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Before We Forget its Horrors: When Does Human Genome Editing Not Become Eugenics?

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Abstract

Biomedical advances in genomics, particularly the sequencing of the human genome and the subsequent development of a very versatile human genome editing (HGE) tool – the CRISPR Cas9 – have deepened concerns of many over possible eugenic abuses in the deployment of the technology in clinical settings. This is not surprising considering the ignominious history associated with the eugenic movement of the past. This article, using a human-rights focused and theoretical approach, contests the arguments and counter arguments for and against the eugenic goals of HGE, particularly concerning human germline genome editing (HGGE). In doing this, it interspersed the discourse with particularized African perspectives on eugenics and HGE. The article, after establishing the claim of the pursuit of eugenic goals regarding HGGE, goes ahead to offer five suggestions on the implications of these for the design of appropriate legal and regulatory frameworks in response. Foundational is the recognition that law should promote and not stifle innovation. Law, however, should be based on "good science" backed with ascertainable scientific and clinical evidence, not pseudoscience. Likewise, an appropriate legal and regulatory response should consolidate and advance basic human rights including the rights of people living with disability.

Keywords:

Eugenics, genome editing, human rights, legal framework, African perspectives

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Contents

1. Introduction

Although scientific interest in genetic research has been ongoing for some time, recent developments have particularly piqued global interest in human genome editing (HGE). These are the complete sequencing of the human genome,[1] the development of gene editing tools especially the Clustered Regularly Interspaced Short Palindromic Repeats (CRISPR-Cas9)[2] editing technology and its employment by a Chinese scientist, He Jiankui, to edit the genetic traits of two children. In particular, there are deep concerns of critics over the implied pursuit of eugenic goals in HGE. Primary in these concerns, perhaps, is the possibility and the danger of the society slipping into the

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Acronyms

DNA	Deoxyribonucleic acid
HGE	Human genome editing
HGGE	Human germline genome editing

[1] Lewis Vaughn (2017). *Bioethics: Principles, Issues, and Cases*, (Oxford University Press, New York) p. 539.

[2] As Montoya puts it "CRISPR's operation is best understood by breaking it into two components. 'CRISPR' is a short DNA sequence that provides a code to, and then works in tandem with, RNA to guide and detect specific sequences in the genome. Essentially, CRISPR provides a roadmap that instructs a molecule on how to get to its ultimate destination. 'Cas9' refers to the protein that cuts the desired DNA site. These Cas9 proteins virtually function like a pair of molecular scissors that cleave the targeted locations in the genome. Although seemingly similar to some of its more recent predecessors, CRISPR is superior in numerous ways." See Fernando Montoya (2020). "Intergenerational Control: Why Genetic Modification of Embryos via CRISPRCas9 is Not a Fundamental Parental Right" 69(3) *American University Law Review*, 1015, p. 1023 https://digitalcommons.wcl.american.edu/aulr/vol69/iss3/6 (Last accessed, 10 April 2023).

unwholesome eugenic practices of the past in the near future unless social, legal and regulatory efforts are made to checkmate this.[3]

Now, HGE primarily seeks to modify the DNA of a person's somatic (non-reproductive) cells or of a person's germline (reproductive) cells.[4] The former targets the treatment of diseases in actual patients while the latter targets the removal of undesired genetic traits to prevent the passing on of same down the generational line.[5]

The question therefore is whether or not HGE would amount to atrocious eugenic practices?[6] Arguments and counter arguments here revolve around issues concerning a coercive or voluntary legal and regulatory regime, concepts of normality and abnormality, possible increased inequalities, commodification of the human body, ableist ideology, and intergenerational justice.[7] But, is everything about eugenics bad news? Are the concerns of critics not currently met by the position of liberal eugenicists with focus on voluntary individual choices as opposed to forced choices imposed on the populace?

This article, using a human-rights focused and theoretical approach, appraises these concerns and others in determining the extent to which HGE

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[3] Marius Turda (2022). "Legacies of Eugenics: Confronting the Past, forging a Future" 45(13) *Ethnic and Racial Studies* 2470 https://doi.org/10.1080/01419870.2022.2095222 (Last accessed, 10 April 2023).

[4] Niall Coghlan (2022). "Heritable Human Genome Editing: The Bioethical battle for the Basis and future of Human Rights" *Implications Philosophiques* https://hdl.handle.net/1814/74509 (Last accessed, 28 April 2023).

[5] Dorota Krekora-Zając (2020), "Civil Liability for Damages related to Germline and Embryo Editing against the Legal Admissibility of Gene Editing" 6(30) *Palgrave Communications* https://doi.org/10.1057/s41599-020-0399-2 (Last accessed, 28 April 2023); David Lorenzo *et al* (2022), "Ethics and Genomic Editing Using the Crispr-Cas9 Technique: Challenges and Conflicts" 16 *Nanoethics* 313, p. 315 https://doi.org/10.1007/s11569-022-00425-y (Last accessed, 31 December 2023); Merel M Spaander (2022), "The European Court of Human Rights and the Emergence of Human Germline Genome Editing: 'The Right to Life' and 'the Right to (Artificial) Procreation" 29 *European Journal of Health Law* 458.

[6] Felipe E Vizcarrondo (2014). "Human Enhancement: The New Eugenics" 81(3) *The Linacre Quarterly* 239.

[7] *See* Arthur L Caplan, Glenn McGee & David Magnus (1999), "What is Immoral about Eugenics?" 319 *British Medical Journal* 1284; Katherine Drabiak (2020), "The Nuffield Council's Green Light for Genome Editing Human Embryos defies Fundamental Human Rights Law" 34(3) *Bioethics* 223; Andrea Boggio & Rumiana Yotova (2021), "Gene Editing of Human Embryos is not contrary to Human Rights Law: A Reply to Drabiak" 35(9) *Bioethics* 956.

may amount to obnoxious eugenic practices. This is done with a view to outlining some suggestions which may underlie subsequent legal policies and interventions in this interesting area of biomedical advancement.

It is observed that eugenics may not actually be an implicitly evil concept or desire as virtually all parents from different cultures of the world desire the 'good birth' goal of eugenics. This is evident even from African perspectives, where in indigenous communities, eugenic concerns seem to be implicit in the diligent investigations undertaken by families of prospective couples into family traits including history of any illnesses before allowing their children to enter prospective marital unions.

The real deal therefore lies in the adoption of an appropriate legal and regulatory framework for medical procedures involving HGE. Such a framework is one that should among others recognize the basic societal needs to advance and not stifle innovations, prevent the society from ever descending into the atrocious abyss of the past, and ensure that law is based on good science backed with credible scientific and clinical evidence, and not pseudoscience.

To this end, the next section deals with the concept of eugenics and its historical fallacies, and Section 3 examines the wonders of genome editing. The fourth section evaluates the pro and con arguments against somatic and germline HGE in view of the eugenic fault line while in the fifth section, an attempt is made to answer the question whether eugenics is bad news in every respect of its connotation.. In the sixth section, some suggestions are offered on possible directions for the design of an appropriate legal and regulatory framework towards the present or foreseeable future deployment of HGE technology. The seventh section contains the conclusion.

