



GENE EDITING IN LIGHT OF THE RIGHT TO HUMAN DIGNITY AND FREEDOM
FROM DISCRIMINATION OF UNBORN DISABLED PERSONS.

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Declaration

I, Abigail Sibi, do hereby declare that this research is my original work and that to the best of my knowledge and belief, it has not been previously, in its entirety or in part, been submitted to any other university for a degree or diploma. Other works cited or referred to are accordingly acknowledged.

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Abstract

This paper discusses CRISPR-Cas 9's¹ resulting effect on disabled persons and the implication of its application on their human dignity and freedom from discrimination. This gene editing technology could be advantageous, in that it could reduce human suffering. It enables prenatal screening, carrying out predictive tests, detecting etc and eventually editing out undesirable genetic characteristics. Advantages of gene editing as per the international summit on gene editing include increasing tolerance to the environment, preventing aging and modifying mental capabilities.²

Gene editing enables alteration of these undesirable traits that could make the child disabled, which then pre-empts parents to discard their unborn children's disability traits since disability is viewed as a 'disease'.³ Such traits include traits that cause Huntington's disease, cystic fibrosis and sickle cell.⁴ It is therefore foreseeable, that easy access to the technology due to low costs will result in the wide misuse of the technology.⁵ This eventuality would be considered advantageous to some while others are concerned that it will increase stigmatization of disabled persons.⁶ 'Correcting'⁷ disability and filtering out genetic disabilities reduces the dignity of the human person to their genetic make-up rather than the very essence of being human.

This research seeks to determine whether gene editing is discriminatory and whether international instruments adequately provide protection for the dignity and freedom from discrimination of disabled persons and the unborn foetus. However, it is important to note that legislation will not prevent parents from being biased on the genetic traits of their unborn children.

¹ Clustered regularly interspaced palindromic repeats, Redman M, King A, Watson C, 'What is CRISPR/Cas9?' 101 *Archives of Disease in Childhood - Education and Practice*, 4, 2016,213-215.

² International summit on gene editing, Committee on science, technology, law policy and global affairs, December 5-8.

³ Mattlin B, 8 March 2019 'Disability and disease aren't interchangeable,' Washington Post https://www.washingtonpost.com/opinions/disability-and-disease-arent-interchangeable/2019/03/07/5c904946-d325-11e8-b2d2-f397227b43f0_story.html on 26 September 2019. Disability is an existing condition while disease is when a person's body is invaded by a pathogen which is separate from a person's personhood and it can be cured unlike a disability.

⁴ International summit on gene editing, Committee on science, technology, law policy and global affairs, December, 2015,5-8.

⁵Conti A, Drawing the line: Disability, Genetic Intervention and Bioethics.

⁶ Generations Ahead, *A disability rights analysis of genetic technologies*, March 29-31 2009, 5.

⁷ Cutting out genes that cause disability comes across as correcting by scientists while for disabled persons it connotes a negative implication that disability is a mistake that needs to be corrected.

List of cases

A.K v Latvia, ECHR, No 33011/08.

Buck v Bell, (1927) The Supreme Court of the United States.

Degraffenreid v General Motors Assembly (1976), United States District court.

Ghaidan v Godin-Mendoza (2004), United Kingdom Supreme Court.

Howard Florey/Relaxin patent (2002), European Patent Office

Jérôme Lejeune Foundation v The Council of State (French Conseil D' état), European Court on Human Rights.

Kealey v Berezowski (1996), Ontario Court of Justice.

Manuel Wackenheim v France, Communication No 854/1999, UN Human Rights Committee

Paton v U.K (1980), European Commission on Human Rights.

Perera v Civil Service Commission (1983), Court of Appeal of Britain

Purhoit and Moore v Gambia, African commission on human rights, communication no 241/01, 2003.

Roe v Wade (1973), The United States Supreme Court.

Smith v Brennan (1960), Supreme Court of New Jersey.

