tools did allow targeted changes but were very costly, difficult to handle, and also were lacking in precision. The breakthrough that made the difference and marked the turning point was the discovery of CRISPR-Cas9 in 2012, which combined the use of a bacterial immune system with DNA editing technology for the first time in history, giving it unparalleled accuracy and efficiency.[5]

With the use of guide RNA to show the Cas9 enzyme the exact spots within the genome to edit, the researchers were now capable of creating mutations or adding new sequences. As a result of this practicability, the expenses were lower plus the genetic research was accessible to the entire globe. The Nobel Prize in Chemistry 2020, given to Emmanuelle Charpentier and Jennifer Doudna, was a clear sign of the great impact of their work worldwide. Though the plain working of CRISPR also indicated the amplified ethical risks as more powerful interventions became available for small labs and private individuals[6].

Now, as CRISPR developed, with it developed two new concepts, which are somatic gene therapy on one hand and germline intervention on the other. Somatic gene therapy aims at non-reproductive cells; thus, any changes made will only be limited to the treated individual and not passed on to the next generation. Such an approach has demonstrated success in clinical trials targeting blood disorders such as β-thalassemia and sickle cell disease. On the other hand, Germline genetic editing works by changing reproductive cells or embryos, and therefore, any modifications become inheritable. Although it has the potential to completely eliminate genetic diseases, this method still poses a long list of fears, such as unexpected mutations and consent issues among future generations. In line with this, most countries allow somatic applications under

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[4] Adam Conti, Drawing the Line: Disability, Genetic Intervention and Bioethics, 6 LAWS 14 (2017).

[5] *Id.*

[6] Deeptayan Ghosh & Amiya M. Arickatt, Legalising Germline Editing for the Cure of Congenital Diseases and Disabilities in India: A Human Rights Perspective, 6 INT'l J.L. MGMT. & HUMAN. 3809 (2023).

strict regulations but give a great number of restrictions and even bans on germline interventions, which is a testament to the magnitude of their ethical and social issues[7].

Now the applications of Gene editing fall broadly into two categories: **therapeutic** and **enhancement oriented**.

Therapeutic intervention methods seek to eliminate the mutations that lead to diseases and thus, to provide health and welfare. Besides, these therapeutic applications encompass the gene therapies for rare monogenic diseases, the oncological therapies through gene editing and also, the innovative antivirals based on the genome technologies such as the treatment of HIV and COVID-19. The use of somatic gene editing, in this case, is completely in harmony with the core values of the medical healing profession[8].

Conversely, enhancement applications are characterized as non-therapeutic and go a step further to the area of development or building of new features. For example, it might be the choice or creation of embryos for some particularities like length, intellect, or quality of movement. Enhancement was expressively the confirmation of a move away from curing and into customizing of people, which is a route laying with the dangers of commodification and social segregation[9].

The deceit by He Jiankui scandal in China (2018), which tampered the twin embryos to make them resistant to HIV, is a good example of the risks of the enhancement-based study without any moral restraint in control. This incident provoked an outcry all over the world and thus, made the calls for more tightly regulated international guidelines for gene-editing technologies stronger[10].

Today, healthcare is being transformed by the use of CRISPR-based genetic editing technologies in clinical applications. Since 2017, the results of trials for both β-thalassemia and sickle cell disease have been very promising, to the point that several patients have become free of the need

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[7] *Id.*
[8] Adam Conti, Drawing the Line: Disability, Genetic Intervention and Bioethics, 6 LAWS 14 (2017).
[9] *Id.*
[10] Deeptayan Ghosh & Amiya M. Arickatt, Legalising Germline Editing for the Cure of Congenital Diseases and Disabilities in India: A Human Rights Perspective, 6 INT'l J.L. MGMT. & HUMAN. 3809 (2023).

for transfusions. Along with cancer, research is developing in the area of CAR-T treatments which are immune cells genetically altered to attack tumors, the field of infectious diseases in which viruses are disabled by editing their DNA, organ transplantation where pigs' organs are edited for better compatibility with humans, and neurology through animal models used for Huntington’s and Alzheimer’s diseases. While the majority of them are still at the stage of experiments, these breakthroughs indicate a migration from the realm of possibilities to actual therapeutic instruments that have the potential to revolutionize healthcare.