2. Eugenics – what went wrong?

Eugenics is an ancient concept[8] traceable at least to the time of Plato who in his *Republic* advocated for governmental regulation of reproduction to strengthen the guardian class.[9] Plato believes that the practice of selective

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[8] *See* Charlotte Chaulin (2020), "Improving the Human Species: Eugenics in Europe, Nineteenth–Twentieth Century" *Encyclopédie d'histoire numérique de l'Europe* https://ehne.fr/en/node/12517 (Last accessed, on 10 April 2023).

[9] Inmaculada de Melo-Martin & Sara Goering (2022). "Eugenics" in Edward N. Zalta ed., *The Stanford Encyclopedia of Philosophy* (Summer 2022 Edition) https://plato.stanford.edu/archives/sum2022/entries/eugenics/ (Last accessed, 09 March 2023). Plato had "proposed the establishment of an additional class of citizens, the guardians who are responsible for management of the society itself. In fact, Plato

breeding in animals ought also to be replicated for human beings.[10] Modern eugenics, flowing from Darwinism, is a bio-social ideology advancing the deliberate manipulation of biological factors towards the creation of a race of people possessing desirable traits, in the process, eliminating those with traits considered inferior or undesirable.[11] It etymologically means "good birth" or "well born" as derived from the Greek words *eu* meaning "good" and *genes* meaning "birth".[12]

As a modern term, the word eugenics is said to have been coined by Francis Galton, a cousin of Charles Darwin, in 1883.[13] He initially describes it as the scientific endeavor towards giving "the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable than they otherwise would have had."[14] He later refined his definition, conceiving eugenics as "the science which deals with all influences that improve the inborn quality of a race; also with those that develop them to the utmost advantage."[15] Eugenics, in this sense, is of two strands. First is *positive eugenics* which advocates societal encouragement of breeding of people who

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held that effective social life requires guardians of two distinct sorts: there must be both soldiers whose function is to defend the state against external enemies and to enforce its laws, and rulers who resolve disagreements among citizens and make decisions about public policy. The guardians collectively, then, are those individuals whose special craft is just the task of governance itself." See Philosophy Pages. "Plato: The State and the Soul" http://www.philosophypages.com/hy/2g.htm (Last accessed, 01 April 2023).

[10] See Samantha Schexnayder (2021), "Eugenics in the United States: The Forgotten Movement" 5 *Chênière: The Nicholls Undergraduate Humanities Review* https://www.nicholls.edu/cheniere/2021/05/20/eugenics-in-the-united-states-the-forgotten-movement/ (Last accessed, 6 February 2023). See also Robert A Wilson (2018). "Eugenics never went away" (5 June 2018) https://aeon.co/essays/eugenics-today-where-eugenic-sterilisation-continues-now (Last accessed, 6 February 2023).

[11] Ibid.

[12] Henk ten Have & Maria do Céu Patrão Neves (2021). *Dictionary of Global Bioethics* (Springer 2021) p. 487.

[13] See David N. Whitney (2019). *Maladies of Modernity: Scientism and the Deformation of Political Order* (St. Augustine's Press) p. 107.

[14] Francis Galton (1907). *Inquiries into Human Faculty and its Development* (2nd edn, J.M. Dent & Co.) (1883) p. 17 http://galton.org/books/human-faculty/text/galton-1883-humanfaculty-v4.pdf (Last accessed, 23 April 2023).

[15] Francis Galton (1904). "Eugenics: Its Definition, Scope, and Aims" 10 *American Journal of Sociology* 1.

possess desirable traits. Second, is *negative eugenics* which discourages the breeding among those who lack these desired traits.[16]

Eugenics is thus an idea (in idealism) of striving for the perfection of desirable traits in the population. In practice however, eugenics has in the past translated into highly obnoxious policies such as forced incarceration, sterilizations and even murder of countless numbers of people lumped up in various categories such as "the feebleminded, the pauper class, alcoholics, criminals, epileptics, the insane, the constitutionally weak class, those predisposed to specific diseases, the deformed, and those with defective organs such as the blind, deaf, and mute."[17]

Driven by a false scientific premise that virtually all biological and behavioral traits are inherited, eugenics became a dangerous concept which targeted the weak, poor, physically challenged people and those suffering from mental illnesses. It also became a gender and racial biased tool used to unfairly target women and racial minorities.[18] Drawing from Darwin's thesis on "evolution and natural selection",[19] eugenics, in the early 20th century, became a popular social and pseudoscientific movement in countries such as Germany, Great Britain, the Scandinavian countries and the United States. It was widely supported and advocated by supposedly good intentioned people including politicians, policy makers, and scientists across the ideological spectrum despite its "racist, sexist, ableist, xenophobic, and classist" undertones.[20]

2.1 Eugenics in the United States

Positive eugenics in the United States, took the form of programs such as the "Fitter Family Fairs" where families participated in local fairs, competing for prizes "much in the way that livestock is judged for conformation and physical

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[16] *See* Bret D Asbury (2015). "Backdoor to Eugenics? The Risks of Prenatal Diagnosis for Poor, Black Women" 23(1) *Duke Journal of Gender Law & Policy* pp. 4-5.

[17] Schexnayder (*supra* note 10). See for example, The Eugenical Sterilization Act, Act of Mar. 20, 1924, ch. 394, 1924 Va. Acts 569 (repealed 1974) and Racial Integrity Act, 1924.

[18] Galton had in 1865 outlandishly claimed that "[T]alent is transmitted by inheritance in a very remarkable degree." See Francis Galton (1865). "Hereditary Talent and Character" 12 *Macmillan's* Magazine p. 157 http://galton.org/essays/1860-1869/galton-1865-hereditary-talent.pdf. (Last accessed, 23 April 2023).

[19] Asbury, *supra* note 16, p. 4.

[20] Melo-Martin & Goering, *supra* note 9.

dexterity."[21] Forced sterilizations of women in particular formed the crux of the negative eugenics leg.[22]

The state of Indiana became the first to enact the world's first eugenics law under which state-run institutions could involuntarily sterilize individuals where a decision has been made that they are unfit to reproduce due to physical or mental illnesses.[23] Eventually, 31 other states enacted "eugenic-sterilization laws during the twentieth century, and between sixty and seventy thousand people were sterilized under them."[24] The unfortunate peak of the eugenic movement in the United States was perhaps observed in the Supreme Court's decision in *Buck v Bell*,[25] which validated the involuntary sterilization of a "feebleminded" woman as not being inconsistent with the Constitution.[26] In this case, Justice Oliver Wendell Holmes had infamously declared his "three generations of imbecile are enough" statement:

> We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime,

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[21] Ibid.

[22] Eugenic policies in the United States "disproportionately targeted Latinxs, Native Americans, African Americans, poor whites and people with disabilities during the entirety of the 20th century." See "Fact Sheet: Eugenics and Scientific Racism" (18 May 2022) https://www.genome.gov/about-genomics/fact-sheets/Eugenics-and-Scientific-Racism (Last accessed, 10 April 2023).

[23] JT Eberl (2022). "Enhancement Technologies and Children" in Nico Nortjé & Johan C Bester, eds, *Pediatric Ethics: Theory and Practice* (Springer) p. 333.