Vo v France (2004), ECtHR.

List of legal instruments

Additional Protocol on the Prohibition of Cloning Human Beings

Convention on Human Rights and Biomedicine

Convention on the Rights of Persons with Disabilities

Convention on the Rights of the Child

Council of Europe Convention on Action against Trafficking in Human Beings

European Convention on Human Rights

International Covenant on Civil and Political Rights

International Covenant on Economic, Social and Cultural Rights

United Nations Educational, Scientific and Cultural Organization Convention

Universal Declaration of Human Rights

Universal Declaration on Bioethics and Human Rights

Universal Declaration on the Human Genome and Human Rights

List of abbreviations

CRISPR- Clustered Regularly Interspaced Short Palindromic Repeats

CRPD- Convention on the Rights of Persons with Disabilities

DNA- Deoxyribonucleic acid

ECHR- European Convention of Human Rights

ECtHR- European Court on Human Rights

ICCPR- International Covenant on Civil and Political Rights

ICESR- International Covenant on Economic, Social and Cultural Rights

HIV- Human Immunodeficiency Virus

IVF- In Vitro Fertilization

UDHR- Universal Declaration on Human Rights

UN- United Nations

UNESCO- United Nations Educational, Scientific and Cultural Organization

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CHAPTER ONE

1.1 Introduction

Recently, a scientist in China, He Jiankui, announced that he had succeeded in creating genetically modified twins using CRISPR-Cas9.⁸ He stated that his aim was to prevent the children from contracting HIV from their parents.⁹ He was later sentenced to three years imprisonment for illegal medical practices.¹⁰ This has since been criticized since China's law does not consider the unethical practice on gene manipulation a crime, the case was instead reduced to illegal medical practice on the grounds that He Jiankui did not have a medical license.¹¹

Genome editing is the process by which scientists can modify a living being's DNA through adding, deleting or changing genetic composition.¹² The CRISPR-Cas9 is an invention that makes gene modification easier, faster and cheaper.¹³ It is a remarkable breakthrough in the scientific arena that will benefit the human species tremendously since humans have been trying to fight mortality since time immemorial. This invention promises a better future with extensive lives, free of diseases and defects. It would potentially be able to cure genetic illnesses like Sickle-cell anemia and treat Cancer. However, ethical, social and legal questions around human rights arise particularly due to the possibility or the successful creation of genetically enhanced or perfected human beings. Enhancement implies improving one's natural state such as a higher intelligence quotient and cosmetic surgeries among others.

This paper aims to discuss these concerns with respect to the rights of disabled persons pertaining to their dignity and the right to freedom from discrimination.

1.2 Background

⁸Belluz J, 'A Chinese government investigation found He Jiankui violated state law in pursuit of personal fame and fortune' Vox, 22 January 2019 <https://www.vox.com/science-and-health/2018/11/30/18119589/crispr-technology-he-jiankui> on 21 September 2019.

⁹BBC News 28 November 2018 <https://www.bbc.com/news/world-asia-china-46368731> on 21 September 2019.

¹⁰<https://www.sciencemag.org/news/2019/12/chinese-scientist-who-produced-genetically-altered-babies-sentenced-3-years-jail> on 21 March 2020.

¹¹<https://www.thehastingscenter.org/chinese-bioethicists-he-jiankuis-crime-is-more-than-illegal-medical-practice/> on 21 March 2020.

¹²<https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting> on 21 September 2019.

¹³ Genetic literacy project <https://geneticliteracyproject.org/category/gene-editing> on 21 September 2019.

The Universal Declaration on the Human Genome and Human Rights stipulates under Article 24 that germ-line inventions are against human dignity.¹⁴ The possibility of creation of human beings with perfect genes, genes that have been edited and are without undesirable traits, will compromise human dignity as a person's dignity will be reduced to their genes rather than the very aspect that makes them human.