However, Societal influence of gene editing has been very ambiguous. It can certainly give us the chance to get rid of hereditary diseases and provide people with more well-being but it also has a risk of deepening the gap of inequality if the access to it is only for the rich people giving rise to so called “genetic health gaps”. A concept of “designer babies” stirs up fears of normalization pressures, among which non-modified traits or disabilities may become stigmatized, thus, resulting in modern eugenics that is being justified by science. The following developments hinge on the issue of control: gene editing could be either a tool for social justice capable of eradicating diseases in an equitable manner or a means to further the division by turning genetic advantages into commodities.

Ethical debates around Gene- editing in humans revolves around four major issues, among which are justice and access. Justice and access shed light on the potential for health disparities to be deepened by the chances of unequal availability of the resources. Principally in the case of germline editing, fairness and consent are the facets underlining very strong questions since those future generations can never give consent to inherited modifications. Moreover, diversity and inclusion are the issues that go with the possibility of disability or non-normative traits being wiped out instead of being valued, thus, these issues are at odds with human rights frameworks such as the UNCRPD. At last, human dignity is among the issues that are flouted if individuals are reduced to genetic commodities, which is the very least of respect for human uniqueness. Some scholars are of the opinion that “liberal eugenics,” which refers to a situation where market forces play a role in genetic enhancement that makes inequality to be furthered, is something that we should stay away from. Such a position of affairs calls for very strong ethical governance for the purpose of bringing technological advancement that is in harmony with values of justice and dignity.

DISABILITY RIGHTS IN INDIA'S LEGAL FRAMEWORK

The legal framework that supports disability rights in India includes both the constitutional rights and legislative provisions which are upheld by international commitments. From equality and dignity to ensuring the inclusion of people with disability, the framework tries to get rid of the idea that disabilities are something which should be corrected or removed. The emergence of gene editing, however, is in conflict with the rights-based approach as it, by default, switches back to the "medical model" of disability which considers certain lives to be less valuable or less worthy of coming into existence.

The RPwD Act[11], originally passed to bring Indian laws in line with the UNCRPD, was a clear indication of a move from the welfare paradigm to the rights one. The Act acknowledges 21 different types of disabilities and ensures that there is non-discrimination in education, employment, and public participation. More significantly, it highlights the importance of dignity, autonomy, and liberty, thus, persons with disabilities are at the same time rights holders and not beneficiaries of the care. The Act moves away from the deficit model by placing the concept of disability in social barriers-which can be physical, institutional, and attitudinal rather than individual impairment. This perspective is in opposition to the concept of gene editing which is based on the presumption that disability is a defect that needs to be genetically corrected. However, the Act might still come across issues if it gets reinterpreted in a scientific way and the challenges could be, among other things, changes in the understanding of "normal" in the genetic era.

India's Constitution emphasizes a rights-based approach. Article 14[12] defines the concept of equal opportunities and equal rights under the law. Article 19[13] gives individuals the right to autonomy and participation in the societal activities. Article 21[14], which is often referred to as the heart of the Constitution, besides ensuring the right to life and personal liberty, as has been broadly interpreted, also includes the right to dignity and bodily integrity. The courts' decisions are also supportive of this system: the Supreme Court in Vikash Kumar v. UPSC (2021)[15] has interpreted

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[11] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).
[12] INDIA CONST. art. 14
[13] INDIA CONST. art. 19
[14] INDIA CONST. art. 21
[15] Vikash Kumar v. Union Public Service Commission, (2021) 5 SCC 370

the rights of persons with disabilities in the light of dignity and substantive equality, and, in Justice K.S. Puttaswamy v. Union of India (2017)[16], it has gone so far as to confirm privacy and autonomy as the basic tenets of Article 21[17]. These concepts imply that gene-editing regulations which force people to be the same or those which consider disabled people as inferior, may be going against the constitution. At the same time, the use of genes for therapeutic purposes may be an instrument of freedom for the individuals, however, germline interferences that are aimed at excluding the birth of people with certain characteristics, are capable of derogating from dignity thus, they are the ones that violate constitutional safeguards.

One of the most significant events that revolved around the RPwD Act[18] was the ratification made by India to the UNCRPD[19] in 2007. The Convention is an international instrument which recognizes the social model of disability, and it gives priority to the values of dignity, non-discrimination, and recognition of difference. Article 3[20] points out that inclusion and respect for diversity should be the key features of guiding principles. In this context, genetic interventions for the purpose of eliminating disabilities seem to be in contradiction with the overall character of the Convention as such they represent disability as an abnormality rather than a human variation. The UNCRPD[21] requires states to take steps to eliminate stereotypes and depict the persons with disabilities as worthy members of the society. As such, India's international obligations serve as a warning against the indiscriminate use of gene-editing techniques, which could lead to the continuation of differential treatment under the pretext of medical advancement.