[24] See Charles P Kendregan (1966). "Sixty Years of Compulsory Eugenic Sterilization: Three Generations of Imbeciles and the Constitution of the United States" 43 *Chicago-Kent Law Review* 123; Andrea DenHoed (2016). "The Forgotten Lessons of the American Eugenics Movement" *The New Yorker* (April 27, 2016) https://www.newyorker.com/books/page-turner/the-forgotten-lessons-of-the-american-eugenics-movement (Last accessed, 6 February 2023).

[25] 274 U.S. 200, 208 (1927); compare with the 1942 Supreme Court's decision in *Skinner v Oklahoma*, 316 U.S. 535, 62 Sup. Ct. 1110 (1942) which declared the Oklahoma's sterilization statute as being inconsistent with the constitutional guarantee of equality of protection.

[26] It is perhaps a most unfortunate decision as subsequent discovery holds that Carrie Buck possessed no genetic defect as contained in the text of the Virginia Historic marker commemorating the *Buck* case, *supra* note 25. See PA Lombardo (2003). "Taking Eugenics Seriously: Three Generations of ??? are Enough?" 30 *Florida State University Law Review* 191, p. 200.

> or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.[27]

2.2 Eugenics in Germany

Eugenic practices were not a distinctly US thing alone as other countries equally had their fair share of forced incarceration and sterilizations towards the attainment of eugenic goals.[28] The Nazi regime in Germany however took eugenics[29] to a more extreme level by its pursuit of the realization of a pure Aryan race[30] under which hundreds of thousands of Germans were either sterilized[31] or murdered.[32] Particularly targeted were Jews, Gypsies, homosexuals, and individuals with physical and mental handicaps."[33]

Hitler had in 1933 passed a law[34] which mandated "forced sterilization of any individual believed to be suffering from a genetic disorder such as congenital imbecility, schizophrenia, epilepsy, hereditary blindness, serious congenital deformities, or chronic alcoholism." Eventually, the Nazi regime concluded forced sterilization insufficient and in 1939, Hitler initiated the Aktion T4 program which gave legal backing to the involuntary euthanasia (murder) of deviants, handicapped, mentally ill persons and others considered unfit to live. The turning point came with the use of gas chambers and eventual genocide of six million Jews,[35] and murder of 75,000 disabled Aryans

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[27] Buck, *supra* note 25 p. 207 (internal citations omitted). See also Kendregan, *supra* note 24.

[28] See for example the Alberta Sexual Sterilization Act, 1928 (Canada) which is said to have been actively used until its repeal in 1972. See also Wilson, *supra* note10.

[29] Or "racial hygiene" in the German context.

[30] Germany in 1936 had launched *Lebensborn*, a programme "designed to promote the birth of Aryan children." See Chaulin, *supra* note 8.

[31] Eugenics as state policy in Germany is also believed to have led to the enactment of the Marital Hygiene Law in 1933. Under the legislation, healthy German Aryans must not go into marriage with anyone considered as possessing "diseased, inferior, or dangerous genetic material". See "Eugenics" https://encyclopedia.ushmm.org/content/en/article/eugenics (Last accessed, 6 February 2023).

[32] According to Asbury, "400,000 'pure-blooded' Germans were categorized as genetically defective and were sterilized". See Asbury, *supra* note 16 p. 7.

[33] Chaulin, *supra* note 8.

[34] The Law for the Prevention of Genetically Diseased Progeny 1933 (Germany).

[35] Chaulin, *supra* note 8.

considered undeserving of continuous medical care in institutions such as sanatoria, nursing homes, and hospitals.[36]

2.3 Post Nazis' Atrocities

Flowing from the above atrocities of the Nazis, post-World War II, from 1945 onwards, eugenics became discredited and nations made serious efforts to distance themselves from it. Did eugenic movements and practices die out? It is interesting that the simple answer is no. Instead, many eugenic societies or associations simply modified their names, erasing any association with the term but not necessarily with its essence or goals. For instance, the American Eugenics Society became the Society for the Study of Social Biology[37] while the British Eugenics Education Society (EES) became the Galton Institute in 1989 which in 2021 in turn became the Adelphi Genetics Forum.[38]

Indeed, many today are of the opinion that eugenics never went away. That, it has instead been reformed to take more subtle forms of human enhancement endeavors such as "family balancing" evidenced in the use of preimplantation genetic diagnosis (PGD) or any other form of selective breeding to predetermine the sex of one's baby or the genetic manipulation of an embryo towards the attainment of desired physical and other features. Here lies the concern with whether the development and clinical use of HGE might in the short or long run amount to eugenics. But, first, what is HGE?

3. The Wonders of Human Genome Editing

The battle against diseases and for the advancement of the human life has been ongoing since immemorial times. No parent naturally desires a condition which subjects their child to physical or mental miseries and medical advances have been made to meet such needs making life worth living for many who otherwise would have found it tiresome. Yet, countless number of children are born every day with complicated health challenges,[39] especially those suffering from genetic abnormalities.[40] Among such genetic abnormalities are "autosomal dominant conditions, including the late onset and always fatal

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[36] Asbury, *supra* note 16 p. 7.

[37] Melo-Martin & Goering (*supra* note 9).

[38] https://adelphigenetics.org/history (Last accessed, 10 April 2023).

[39] Carolyn Jacobs Chachkin (2007). "What Potent Blood: Non-Invasive Prenatal Genetic Diagnosis and the Transformation of Modern Prenatal Care" 33(9) *American Journal of Law and Medicine* 9, pp. 47-48.

[40] Julia D Mahoney & Gil Siegal (2018). "Beyond Nature? Genomic Modification and the Future of Humanity" 81(3) *Law and Contemporary Problems* 195, p. 198.

Huntington's disease."[41] Others are autosomal recessive disorders such as sickle cell disease (which results in lifelong health challenges as a result of red blood cell abnormalities) and Tay Sachs disease (a neurodegenerative disorder with high fatality rate in early childhood).

To combat these, a lot of resources and efforts have been put into biomedical research resulting in the past in procedures such as gene[42] therapy initiatives with some success.[43] There are two main methods of gene therapy –gene transfer (or addition) and genome editing. The former is the earlier method and it involves introducing either "a new gene into cells to help fight a disease" or "a non-faulty copy of a gene to stand in for the altered copy causing disease."[44] The latter is the newer method.[45] It involves use of molecular tools to modify cells' deoxyribonucleic acid (DNA). HGE may be done to turn on a gene that is necessary to fight a disease, turn off an improperly functioning gene, remove a problematic piece of DNA or fix a genetic alteration underlying a disorder so that the gene can function properly."[46]

As previously noted, HGE may, in this regard, primarily seek to modify the DNA of a person's somatic (non-reproductive) cells or of a person's heritable (reproductive) cells.[47] While the latter targets the modification of undesired genetic traits to prevent the passing on of same down the generational line, the former targets the treatment of diseases in actual patients.[48] It seems somatic genome editing follows the previous "well-established approach to

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[41] Ibid.