The Convention on Human Rights and Biomedicine in Article 11 provides that a person should not be discriminated against because of his or her genetic characteristics.¹⁵ The term 'curing disability' in itself is discriminatory being that it presents a view that getting rid of this impairment is what enables a person to participate in society.¹⁶ Gene editing allows for creation of a hierarchy and presumptions on the type of persons whose lives are worthwhile and those whose lives are not valuable are raised.¹⁷

Article 1 of the Additional Protocol on the Prohibition of Cloning Human Beings prescribes that any trial at creating a human being with the same genetic material as another is prohibited.¹⁸

The Convention on Human Rights and Biomedicine sets out under Article 13 that 'altering of a human gene is permitted when it is to prevent, diagnose or for therapeutic purposes and not to improve the genome of any descendants.'¹⁹

Proponents of gene editing will argue that editing out disabled persons is a preventive measure against disability which is then seen as a disease and therefore permitted. The Convention defines disability as a dynamic factor that arises because of the association of persons with disability and attitudinal and environmental factors that prevents them from fully participating in the community and on an equal footing with others.²⁰ Disability is mainly concerned with the challenges that a

¹⁴Article 24 Universal Declaration on the Human Genome and Human Rights, 11th November 1997.

¹⁵ Article 11, 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, 164 UNTS.

¹⁶ Reindal M, 'Disability, gene therapy and eugenics- a challenge to John Harris' 26 *Journal of Medical Ethics* 2.

¹⁷ Ruha B, 'Interrogating Equity: A Disability Justice Approach to genetic engineering' xxxii, *Issues in Science and Technology* 3, 2016.

¹⁸ Article 1, Additional Protocol to the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, on the Prohibition of Cloning Human Beings, 168 UNTS.

¹⁹ Article 13, 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.

²⁰ Preamble, United Nations Convention on the Rights of Persons with Disabilities.

person with impairment faces when interacting with others while disease is more focused on the body it is not an external factor.²¹ However, disability is not to be perceived as purely social nor medical since disabled persons can encounter challenges arising from their health conditions.²²

The law has failed its people as there is a lacuna in the international society that aims to adequately protect the rights of the disabled when it comes to gene editing. There are no laws in place to regulate gene editing considering this is a potential threat to the right to life. Benjamin Ruha asserts that ‘it is a fallacy to assume that legal protections established to prevent bias, will completely reduce bias in employment and insurance.’²³ Once gene editing is accessible to all, those who choose not to use it, when looking for jobs or when seeking insurance covers will be shunned since most people will have modified or altered their genes, leaving only a few with disability. Employers and insurance brokers will give preference to the ones with ‘perfect genes’ because they have a lower risk of loss and the law will not be able to control what happens in all areas. On the other hand, we must then question what rights we are limiting by prohibiting genetic modification.

Some of the rights that will be limited include rights enshrined in article 23 of the International Covenant on Civil and Political Rights provides for the right to start a family.²⁴ The use of IVF has been accepted as a way of exercising one’s right to life and from this, it would be correct to assume that gene modification is a means to start a family.²⁵ Moreover, Article 12 of the UNESCO sets forth that all persons have a right to access beneficial technology in medicine, biology and genetics in the human genome that aims to reduce suffering.²⁶ Alterations in the human genome may prevent ailments and therefore reduce suffering.

1.3 Statement of the problem

Gene editing in the human genome gives parents a chance to alter undesirable characteristics of their future children. However, the need to alter the genetic make-up of fetuses to prevent undesirable traits such as disability implies that disabled persons are sick or defective persons that

²¹ Herndl P, ‘Disease versus Disability: The Medical Humanities and Disability Studies’ 120 *PMLA* 2, 2005,593.

²² Thomas C, *Female forms: experiencing and understanding disability*, Open University Press, Buckingham, 1999.

²³ Ruha B, ‘Interrogating Equity: A Disability Justice Approach to genetic engineering’.