The debate between gene editing and the support of disabled people is a battle of conflicting philosophies. Changes in the germ line, which aim at total exclusion of disabilities, can go a long way to make the disabled people look as if they are the least desired human beings. While the Indian rights-based regime is focused on the principles of inclusive, participative, and equal access of the disabled. The center of the ethical problem shifts: does getting rid of disability give less pain

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[16] Justice K.S. Puttaswamy (Retd.) v. Union of India, (2017) 10 SCC 1
[17] INDIA CONST. art. 21
[18] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).
[19] Convention on the Rights of Persons with Disabilities, Dec. 13, 2006, 2515 U.N.T.S. 3.
[20] Convention on the Rights of Persons with Disabilities, Art. 3, Dec. 13, 2006, 2515 U.N.T.S. 3.
[21] *Ibid.*

to the world or does it simply get rid of diversity? Gene editing proponents are always saying that it gives power and freedom from disease to the individuals concerned, whereas opponents argue that this way of thinking robs disabled people of their identities and refers them to the defeated social support group. Those who stand for the rights of disabled people argue that by getting rid of certain traits, the society would be less likely to accept this group of people and would then become less obligated to provide help and support to them.

The conflict between gene-editing technologies and India's rights- based framework is not merely ethical but also doctrinally rooted. The Rights of Persons with Disabilities Act, 2016 puts into play a rights-based framework for the recognition and protection of disabled by recognising it as a product of social and structural stigma rather than an individual impairment. Gene-editing practices—specifically those which are prevalent in modification and enhancement—risk additional stigmatisation of medicalised and deficit-oriented conception of disability which the RPwD Act specifically tries to eradicate. When such genetic intervention characterises certain traits as undesirable, they undermine Section 3 of the RPwD Act[22], which mandates equality, dignity, and non-discrimination. Such practices also attract constitutional scrutiny under Article 14[23], as they create an arbitrary hierarchy of human worth, and under Article 21[24], where dignity has been recognised as an intrinsic and non-negotiable component of the right to life. Consequently, any regulatory regime that permits gene editing without explicitly safeguarding disability rights risks being constitutionally infirm and statutorily ultra vires the RPwD Act.

Hence, the stakes for India are especially high in a country where the social stigma attached to disability is still very strong even though the laws are progressive. Without proper safeguards, embracing gene editing can become a cause to the rise of discrimination and an increase in the validation of exclusionary attitudes- that is seeing disability from a rights and social justice perspective as a biological defect to be eradicated instead of a matter of rights and social justice.

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[22] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).
[23] INDIA CONST. art. 14
[24] INDIA CONST. art. 21

The strategy is to reduce the two concepts both the promise of equality in the Indian Constitution and the statutory protections guaranteed by the RPwD Act[25] are at risk.

So, the question for India is how it can take advantage of the gene therapy while still staying true to the India's rights-based legal framework which is laden with normative commitments. Without the need for distinctions in regulation, it allows some medical uses and disallows those applications that advance eugenic practices or genetic discrimination.

CURRENT LEGAL AND REGULATORY DISCOURSE ON GENE EDITING IN INDIA

Current Legal and Regulatory frameworks present in India

While worldwide discussions on gene editing are focusing more on the establishment of comprehensive ethical and legal safeguards, India's regulatory framework is still fragmented and not very developed. The current governance systems are mainly based on soft law instruments and general drug regulations, neither of which provides the necessary clarity to deal with the specific challenges of gene editing. As a result, there is a regulatory vacuum that complicates scientific innovation, weakens the rights of protection, and increases the possibility of misuse. Given below are some of the current governance systems and their shortcomings in addressing Gene editing in humans.

(i) The ICMR Guidelines: Ethical but non-binding

India’s regulatory engagement with gene editing is primarily mediated through two non-binding instruments: the *National Ethical Guidelines for Biomedical and Health Research Involving Human Participants* (2017) and the *National Guidelines for Gene Therapy Product Development and Clinical Trials* (2019). While the former works as general ethical framework applicable across biomedical research, the latter is a sector-specific instrument addressing gene therapy products. Essentially, both guidelines are advisory in nature and lack statutory force as they are not binding statutes. They do not create enforceable rights, prescribe penalties, or provide remedies in the event of non-compliance.

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[25] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).