[42] "As a foundational matter, genes are the source of hereditary traits in humans and other living organisms. Genes are a part of the human genome. Within the human genome, pairs of chromosomes contain 'approximately 22,000 genes.' Each of these approximately 22,000 genes is 'encoded as DNA' contained in the nucleus of the cell." See Myrisha S Lewis (2021). "Is Germline Gene Editing Exceptional?" 51 *Seton Hall Law Review* 735, p. 744.

[43] MedlinePlus (2022). "How Does Gene Therapy Work" (U.S. National Library of Medicine), https://medlineplus.gov/genetics/understanding/therapy/procedures/ (Last accessed, 11 April 2023).

[44] Ibid.

[45] "Genome editing is a biomedical tool that can make 'precise alterations, additions, [and] deletions' to an organism's genetic makeup." See Scott J Schweikart (2021). "Global Regulation of Germline Genome Editing: Ethical Considerations and Application of International Human Rights Law" 43 *Loyola of Los Angeles International & Comparative Law Review* 279.

[46] MedlinePlus, *supra* note 43.

[47] Coghlan, *supra* note 4.

[48] Krekora-Zając, *supra* note 5; Lorenzo *et al, supra* note 5; Spaander, *supra* note 5.

developing treatments for genetic conditions”.[49] It therefore enjoys widespread support as a credible procedure in the fight against diseases.[50]

The same could however not be easily said concerning germline genome editing. Its goal of permanently modifying heritable genetic traits has attracted a number of concerns. Principal among these are safety concerns relating to unforeseen consequences of such a change. Two of such are the possibility of mosaicism and off-target effects. Mosaicism occurs where the genetic modification is not uniform –a situation which yields both edited and unedited cells. A genetic modification would, on the other hand, be off-target where it yields unintended consequences. That is, it fails to achieve the intended result or does something else in addition.[51]

The whole world was for example in 2018 taken aback with the announcement of a now discredited Chinese scientist, Dr He Jiankui, of the birth of two girls, Lulu and Nana, through the use of a CRISPR-Cas9 genome editing tool. Since the father of the twin girls was HIV-positive, the genome editing tool targeted the removal of “the doorway through which HIV enter[s] to infect people.”[52] However, there is an indication that none of the twins has the exact modified gene as intended by the scientist.[53] Dr He himself had admitted that the babies “suffered from mosaicism, with one baby having cells that were both edited and unedited.”[54] Also, as pointed out by Myrisha Lewis,[55]

> Additionally, the gene that Dr. He Jiankui targeted did not necessarily confer automatic protection against HIV-1. Further, the targeted mutation, CCR5, corresponds to increased susceptibility to West Nile

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[49] Mahoney & Siegal, *supra* note 40 p. 199.

[50] When CRISPR is used for somatic-based procedures, the range of its potential therapeutic uses may be from “cancer immunotherapy, to treating infectious diseases, to creating stem cell models of disease.” Schweikart, *supra* note 45 p. 283.

[51] Lewis, *supra* note 42 p. 747-48. See also Schweikart, *supra* note 45 p. 282.

[52] Montoya, *supra* note 1 p. 1015. The scientist had “claimed that he had altered a gene called CCR5, which allows the AIDS-causing virus to infect an important class of cells in the human immune system.” See Henry T Greely (2019). “He Jiankui, Embryo Editing, CCR5, The London Patient, and Jumping to Conclusions” (*STAT News*, 15 April 2019) https://www.statnews.com/2019/04/15/jiankui-embryo-editing-ccr5 (Last accessed, 12 April 2023); Sreekumar Nellickappilly (2023). *Debating Bioethics* (Routledge) pp. 120-122.

[53] Greely, *supra* note 52.

[54] Lewis, *supra* note 42 p. 748.

[55] Ibid. See also Henry T Greely (2019). “CRISPR’d Babies: Human Germline Genome Editing in the ‘He Jiankui affair’” 6 *Journal of Law and the Biosciences* 111 https://doi.org/10.1093/jlb/lsz010.

> virus, influenza, enhanced memory, and possibly a shortened life span. Other research indicates that the CCR5 gene could be connected to improved stroke recovery outcomes.

Beyond the use of human germline genome editing (HGGE) to prevent, treat and cure diseases, its ability to enhance human genome has also been highlighted. Such touted enhancement entails the achievement of desired human features in the areas of higher IQ, color of the eyes or hair, height, greater resistance to diseases, mental alertness till old age, and others.[56] The issue of enhancement certainly suggests eugenic goals even if that of disease prevention, treatment and cure does not. And, here lies the essence of the question of the extent to which HGE would or would not amount to atrocious eugenics practices?[57]

4. Human Genome Editing as Eugenics?

Caplan, McGee and Magnus[58] have classified the arguments against germline genetic engineering towards the avoidance of certain undesirable traits into three – "worries about the presence of force or compulsion, the imposition of arbitrary standards of perfection, or inequities that might arise from allowing the practice of eugenic choice." Other arguments have also been advanced as examined in this section.

4.1 Coercive versus voluntary reproductive choices

Indeed, the use of force in ordering reproductive choices was the hallmark of the low era of past eugenic programs of different nations. Reproductive choices were taken away from individuals, and the state –by the use of its coercive apparatuses– could determine who can reproduce and with whom they may mate for the purpose of reproduction.

What if there is no compulsion and the choice to use germline genome editing technology is that of individuals? Modern liberal eugenicists believe that no rational objection can trump the basic right of a couple or prospective parent to make reproductive choices to prevent the passing on of a genetic disease to a child or to grant the child a higher IQ through genetic modification. This point is important and permits few objections.

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[56] National Academies of Sciences, Engineering, and Medicine (2017). *Human Genome Editing: Science, Ethics, and Governance* (The National Academies Press) p. 137 https://doi.org/10.17226/24623 (Last accessed, 12 April 2023); Montoya, *supra* note 1 p. 1026.

[57] Vizcarrondo, *supra* note 6.

[58] Caplan, McGee & Magnus, *supra* note 7. See also Drabiak, *supra* note 7.

One such objection concerns what has been observed in the past relating to how societal norms change over time, particularly with legal normalization of what previously was unthinkable, considered wrong or accepted as deviant behavior. Post legal normalization environment might become so heated up with active mobilization and advocacy from interest groups (commercial and non-commercial), that gradually the myth of individuals being able to make rational choices on the subject matter becomes more and more obvious.

Another objection relates to the moral integrity of allowing individuals to choose reprogenetic technologies, altering or modifying heritable genes for other reasons beyond that of preventing, treating or curing diseases. This raises the existing concern on what actually should be the goal of medical science. As Jonathan Herring[59] puts it,

> What exactly is the scope of medicine? There is indeed a wide debate on what health care should be aiming to do. It is, no doubt, unclear what ultimate ideal medicine is striving to achieve. Is it a life without illness or death? Would that be a life that we would want? Philosophers have debated long and hard whether life without death would make us happier or not.