²⁴ Article 23, International Covenant on Civil and Political Rights, 19 December 1966, 14668 UNTS.

²⁵ Mark P, ‘Tying Prometheus Down: The International Law of Human Genetic Manipulation,’ 3 *The Chicago Journal of International Law* 1.

²⁶ Article 12, United Nations, Educational, Scientific and Cultural Organisation, 4 November 1946.

society needs to rid itself. The existing legal instruments will not adequately prevent discrimination that arises from gene editing and protect the dignity of disabled persons.

1.4 Statement of objective

The objective of this paper is to determine whether gene editing violates the human dignity and freedom from discrimination of disabled persons.

1.5 Research objectives

This research's focus is to investigate the impact of gene editing regarding the right to human dignity and freedom from discrimination of disabled persons with the following objectives;

1. To determine to what extent the fetus has been considered to have human rights.
2. To investigate the adequacy of international regulations in protecting the legal entitlements of disabled persons.
3. To address violations of the rights of fetuses of disabled persons and establish the discriminatory nature of gene editing

1.6 Research questions

This study will be guided by the following inquiries;

1. Does the fetus of disabled persons constitute legal persons capable of having legal rights?
2. Does the existing regulation on gene editing fully protect the rights of disabled persons?
3. Is gene editing discriminatory towards disabled persons?

1.7 Hypothesis

Genetic modification in the human genome is discrimination against disabled persons and impacts negatively on their human dignity. Unregulated gene editing and inadequacies in international instruments to protect gene editing will prompt widespread discrimination on disabled persons.

1.8 Justification of research

The prerequisite of carrying out this research is to tackle the impact of gene editing on the rights of disabled persons. It is important to take into consideration the gravity of gene modification and debate on whether the harms that it may cause are greater than the benefits it promises. This is in

light of the fact that the human population is comprised of a large number of disabled persons and that most countries, such as Kenya have no legislation to regulate gene editing.

1.9 Literature review

The European Centre for Law and Justice recognises that ‘one is born with inherent dignity and states that the right to life should be granted to disabled persons before and after birth.’²⁷ The Committee on the United Nations Convention on the Rights of Persons with Disabilities concerned with equality and non-discrimination recognises the right to life of the unborn but fails to account for disabled persons.²⁸

Christophe argues that editing human beings with the aim of seeking perfection is similar to treating the child as a good for the market.²⁹ To that extent, the Council of Europe Convention on Action against Trafficking in Human Beings in its preamble, provides that trafficking in human beings is a contravention of human rights and is a transgression of persons’ human dignity and integrity.³⁰ In Kant’s view all things have a price, meaning they can be replaced, or a dignity that which has intrinsic value and has no price.³¹

The importance of human dignity was emphasized in the case of *Wackenheim v France* (2002) where the court held that dwarf tossing was against human dignity and therefore the claimant could not earn a living from the activity.³² However, in 2016, the Council of State, French Court, banned the broadcasting of the film ‘Dear Future mom’, which showed children with Down Syndrome sending a message to expectant women, basing its decision on the reasoning that the women who had killed their unborn children will be affected by the film and therefore, concluded that the film was inappropriate.³³ The decision of the court breached article 10 of the European Convention on

²⁷ European Centre for Law and Justice, Disabled persons: The right to exist, https://eclj.org/eugenics/un/disabled-persons-the-right-to-exist#_ftnref1.

²⁸ European Centre for Law and Justice, Disabled persons: The right to exist, https://eclj.org/eugenics/un/disabled-persons-the-right-to-exist#_ftnref1.

²⁹ Christophe Foltzenlogel, Consideration of a draft report on new genetic technologies in human beings, <https://eclj.org/eugenics/pace/discussion-dun-projet-de-rapport-sur-les-modifications-gntiques-chez-lembrion>.

³⁰ Council of Europe Convention on Action against Trafficking in Human Beings, Treaty Series No 197.