The 2019 Gene therapy guidelines expressly ban germline editing and mandate strict oversight through committees: it's still advisory and not binding. In the absence of statutory force, violations of these guidelines cannot be punished, creating regulatory slack—particularly in privately funded or cross-border research. Hence, the structural downside is what India's framework has from jurisdictions such as the United Kingdom, where ethical limitations are embedded within binding statutory instruments rather than soft-law guidance.

(ii) The New Drugs and Clinical Trials Rules, 2019

The New Drugs and Clinical Trials Rules, 2019 (NDCTR), which comes under the Drugs and Cosmetics Act, puts gene therapy products under the head of "new drugs" which in end subjects them just to general clinical trial approval. While this classification ensures baseline safety oversight, it is comparatively inadequate for governing gene editing. The NDCTR does not distinguish between somatic and germline interventions, nor does it differentiate therapeutic applications from enhancement-oriented modifications. By not recognising fundamental categories and putting them under a single head, the Rules risk treating constitutionally unequal practices as legally equal.

This failure of classification attracts scrutiny under Article 14 of the Constitution. As established in *State of West Bengal v. Anwar Ali Sarkar*, regulatory organizations must treat unequal people differently where their consequences diverge materially. Germline gene editing—by virtue of its heritable and irreversible effects—raises unique concerns relating to dignity, intergenerational justice, and discrimination, which the NDCTR is structurally incapable of addressing. Furthermore, the application of general drug regulations to gene editing represents not Consequently, the application of general drug regulation to gene editing represents not regulatory neutrality but regulatory inadequacy.

(iii) Other Frameworks: Environmental and Biosafety Rules

Looking into other frameworks under Biotechnology oversight, two laws come into picture, one with a wider scope is based on the Environment Protection Act, 1986[26] and the other is based on the Rules for the Manufacture, Use, Import, Export, and Storage of Hazardous

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[26] Environment (Protection) Act, No. 29 of 1986, Acts of Parliament, 1986 (India).

Microorganisms/Genetically Engineered Organisms or Cells (1989)[27], usually referred to as the Biosafety Rules. The latter looks into the release of genetically modified organisms (GMOs) in India, especially in the field of agriculture, by laying down the procedures of risk assessment, security, and environmental safety.

Hence, there is existence of a biosafety framework in India, but it does not cover human gene editing, and it is actually highly risky to use agricultural biosafety rules in human genetics, as it can open a Pandora's box of issues that come up with it. Most importantly, these rules do not have a place for human rights- based framework for the participants, thereby issues regarding human dignity and right to self-determination remain unprotected in this area of Biomedicine.

(iv) The Digital Personal Data Protection Act, 2023

The Digital Personal Data Protection Act, 2023, establishes a consent-based framework for the collection and processing of personal data. While the Act does not explicitly classify genetic data as a distinct category of sensitive personal data, its broad definition of "personal data" under Section 2(t), read with the Supreme Court's recognition of genetic information as integral to decisional privacy in *Justice K.S. Puttaswamy v. Union of India*, allows genetic data to be implicitly protected within its scope.

However, this protection remains informational rather than substantive. The DPDP Act governs the processing of data but does not regulate the biological manipulation of genetic material itself. Nor does it prohibit the discriminatory use of genetic information in employment, insurance, or reproductive decision-making. As a result, while the Act may prevent unauthorised data breaches, it is ill-equipped to address genetic determinism or structural discrimination arising from lawful but unethical uses of genetic data. This regulatory gap underscores the need for sector-specific legislation that supplements data protection with enforceable anti-discrimination norms.

Regulatory Gaps Identified

Hence, within these frameworks, the main issues identified are:

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[27] Rules for the Manufacture, Use, Import, Export and Storage of Hazardous Microorganisms/Genetically Engineered Organisms or Cells, S.O. 592(E), Gazette of India (1989) (India).

- **Therapy and enhancement confusion**: Both NDCTR and ICMR rules do not differentiate between therapeutic interventions that are allowed (for example, treatment of monogenic diseases) and those that are forbidden, germline or enhancement-driven modifications.
- **Lack of representation of disability rights voices**: The composition of oversight bodies like GTAEC does not include members of the disability rights groups. These groups could provide a unique view of the risks/opportunities related to the misuse of eugenics.
- **The ethical norms that are non-binding**: In contrast to the UK, India has not made ethics guidelines for genome research part of the law. Instead, they remain unenforceable.
- **The lack of punishment schemes that are specifically aimed**: Although some penal provisions under the Drugs and Cosmetics Act or the Environment Protection Act can be invoked, none are specifically directed at gene editing misconduct, thereby allowing regulatory gaps and arbitrage to be exploited, particularly by private or cross-border projects.