Should promotion of health be the central goal of medicine when some 90% of health indices are factors on which healthcare personnel have no control?[60] Is providing solutions to illnesses primary when even the definition of what constitute an illness is unsettled? For example, can disability be considered an illness? As illustrated by Thompson and Upshur, myopia is widely believed to be "due to normal growth of the *healthy* eyeball."[61] Anyone that has myopia is considered to have a disability, yet the condition is a result of "normal", "healthy" growth of the eyeball. Is someone living with a disability then sick or just different in a unique way? If she is sick, then medical intervention in form of HGE may be permissible, but if the person is different in a unique way, would modifying a responsible gene in embryos not amount to intolerance and discrimination –a message to those with disabilities that they are not needed in the society? In the view of Stuart A. Newman:

> Modification of an existing person's biology to save a life or alleviate suffering, no matter how new or unprecedented the methods, is clearly in the traditional province of medicine. In contrast, modifying the biology of someone who has not yet come into existence, to prevent

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[59] Jonathan Herring (2016). *Medical Law and Ethics* (Oxford University Press) p. 7.

[60] Ibid.

[61] R Paul Thompson & Ross EG Upshur (2018). *Philosophy of Medicine: An Introduction* (Routledge) p. 16.

> malfunctions or enhance desired qualities, is outside medicine's classic mission.[62]

A relevant question to ask here is whether HGE is really the way to go in treating diseases? After all, as an African philosophical thought puts it, "an ineffective drug is only lacking some essential (active) ingredient or herb" (òògùn tí ò jẹ́, ewé rẹ̀ ló kù kan). Why deliberately interfere with such a basic human natural resource –the human genome– instead of advancing research into drug treatment to accomplish the same goal?

Yet another objection is the grave possibility of genetic imbalance in the population. For example, one of the aftermaths of China's mandatory one child policy is the distorted male/female ratio in the country. Due to the cultural preference for male children, many couples went all out, during the pendency of the policy to have only male children. Even now that the government has abandoned the policy, many prefer not to even bear a child again with serious impact on the nation's demography. However, the Chinese experience can of course be distinguished from a non-coercive regime in making of reproductive choices as advocated by liberal eugenicists; but the point of likely distortion in the genetic makeup of the population in the future may not be completely discountenanced.

Nevertheless, this concern is attested to by the huge impact screening for sex has had in East Asian and Central Europe countries where whenever a prenatal test reveals "female" instead of "male", a decision is often made for termination due to cultural preferences for male children. Countries like India and South Korea have –in a bid to arrest the trend– outlawed diagnosis for sex through the use of ultrasound.[63] It is heartening that Article 14 of the European Convention on Human Rights and Biomedicine prohibits the use of assisted reproductive technologies to choose a prospective child's sex unless where the decision to do so is to avoid a "serious hereditary sex-related disease".[64]

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[62] Stuart A. Newman (2018). "Sex, Lies, and Genetic Engineering: Why We Must (But Won't) Ban Human Embryo Modification" in Irus Braverman (ed), *Gene Editing, Law, and the Environment: Life Beyond the Human* (Routledge) p. 134.

[63] Mark W Leach (2022). "Eugenics or Not, Prenatal Genetic Testing's Common Issues Need to Be Addressed" in Megan A Allyse & Marsha Michie (eds) *Born Well: Prenatal Genetics and the Future of Having Children* (Springer) p. 35.

[64] Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (Oviedo, 4.IV.1997) *European Treaty Series - No. 164*.

4.2 What is normal and what is not?

What are the genetic traits to be desired in one's child? The notion of the normal or ideal person is relative –a cultural derivative and a time bound conceptualization. What more, the notion of the ideal person differs from person to person even among people of the same sociocultural identity.[65] Is the use of germline genome editing for enhancement thus a search in futility for the perfection of the human race?

As Caplan, McGee and Magnus assert, the notion of the normal, ideal or perfect human traits may not be totally subjective. This is a valid point as certain traits such as "physical stamina, strength, speed, mathematical ability, dexterity, and acuity of vision, to name only a few" command near universal acceptability as desirable traits.[66] It is however also true that not all people would agree to all traits in the list as being ideal.

And, still on the question whether the search for ideal traits is not in futility, the answer to it may as well be in the affirmative. A quick example here illustrates the point being made. Let us say a potential parent among others has chosen that the prospective child should have very beautiful blue eyes. Will that –upon being born– make the child to be immune from any form of degeneration of the eyes? Will the eyes –throughout the child's life– be shielded from other vicissitudes of life such as infections and accidents which may seriously compromise the good functioning of the eyes? Supposing the child has an accident, gets injured in the eyes and consequently goes blind in both eyes, has the child now become abnormal? Or, has the child simply experienced one of the basic realities of the world humans inhabit – realities that are as normal as life itself?

4.3 Widened inequalities?

This concern is in recognition of the existing inequities in our world. Without doubt, a lot of inequalities already exist in different strata of the societies of the world. Due largely to huge differences in levels of socioeconomic, technological, legal, political and infrastructural developments including access to good and quality health services among and even within countries of the world, ground realities suggest that these inequalities may not abate soon. Bridging the gaps between the haves and have-nots should thus be the goal and pursuit of both public and private bodies, not widening them. Some believe the adoption and use of germline genome editing will further

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[65] An expression which captures this among the Yorubas is, "Bí a tií ṣe ní ilẹ̀ yí, èèwọ̀ ibòmíràn ni" (that which is normal here is a taboo elsewhere).

[66] Caplan, McGee & Magnus, *supra* note 7.

aggravate existing inequalities as the technology might not be available to all couples in all countries.

However, should this limit the adoption and use of a technology designed to make life easier for people? If prospective parents could afford a medical procedure which would make their child avoid a genetic trait which they themselves wish they did not have, should they not be free to avail themselves of it? Will denying them access not amount to exposing them to inequalities in making reproductive choices in comparison to couples who have no such blatantly grievous genetic trait? So, in a way, adopting such a technology might help to address inequalities and not to widen it.

This conclusion however becomes invalid when the focus is on equality of opportunity, a concept used to emphasize the availability of a level playing ground for all in the society in accessing certain goods or benefits. Such availability may suffice –where it exists for all to take advantage of– although only a few people may turn up and be able to enjoy the promise, good, or benefit presented by the opportunity. Such competitiveness as in employment recruitment may not necessarily prejudice the equal opportunity offered as far as the qualifications for the position contain no discriminatory or hidden criteria.

It is however fatal where the opportunity is not even there in the first place as it operates where health resources are only available to some and not all in the society.[67] In this instance, the competition is already skewed in favour of some to the disadvantage of the others. Thus, the goal of equality of opportunity is defeated *ab initio*. The point here is what will be the extent to which HGE resources may be made equally available to all members of the society who may wish to access and exploit them. Ground realities suggest a very low extent.

4.4 Commodification of the human body

The genome editing technology has also been touted as likely to yield a kind of factory line for the production of "designer babies". Such a suggestion surely draws sorely on the human conscience that the human person will become just like a product designed and produced in a (laboratory) factory with underlying commercial motives, though possibly given altruistic coating.

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[67] Larry S Temkin (2016). "The Many Faces of Equal Opportunity" 14(3) *Theory and Research in Education* 255–276; Avidit Acharya & John E Roemer, "Equality of Opportunity as a Measure Of Development" (Policy Brief, UNDP Regional Bureau for Asia and the Pacific Strategy, Policy and Partnerships: 26 January 2022) https://www.undp.org/asia-pacific/publications/equality-opportunity-measure-development (Last accessed, 26 August 2024).

It raises questions of our humanity –its scope, nature, and essentials. Questions relating to human nature are unsurprisingly, in the nature of such philosophical inquiries, unsettled from the positions of those who deny its existence based on biological and anthropological grounds to those who positively assert its biological, historical, cultural, and innate essence particularly as it relates to the existence of "specific moral prohibitions concerning the alteration of, or interference in, the set of properties that make up human nature."[68] Commodification of the human body surely goes to the core of human nature in a way that one may not be blamed for wondering whether the resulting products would still be part of the "human" world as inherited from our forebears.

The question however is whether the human society has already not slipped into the era of making designer babies. Assisted reproduction technologies (ARTs) are now widely available in many countries. Where these are deployed with the use of technologies like those of preimplantation genetic diagnosis (PGD) and Mitochondrial Replacement Therapy (MRT),[69] the argument of making designer babies against the adoption of genome editing technology certainly becomes stale.

This nonetheless does not discountenance the fact that the practice raises eugenic concerns. Some scholars have for instance linked eugenic beliefs and practices with some scientists involved in reproductive and genetic research. For example, Robert Edwards, who together with Patrick Steptoe pioneered the in vitro fertilization (IVF) innovation has been linked with the British Eugenics Society.[70] According to Osagie Obasogie, Edwards "believed that

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[68] Neil Roughley, "Human Nature" in Edward N Zalta & Uri Nodelman (eds), *Stanford Encyclopedia of Philosophy* (Winter 2023 edition) https://plato.stanford.edu/cgi-bin/encyclopedia/archinfo.cgi?entry=human-nature (Last accessed, 26 August 2024).

[69] See The UK Human Fertilisation and Embryology (Mitochondrial Donation) Regulations 2015. The MRT is meant for, "women whose eggs carry mitochondrial diseases. A donor egg is used and the "heart" of it is removed and replaced with the nucleus from the would-be mother's egg. The resulting egg is primarily material from the mother but the mitochondrial DNA is from the donor. The egg is fertilized with sperm from the would-be mother's partner (or donor sperm). The significance of this procedure is that because the mitochondrial DNA is coming from the donor, any mitochondrial disease is not passed on." Herring, *supra* note 59 p. 386. See also Seema Mohapatra (2016). "Politically Correct Eugenics" (2016) 12 *FIU Law Review* 51.

[70] Judith Daar (2017), *The New Eugenics: Selective Breeding in an Era of Reproductive Technologies* (Yale University Press) p. 184; Osagie K Obasogie (2018), "The Eugenics Legacy of the Nobelist Who Fathered IVF" in Osagie K Obasogie & Marcy Darnovsky (eds), *Beyond Bioethics: Toward a New Biopolitics* (University of California Press) p. 73.

increased control over human reproduction could not only treat the infertile but also allow for socially favored characteristics to be selected and bred into the population."[71] Also, as pointed out by Mary Mahowald, any assumed distinction between prenatal termination of embryos subsequent to diagnosis of any genetic disease such as Down syndrome and the regime of compulsory sterilization of "imbeciles" may not be easily established to support the claim that the latter and not the former is eugenic.[72]

4.5 Disability rights – ableist ideology

Eugenics no doubt has ableist[73] undertones –with its discriminatory treatment of people living with disabilities.[74] Under this setting, persons with disabilities are considered unfit or less qualified to reproduce as they are deemed unable to take proper care of children. Unfortunately, discriminatory laws and long held societal prejudices and biases still abound to checkmate the reproductive choices of people living with disabilities. In the words of Robyn Powell, "bias and speculation about the capabilities of parents with disabilities –mirroring those raised during the height of the eugenics movement– have led to present-day discriminatory child welfare, family law, adoption, and reproductive health care policies and practices that assume parental unfitness."[75]

One might therefore not be completely wrong to assert that the same biased attitude informs the current policy encouraging the termination of embryos or fetus diagnosed with genetic abnormalities.[76] Prenatal diagnosis and selective

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[71] Obasogie, Id., p. 75.

[72] Mary B Mahowald (2003), "Aren't We all Eugenicists? Commentary on Paul Lombardo's 'Taking Eugenics Seriously'" 30 *Florida State University Law Review* 221. *See* also Yael Efron & Pnina Lifshitz-Aviram (2020). "Conditional Parentage is the New Eugenics" 8(1) *Child and Family Law Journal* 19.

[73] Ableism is a "system that places value on people's bodies and minds based on societally constructed ideas of normalcy, intelligence, excellence and productivity. These constructed ideas are deeply rooted in anti-Blackness, eugenics, colonialism and capitalism. This form of systemic oppression leads to people and society determining who is valuable and worthy based on a person's appearance and/or their ability to satisfactorily [re]produce, excel and behave." See Robyn M Powell (2021). "Confronting Eugenics Means Finally Confronting its Ableist Roots" 27 *William & Mary Journal of Race, Gender, and Social Justice* 627 quoting Talila A Lewis (2020). *Ableism 2020: An Updated Definition* https://www.talilalewis.com/blog/ableism-2020-an-updated-definition. See also ten Have & Neves, *supra* note 12 p. 77.

[74] Powell, *supra* note 73 p. 607.

[75] Ibid, p. 620.

[76] Generally, *see* National Council on Disability, *Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children* (2012).

abortion (PDSA) no doubt is a form of discrimination against disability. Not only does it animate bias against disability among healthcare workers, but may also institutionalize it, making doctors and nurses to regularly terminate a pregnancy or discard an embryo on the basis of a positive disability diagnosis.[77]

It has even been asserted that despite the efforts of genetic counsellors, many of such termination decisions are made without the concerned prospective parents being fully apprised of the nature and implication of the diagnosed abnormality.[78] In his address to the 2003 American College of Medical Genetics, Charles Epstein noted: "I do not think that we can avoid the fact that there are indeed forces at work, some subtle and others not so subtle, that do exert a coercive force toward utilization of prenatal diagnosis and termination of pregnancy if an abnormal fetus is detected."[79]

Ani Satz has in this regard argued that healthcare as currently funded, practiced and institutionalized is a form of negative eugenics since it somehow seeks to prevent people with disability from coming into existence.[80] Since the notions of disability and normalcy are socially constructed, disability rights advocates would rather encourage scientific advances, policies and laws that will make the lives of people with disability to be more valued, easier, and highly worthy of living.[81]

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https://www.ncd.gov/sites/default/files/Documents/NCD_Parenting_508_0.pdf (Last accessed, 14 April 2023).

[77] Christopher Ostertag (2023), "False Compassion, True Discrimination: The Practice of Prenatal Diagnosis and Selective Abortion" in Nicholas Colgrove, Bruce P Blackshaw & Daniel Rodger (eds), *Agency, Pregnancy and Persons: Essays in Defense of Human Life* (Routledge) p. 231.

[78] Mahowald, *supra* note 72 p. 229. *See* Ostertag, *supra* note 77 p. 233 ["Several studies … on prenatal genetic counseling reveal that, if disability is discussed at all, it is from the perspective of medicine and lacks sufficient appreciation of the social aspects of disability, and, more importantly, genetic counselors often frame the options after a prenatal diagnosis in such a way to support termination."]