Towards a Regulatory Reckoning

The disparate combination of guidelines, general drug laws, and biosafety frameworks is a portrayal of the way India's response to gene editing is cautious but not fully developed. By not codifying binding rules, India may be putting the researchers into a regulatory limbo while at the same time providing inadequate protection for the vulnerable groups, especially the disabled. Without the implementation of clear statutory provisions, the future of gene editing may be moving forward without control and thus producing the results that contradict India's rights-based commitments under the RPwD Act and the UNCRPD.

COMPARATIVE PERSPECTIVES AND CASE STUDIES

The United Kingdom: Statutory Clarity

Often, the UK is mentioned as one of the countries with a well-built legal frame that maintains the Human Fertilisation and Embryology Act (HFEA), 1990[28], and the last Amendment of 2008 as its base. This Act grants the Human Fertilisation and Embryology Authority the power to authorize under the strict rules stipulated in the legislation, for example, a 14-day limit of development and

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[28] Human Fertilisation and Embryology Act 2008, c. 22 (UK).

prohibition of complete reproductive use of the changed embryos. It, In 2016 sanctioned the very first genome editing technique in human embryos strictly for early development research. Statutory clarity like this shows how the law can promote scientific development, and at the same time keep it from the use of degradation or enhancement. The UK licensing pattern can be a legislative reference point that India may borrow from.

The United States: Fragmented Oversight

Regulatory decisions in the U.S. are carried out by various agencies, the primary ones being the Food and Drug Administration (FDA), Congress, and the National Institutes of Health (NIH). Gene therapy for somatic cells is regulated as a drug or biologic and requires extensive clinical approvals. At the same time, Congress has banned the FDA from authorizing germline therapies, while the NIH disallows federal funding for embryo editing. Loose supervision surrounds privately financed research, resulting in regulatory inconsistency.

The American model serves as a reminder of how important it is to separate therapeutic somatic interventions from illegal germline practices. Simultaneously, it shows the dangers that come without a cohesive statutory framework in the form of fragmentation of oversight.

China: The He Jiankui Scandal

The Chinese fiasco of gene editing mismanagement was revealed when He Jiankui, a scientist, genetically edited twins for birth in 2018, and thus, the international community responded with vehement criticism. At that time, China was guided mostly by recommendations rather than strict laws, which in turn allowed such conduct by He Jiankui. In reply, the government beefed up the stringency of rules regulated by the Civil Code (2020) and the related Decree with the implementation of criminal liability for unauthorized embryo editing and provisions for punishments like that of Jiankui, who got a 3-year jail term.

This case is a reminder in the context of India that, without enforceable law, even if guidelines exist, they are powerless in halting unethical or rogue experiments.

Lessons for India

Comparative analysis demonstrates that effective gene-editing governance depends less on ethical consensus and more on institutional design. The United Kingdom’s Human Fertilisation and

Embryology Authority (HFEA)[29] illustrates how ethical limits can be translated into enforceable legal standards through licensing, monitoring, and criminal cautions. Unlike India’s advisory ICMR regime, the HFEA exercises ex ante scrutiny over permissible research and retains the authority to suspend licences and impose penalties.

China’s post–He Jiankui reforms further demonstrate that ethical guidelines without statutory backing are insufficient deterrents. Only after the introduction of criminal liability did effective compliance emerge. These models collectively underscore that India’s reliance on soft law is structurally incapable of preventing rogue experimentation or market-driven eugenic practices. A binding statutory authority, rather than ethical persuasion, is therefore indispensable.

Indian Case Law Context

India hasn't faced a gene editing scandal, but the constitutional approach to rights-based governance goes in line with it. The Supreme Court, in *Justice K.S. Puttaswamy v. Union of India (2017)*[30], accepted privacy, also that of genetic data, as a fundamental right. Equality and dignity for the disabled were brought out in *Vikash Kumar v. UPSC (2021)*[31], while *Suchita Srivastava v. Chandigarh Administration (2009)*[32] was the first case to identify reproductive autonomy and bodily integrity. These court rulings reveal the inclination of India to base the future gene-editing law on the constitutional principles of dignity, autonomy, and equality.

ETHICAL AND SOCIAL DILEMMAS OF GENE EDITING

With gene editing comes the promise of revolution in the healing of mankind which in its essence is accompanied by some serious social and ethical dilemmas. These dilemmas in any way, do not stay confined within the walls of laboratories but encompass a wide spectrum of issues ranging from rights to human dignity besides the composition of the society itself. In India where the legal rules are so much unstable, it is a mandatory task for the country to, first of all, recognize these difficulties and then to make sure that they do not break the country’s constitutional or human rights commitments while still progressing with the technology.

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[29] Human Fertilisation and Embryology Act 2008, c. 22 (UK).
[30] Justice K.S. Puttaswamy (Retd.) v. Union of India, (2017) 10 SCC 1.
[31] Vikash Kumar v. Union Public Service Commission, (2021) 5 SCC 370.
[32] *Suchita Srivastava v. Chandigarh Admin.*, (2009) 9 SCC 1 (India).

Eugenics Fears and Disability Rights

One fear that is as dark as the others is the fear for the reappearance of eugenic thought. Eugenics in the middle of the previous century was a typical state-driven one, while now "liberal eugenics" of the present time may be propelled by the parents or the society's desire to have a child with the traits like intelligence, ability, or physical characteristics. The new narrative is disturbing as it might depict disability as the least desirable thing, thereby disallowing accessibility, inclusion, and accommodations to be funded. These trends in rights enforcement threaten the extremely rights-based provisions of the Persons with Disabilities Rights Act, 2016[33] (RPwD Act) as well as the UNCRPD, that both emphasize dignity, diversity, and equality. The practice of gene editing that makes disability prevention a norm instead of social support is likely to discriminate against the disabled community further and at the same time constitutional protections will be lost.

Autonomy, Consent, and Intergenerational Justice

Somatic gene therapy gives an option for individual patients to consent and hence their autonomy is maintained. On the other hand, germline editing changes embryos or reproductive cells which means that future individuals will not be able to consent to the irrevocable modifications that alter their lives and those of their descendants. Therefore, the issue of intergenerational justice is raised. Indian constitutional jurisprudence, most notably Suchita Srivastava v. Chandigarh Administration (2009)[34] and Puttaswamy v. Union of India[35] (2017), has acknowledged that autonomy and bodily integrity are fundamental rights. These principles are contradicted by germline interventions because without consent, those most affected are denied the ability to make the changes in their lives and future generations.

Risks of Genetic Discrimination

Genetic data opens new avenues for discrimination in employment and insurance. Employers can take advantage of genetic profiling to weed out candidates that are prone to diseases and thus violate the principle of equal opportunities and encourage social segregation. Companies providing insurance might do one of two things; either they could raise the rates or deny the coverage of

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[33] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).
[34] Suchita Srivastava v. Chandigarh Admin., (2009) 9 SCC 1 (India).
[35] Justice K.S. Puttaswamy (Retd.) v. Union of India, (2017) 10 SCC 1.

people who are genetically predisposed to certain diseases creating a two-tier system that puts vulnerable groups at a further disadvantage. These kinds of activities will result in a direct clash with Article 14 and will lessen the effect of the RPwD Act in terms of protecting the disabled. Without reliable legal protection, genetic determinism may even become a factor that solidifies socio-economic inequality.

Genetic Discrimination: Concrete Risks to Persons with Disabilities

The absence of explicit prohibitions on genetic discrimination creates tangible risks for persons with disabilities and those genetically predisposed to disability. Employers may indirectly screen candidates based on genetic susceptibility to future impairments, while insurers may deny coverage or impose higher premiums based on probabilistic genetic assessments. Such practices, though technologically mediated, constitute indirect discrimination under Section 3 of the RPwD Act when genetic predisposition is treated as a proxy for disability.

These scenarios are not speculative. Disability advocacy reports consistently document coercive reproductive counselling and social pressure to avoid the birth of children with perceived impairments. In the absence of statutory safeguards, gene editing risks becoming a tool through which structural ableism is biologically entrenched rather than socially dismantled.

Privacy and Data Protection

Genetic data is among the most confidential types of personal data that even single out an individual and it can be very helpful in predicting health risks of the future. In Puttaswamy (2017), the Supreme Court declared that the right to privacy is a fundamental right and that the mishandling of genetic data is undoubtedly a breach of dignity and autonomy under Article 21. The Digital Personal Data Protection Act, 2023[36] (DPDP) considers DNA as sensitive personal data, and it, therefore, requires consent for its use and storage. In this way, there is a certain level of security against unauthorized access and exploitation.

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[36] Digital Personal Data Protection Act, No. 3 of 2023, Acts of Parliament, 2023 (India).