[79] C Epstein (2003). "Is Modern Genetics the New Eugenics?" 5(6) *Genetics in Medicine* 469, p. 473 cited by Ostertag, *supra* note 75 p. 233.

[80] Ani B Satz (2020), "Healthcare as Eugenics" in I Glenn Cohen *et al* (eds), *Disability, Health, Law, and Bioethics* (Cambridge University Press) pp. 20-21.

[81] See Erik Parens & Adrienne Asch (2003). "The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations" 9 *Mental Retardation and Developmental Disabilities Research Reviews* 40.

4.6 Intergenerational justice

Intergenerational justice (IGJ) is based on the simple fact that the human society is a continuous one, from one generation to another, and, that the actions of one generation affect another generation in tangible ways. If a generation without due thought should then go ahead to manage the resources available to the human society, it might seriously jeopardize the interests of the coming generations. The concept of *intergenerational justice* therefore asserts an obligation on the present generation not to unduly impose costs on future members of the human society while exploring and making use of current benefits. In other words, there should be a just distribution of costs and benefits to not only the present generation but also the next ones.

In indigenous African thought, the obligation the current generation owes is not only to their descendants but even more to their ancestors who are believed to be alive and well in a (parallel) metaphysical world. The world (resources and customs) bequeathed by those who have gone before must therefore not be bastardized in order not to incur their wrath. Indigenous African communities give expression to this obligation through rituals such as the pouring of libation to the "owners of the land",[82] (the ancestors), invoking their names, supplicating to them and beseeching their blessings before embarking on any significant venture.

The view of the communitarian theorists seems to sync with this. The communitarians, according to Janna Thompson, believe in the pre-existence of a common good shared by members of a community which is primary in how they define "their relationships and obligations." With this reality and the transgenerational nature of the community, members who have personalized the common good naturally see themselves as "having obligations from the past that extend into the future."[83] This is expressed in assertions such as the following:

> I am someone's son or daughter, someone else's cousin or uncle ... I belong to this clan, that tribe, this nation. Hence what is good for me

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[82] The word used to describe the owners of the land in Yoruba is "*alálẹ̀*".

[83] Janna Thompson (2009), "Identity and Obligation in a Transgenerational Polity" in Axel Gosseries & Lukas H Meyer (eds), *Intergenerational Justice* (Oxford University Press) p. 28. See also MLJ Wissenburg (2011), "Parenting and Intergenerational Justice: Why Collective Obligations Towards Future Generations Take Second Place to Individual Responsibility" 24 J Agric Environ Ethics 557; Pranay Sanklecha (2017), "Our Obligations to Future Generations: The Limits of Intergenerational Justice and the Necessity of the Ethics of Metaphysics" 47(2-3) *Canadian Journal of Philosophy* 229; Andre Santos Campos (2018), "Intergenerational Justice Today" 13(3) *Philosophy Compass* e12477.

> has to be the good for one who inhabits these roles. As such I inherit from the past of my family, my city, my tribe, my nation, a variety of debts, inheritances, rightful expectations and obligations. These constitute the given of my life, my moral starting point.[84]

Now, HGGE involves the manipulation of the genetic traits of future generations which portends the possibility that the rich diversity of human genes which the current generation has inherited might not be available for the future ones. How this alteration or restriction in the variety of available human genes might impact members of the community in the future might not be easily foreseeable, at least by the current state of scientific knowledge. This calls for caution that today's parents should have the needs of their future generations in mind when facing the decision whether to edit X Gene instead of Y Gene to achieve Z result.

Will HGGE lead to genetic attrition in the future? This surely may not necessarily occur as the relativity of the ideal in human traits from person to person and from culture to culture would defeat such a claim. Simply put, the genetic traits 'A' desires might differ from those desired by 'B', and that alone will reinforce diversity and some sort of balancing except where some form of social conditioning has been promoted by certain interest groups creating some hype on the superiority of certain traits over others.

It may also be argued that concern for the future generation may actually be the motivating force behind a choice of today's prospective parent to alter the genome of their prospective child in a particular way. In compliance with extant legal provisions, such a decision must be made in the best interests of the prospective child.

5. Is Eugenics all bad News? An African Perspective

Various questions need careful analysis. Is everything about eugenics invariably bad news? Does the position of liberal eugenicists with their insistence on voluntary individual choices –as opposed to forced choices imposed on the populace– not suffice to meet the concerns of critics? Also, from the African perspectives, are eugenic concerns not at the base of the diligent investigations undertaken by families of prospective couples into the family traits of suitors before the marriage proposal is sanctioned? Normally, in indigenous communities, such investigations are discreetly made into history of any illnesses (physical or mental) or negative behavioral trait

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[84] A MacIntyre (1981). *After Virtue: A Study in Moral Theory* (Duckworth) p. 220 cited by Thompson, *supra* note 83.

prevalent in the families. It is only when the investigations disclose no unwelcome information that the families would allow their children to enter the marital union.

It does seem that eugenic choices to ensure good birth have been made from time immemorial. As Mahowald puts it, most mothers considerably alter their behavior during pregnancy so as to ensure they have a healthy baby. Such altered behavior sometimes involves personal sacrifices and denials, all in a bid to have a goodly child. Mahowald then approves the position of Paul Lombardo[85] in suggesting that "some eugenic practices are not only morally appropriate but praiseworthy."[86] It may of course be argued that the concern of a mother to do all things to ensure the health of a baby in the womb might be more of a bid to absolve oneself of moral wrong –not to be the cause of the occasioning of harm to one's baby. Viewed this way, will it not be distinguishable from eugenic goals such as intentionally causing harm by terminating a pregnancy?

As previously stated, it does not seem that eugenic thought is strange to indigenous African thoughts and practices. The above example of betrothal and marriage prerequisites illustrates this point. Often, in indigenous Yoruba communities, for example, if it is discovered that a particular sickness or offensive character trait runs in the family of the potential suitor, the marriage initiative would terminate at that point unless the sickness or character trait is not grievous enough.

Some indigenous philosophical sayings also seem to support making of eugenic choices even though some of the sayings might in modern times sound contrary to human rights norms of the dignity of the human person, right to equal treatment and freedom from discrimination among others. An example of agreement with eugenic goals can be observed in an old song which goes thus:

Bí a bá ń tọrọ ọmọ lọ́wọ́ Ọlọ́run (When we beseech God for a child)
Bí a bá ń bèrè ọmọ lọ́wọ́ òrìṣà (When we beseech an idol for a child)
Bí a bá ń fẹjú toto láti bímo ò (When we make strenuous efforts to beget a child)
E bẹ̀rù omo gbà jẹ́ n sinmi (Be careful of the good for nothing child)

The good for nothing child spoken of here cannot be narrowly interpreted as a deformed or mentally challenged child, because it can refer to a rebellious and ill-behaved one. This folk song supports the assertion that pursuit of

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[85] Lombardo, *supra* note 26 p. 191.
[86] Mahowald, *supra* note 72 p. 222.

eugenic goals in the making of reproductive choices does not necessarily contradict indigenous African thoughts and practices. Of course, the good birth goal in the eugenics concept spoken of here in no way approves the atrocious practices subsequently institutionalized by the eugenic movement. There is indeed no evidence of such practices in modern African countries with exception to the experience of colonial Africa.[87] Therefore, that HGE has eugenic undertone is not the real deal, but rather, the legal and regulatory framework within which the medical procedure is carried out.