Limits of the DPDP Act

On the other hand, the DPDP Act[37] faces a lot of challenges despite its major role. The Act mainly focuses on regulating data processing, while it is not the case for the biological manipulation of genes. It neither stops genetic discrimination in the workplace or insurance nor does it allow a clear distinction between therapeutic and enhancement or eugenic applications. Therefore, the informational safeguards provided by the Act are unable to handle the larger social misuse or the ethical concerns of germline interventions.

TOWARDS A RIGHTS-BASED LEGAL FRAMEWORK

The challenges from gene editing in India require not only tight regulations but also the movement towards a broad rights-based legal framework. A legal framework such as this must combine the healing potential of genome editing with the constitutional rights protection of equality, dignity, and autonomy, all the while infusing the perspectives of disability rights. It should go beyond the existing disintegrated guidelines into something more binding–a statutory regime that distinctly spells out those interventions that are allowed and forbids any that are driven by enhancement or discrimination.

India's gene editing rights-based framework should be based on four interdependent components that are also the fundamental human rights: dignity, non-discrimination, accessibility, and autonomy. Dignity would require that acknowledgment be made of every life’s basic necessity, including the lives of disabled people, without using terms that show them as the ones whose lives have to be "fixed." While non-discrimination would mean that gene editing is done in such a manner that it is not used for creating genetic determinism or for excluding the disabled in the field of employment, medical care, and education. Accessibility would stress that health-related interventions should be equally accessible so that they are not concentrated only among the privileged groups. Autonomy would ensure that a person's right to be fully informed of somatic therapies is respected while at the same time also taking into account the issue of intergenerational justice in cases of germline interventions. These principles could not only lead the way in the enactment but also in the practical application of India’s legal design on gene editing.

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[37] *ibid.*

In order to put these principles into practice, safeguards are very important. A total prohibition on enhancement-oriented germline editing, which would particularly be performed on traits like intelligence and physical ability, could effectively stop the process from moving to eugenics and be in line with international standards that separate therapy from enhancement. The creation of a National Authority for Gene Editing and Advanced Biomedicine by means of parliamentary law could be quite beneficial for a regulatory body with powers similar to the UK's Human Fertilisation and Embryology Authority, thus it could function beyond the limited scope of ICMR guidelines. It is mandatory that the independent oversight boards have, among others, representatives of the disability rights movements as well as the civil society so that there is governance that is not only inclusive but is also integrative concerning rights issues in ethical decision-making. In addition, policymaking may adopt public consultation and transparency as integral features, which may be realized by the help of stakeholder hearings, consultations, and open reporting mechanisms, that can facilitate democratic legitimacy and trust as well as prevent the occurrence of exclusion of marginalized groups.

Such a system should also reflect upon the already existing Indian laws as the base platform from which adaptations in governance policies can be made. The RPwD Act, 2016[38] lays the groundwork for the principles of dignity, inclusion, and non-discrimination as the basic aspects of ethics in gene editing. The DPDP Act, 2023[39] also treats genetic data as sensitive personal information related to which appropriate safeguards can be provided to prevent discriminatory use. The New Drugs and Clinical Trials Rules (NDCTR), 2019[40] had already been regulating human clinical trials however, some specific parts on gene editing would be required to separate those treatments which are allowed from those that are prohibited. Apart from that, it is through Articles 14, 19, and 21, rights to equality, liberty, dignity, and autonomy, that constitutional guarantees can form the basis of regulatory mechanisms and provide the power for judicial review to make sure these are reflected in force.

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[38] The Rights of Persons with Disabilities Act, 2016, Act No. 49 of 2016 (India).

[39] Digital Personal Data Protection Act, No. 3 of 2023, Acts of Parliament, 2023 (India).

[40] Ministry of Health & Family Welfare, New Drugs and Clinical Trial Rules, Gazette of India, G.S.R. 227(E) (Mar. 19, 2019), https://cdsco.gov.in/opencms/resources/UploadCDSCOWeb/2018/UploadGazetteNotificationFiles/NewDrugsClinicalTrialsRules2019.pdf

Being in tune with the rest of the world is not only a source of guidance but also of legitimacy. The World Health Organization has suggested that no human germline editing should be performed until issues regarding its safety and ethics have been sorted out and this recommendation has been supported by calls for global governance frameworks. The UNESCO Universal Declaration on the Human Genome and Human Rights (1997)[41] policy is one that emphasizes the genome as the "heritage of the planet" and it also cautions against any kind of conduct that may be considered a violation of dignity. In the same vein, the UNCRPD sees the possibility of disability perspectives being embedded into bioethical decision-making, creating an opportunity for India to portray itself as an inclusive leader in global governance.

India can strengthen the rights-based ecosystem of gene editing by skillfully merging the international best practices with the country's constitutional and statutory framework. This manner would be an ethical one that promotes inclusivity and gains both global credibility as well as local trust.

RECOMMENDATIONS AND POLICY SUGGESTIONS

The comparative, doctrinal, and ethical analysis shows that the current regulatory patchwork in India is not up to the task of handling the specific challenges of gene editing. To avoid the occurrence of regulatory gaps as well as violations of rights, India must take the initiative to establish a uniform and practicable framework. The following recommendations result:

(i) Enact a Comprehensive Human Gene Editing Regulation Act

A stand-alone legislation that directly explains the human gene editing procedures should be passed by the Parliament. Such an Act must discuss the therapeutic interventions that can be allowed as well as the modifications that lead to the improvement of the human germline and that are forbidden. Besides stating the prohibitions to enhancement, it should also open the door to therapeutic research with strict safety measures in place.

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[41] Universal Declaration on the Human Genome and Human Rights, Nov. 11, 1997, 36 I.L.M. 1412.

(ii) Establish a National Bioethics and Gene Editing Authority

Considering its features as the Human Fertilisation and Embryology Authority in the UK, this institution should not only be empowered legally to license, supervise, and regulate all gene editing research and requests but also to perform all these activities in a transparent manner, publish public reports and take decisions that are obligatory for compliance, unlike the present advisory role of the ICMR.

(iii) Mandate the Inclusion of Disability Rights Advocates

The persons with disabilities and representatives of disability rights organizations should be included in any policymaking or ethical review board. It would take into account India's obligations under the RPwD Act and UNCRPD by integrating the lived experiences and rights perspectives into the governance structures, thus preventing technocratic drift towards eugenic practices.

(iv) Tighten Data Protection for Genetic Information

The 2023 Digital Personal Data Protection Act should be adjusted not only to ban the misuse of genetic data but also the discriminatory use of the data in the labor market, the insurance market, and other socio-economic fields. A change of the DPDP Act to have anti-discrimination provisions directly linked to genetic information would bring this goal to fruition.

(v) Create Legal Safeguards Against Genetic Discrimination

Like the model of U.S. Genetic Information Nondiscrimination Act (GINA, 2008), India could prohibit employers and organisations providing insurance from using genetic information as the basis for the making of exclusionary decisions. This legislation would be the source of reinforcing the equality principle under Article 14 and putting into practice the dignity right under Article 21.

(vi) Promote International Cooperation with Local Adaptation

India should be keen to member in the international concerted actions sponsored by such organizations as the WHO, UNESCO, and UN disability rights mechanisms that aim at setting up universally acceptable norms related to gene editing. Still, establishing these world-wide regulations need to consider India’s socio-legal issues, especially the deep-rooted prejudice against disability and the unequal distribution of the healthcare resources. India will then not only be recognized as a leader in rights-based bioethics but will also have the chance of being a loyal follower of Western norms.

These recommendations together offer a path from India's disjointed legislation to one which is holistic that recognizes both scientific innovation as well as fundamental rights.

CONCLUSION

This paper argues that India must decisively reject a market-driven, enhancement-oriented model of gene editing and instead adopt a constitutionally anchored, disability-inclusive regulatory framework. The absence of binding statutory safeguards does not represent regulatory neutrality but constitutes tacit endorsement of genetic determinism—an outcome fundamentally incompatible with Articles 14 and 21 of the Constitution and the Rights of Persons with Disabilities Act, 2016.

While somatic gene editing aimed at treating serious diseases may be reconciled with constitutional values through informed consent and proportional regulation, germline and enhancement-driven interventions raise irreconcilable concerns relating to dignity, intergenerational justice, and discrimination. These practices cannot be legitimised through advisory guidelines or general drug regulation. They require explicit legislative prohibition.

India therefore requires a dedicated Gene Editing Regulation Act establishing a statutory authority empowered to license research, impose penalties, prohibit enhancement-oriented applications, and incorporate disability rights representation into decision-making. Judicial review must remain available to ensure that scientific advancement does not eclipse constitutional morality. Only through such a framework can India reconcile innovation with its rights-based disability regime and emerge as a principled leader in global bioethical governance.