6. Legal and Regulatory Implications

Bearing in mind the eugenic undertone of HGGE, some implications for the design of an appropriate legal and regulatory framework may be identified as the following discussion indicates. First, it is germane to acknowledge that, law on a general level, must not stifle but promote innovation. The need of the human society to take advantage of innovative and transformative ideas supersedes any perceived disadvantages of such ideas, provided that regulatory framework adequately addresses such concerns.

However, it is important to ensure that the law regulating an innovative field is based on good science, not pseudoscience. Part of the reasons the society in the past fell into such atrocious abyss is because the ideas informing eugenical laws were not derived from sound scientific evidence. Legal approval and regulation of HGE should thus be based on solid scientific and clinical evidence. Drawing from this, legal and regulatory vigilance is needed to ensure that society does not again descend to the atrocious abyss of the past.

Towards ensuring this, it must be held sacrosanct that reproductive choices are left to the free will of individuals without any form of compulsion. That is, the decision to genetically edit one’s prospective child must be that of the parent without any form of real or apparent coercion. A free will decision, without doubt, is one based on *informed consent* expressly given and based on full information.[88] Where the prospective parent has no capacity to consent, the decision may only be taken in her best interest after due regard to the

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[87] Carla Turner (2024), “The Eugenic Underpinnings of Apartheid South Africa, and its Influence on the South Africa School System”178(71) *Theoria* 75. See also Chloe Campell (2012), “Eugenics in Colonial Kenya” in Alison Bashford & Philippa Levine (eds), *The Oxford Handbook of the History of Eugenics* (Oxford University Press) 289-300.

[88] UNESCO Universal Declaration on Bioethics and Human Rights 2005 (UDBHR 2005), art 6.

protection (she is entitled to) under national laws and with her full possible participation in the decision-making process.[89]

An appropriate legal and regulatory framework will also consider the issue of liability for malpractice and unintended consequences. Such a framework will provide answers to questions like –who in the event of malpractice or unintended effects is liable: parents, doctors, health providers? Also, can the child who suffers an unintended effect sue? If the child is to sue, who is to be sued –doctors, parents or both? What course of action is plausible if there is neither malpractice nor unintended effects, but the child upon reaching the age of majority later comes up to reject her edited traits, asserting unnaturalness or a feeling of being a stranger in her own body? Is there any remedy available to her?

Moreover, there is the need to give due attention to the issue of a human rights compliant legal and regulatory framework. Primary perhaps is the right to dignity of the human person which has been described as the fulcrum of all human rights regimes. Immanuel Kant defines it "as an intrinsic, unconditional, and absolute value of human beings who should be treated as ends in themselves (ethical dimension)."[90] As stipulated in Article 1 of the Universal Declaration of Human Rights (1948), all human beings are entitled to dignity of their persons. Each individual's interests and welfare should thus take priority over those of science or society.[91]

Privacy rights of patients (parents) and of potential children also need to be protected. If African cultural values are to be taken into consideration, it is most likely that people who undergo HGE and their children would face some bias and possible discrimination in important social settings. Legal prohibition of such discrimination is important but not enough to prevent same. Their relevant personal data must thus be protected and confidentially maintained to arrest such a development.[92] However, this is not to discountenance the need for an appropriate legal framework to guarantee the principles of equal treatment, equity, justice and non-discrimination.[93]

Assuring a basic right to health is also crucial, particularly in the light of the criticism that HGE is likely to be elitist, another device to further widen the gap between the haves and the have-nots. The General Comment No. 14 of the Committee on Economic, Social and Cultural Rights (2000) has

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[89] Id., UDBHR 2005, art 7.

[90] ten Have & Neves, *supra* note 12 p. 613.

[91] UDBHR 2005, *supra* note 88, art 3.

[92] Id., UDBHR 2005, art 9.

[93] Id., UDBHR 2005, arts 10-11.

specified the normative components of the right to health as implying a healthcare system that is available, accessible, acceptable, and is of good quality. A healthcare system is, *inter alia*, acceptable when cultural sensitivity is inbuilt and when it is based on universally sound medical ethics. It is accessible when it is affordable and non-discriminatory. Accessibility is also measured by the extent to which medical facilities are widespread and physically available to patients including whether information relating to essential services is or is not available to ordinary citizens.[94]

Eugenic concerns over HGE equally demands a legal and regulatory framework that recognises disability rights. Deliberate efforts to checkmate ableism is needed to assure anti-discriminatory legal environment for people with disability who may more correctly be described as "people differently abled."[95] It is indeed essential that "in applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected."[96]

Likewise essential is recognition and enforcement of the right to freedom of conscience, thought and religion, particularly the right to conscientiously refuse participation in certain HGE procedures. For example, a doctor who has a conscientious problem in procedures involving terminating an embryo for any reason should have the protection of law and a conducive regulatory environment not to be coerced into so participating.[97] And, of course, as previously highlighted, it is important to give due regard to the impact of HGE on future generations, especially "their genetic constitution".[98]

7. Conclusion

Definitely, the goal of HGE –where it concerns the making of reproductive choices– greatly matches the good birth goal of eugenics as previously defined and discussed. It also holds that somatic gene editing seems to sync more with the core goal of medicine than that of genetic modification for non-disease

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[94] ten Have & Neves, *supra* note 12 p. 87. *See* also the 1997 UNESCO Universal Declaration on the Human Genome and Human Rights, art 12(a); UDBHR 2005, art 14.

[95] *Supra* note 12 p. 77.

[96] UDBHR 2005, art 8.

[97] *See* James F Childress (2020), *Public Bioethics: Principles and Problems* (Oxford University Press) pp. 127-151.

[98] UDBHR 2005, art 16.

purposes. That of germline gene editing seems to be outside the primary scope of medicine and if pursued might strictly be for eugenic purposes alone.

Thus, provided safety concerns are properly taken care of and adequate legal and regulatory regime is put in place to effectively address the needs of not only parents but also those of the potential child and of the future human society, somatic genome editing might still be acceptable. Such an appropriate legal and regulatory regime is one that leaves reproductive choices to the free will of individuals without any form of compulsion.

It should also recognize and ensure the non-infringement of human rights such as the right to dignity of the human person, right to health, equal treatment and freedom from discrimination, disability rights. Other avenues of attention relate to rights such as that of conscience, thought and religion. Such a legal regime should also take into consideration the issue of how liability for unintended consequences of genome editing procedures will be resolved. Who is liable –doctors, health providers, all health personnel involved? Does or should a physician owe a duty of care to the child where things go wrong in a sufficient way to enable the child to sue? Does a potential parent owe the child a duty of care to warrant suing the parent in the event of things going awfully wrong? These are some of the issues that must be proactively addressed. ■

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