³¹ Immanuel K, *The Moral Law: Groundwork of the Metaphysics of Morals*, 2 ed, Routledge, 2012, 96.

³² *Manuel Wackenheim v France*, Communication No 854/1999, UN Human Rights Committee.

³³ *Jerome Lejeune Foundation v The Council of State (French Conseil D’état)* <http://www.conseil-etat.fr/fr/arianeweb/CE/decision/2016-11-10/384691>.

Human Rights on freedom of expression³⁴ and in article 14 on prohibition of discrimination.³⁵ The decision implied that the disabled persons are not worthy to be born neither do they have the right to express themselves nor the right to be treated equally as other human beings. In addition, the case law in *A.K v Latvia* (2014), a mother complained of not being able to abort her child who had Down Syndrome owing to the negligence of the doctor to inform her of the genetic defects of her child.³⁶ The court limited itself to procedural matters and stated that it was the duty of the domestic courts to address the issue of A.K not receiving proper medical information.³⁷

Stephen Mark argues that genetically modified persons may benefit from positive discrimination in that they will be smarter, stronger, faster and more creative.³⁸ Adam Conti further states in his article that gene editing will pose great risks for the disabled in that they will be stigmatised and discriminated.³⁹ Most researchers discuss discrimination as a consequence of gene editing but none discuss it in relation to the judgements made by the parents of a foetus with undesirable characteristics.

There has been limited discussions on how genome editing should be regulated.⁴⁰ Giulia Cavaliere, Katriene Devolder and Alberto Giublini propose an enlightened democratic approach that is inclusive of the opinions of different groups and an informed discussion regarding the ethical-political questions that is, how and whom should come up with regulations concerning genome editing.⁴¹ The article criticizes the elitist approach and the democratic approach in regulation of genome editing.⁴²

1.11 Methodology

³⁴ Article 10, ECHR.

³⁵ Article 14, ECHR.

³⁶ *A.K v Latvia*, ECHR, No 33011/08.

³⁷ *A.K v Latvia*, ECHR, No 33011/08.

³⁸ Mark P, 'Tying Prometheus Down: The International Law of Human Genetic Manipulation,' 3 *The Chicago Journal of International Law* 1.

³⁹ Conti A, *Drawing the line: Disability, Genetic Intervention and Bioethics*.

⁴⁰ Baylis F, 'Human germline, genome editing and broad societal consensus', 1, *Nature Human Behaviour*, 103, 2017.

⁴¹ Cavaliere G, Devolder K, Giublini A, 'Regulating Genome Editing: For an Enlightened Democratic Governance,' 28, *Cambridge quarterly of Healthcare Ethics*, 1, 2019, 76-88.

⁴² Cavaliere G, Devolder K, Giublini A, 'Regulating Genome Editing: For an Enlightened Democratic Governance,' 28, *Cambridge quarterly of Healthcare Ethics*, 1, 2019, 76-88.

The method of research that will be used in conducting this research is desktop research. The sources relied on are from books, online journals and articles published. Some of the online sources are provided by the Strathmore University Library such as Cambridge journals, Chicago journals and Wiley online library. The laws examined are International laws and conventions. The case studies are from European courts. To capture a scenario in which gene editing was successful newspaper articles were relied on.

1.12 Limitations

The research relied on secondary resources as it would be difficult to conduct interviews in Kenya where this technology has not yet been introduced. Further, there are no regulations in Kenya with regards to gene editing that could be analysed. Therefore, the laws relied on are international laws and case laws from outside Kenya.

1.13 Assumptions

The assumptions that are in the research are as stated below;

1. Gene editing CRISPR-Cas 9 technology has been conducted on human beings.
2. There are no adequate international laws to comprehensively regulate gene editing.
3. Genetic modification is a discriminatory tool against the disabled persons.

1.14 Chapter breakdown

Chapter one consists of the introduction, the background of the study, literature review, the research methodology, hypothesis, justification of the research, statement of objectives and research questions.

Chapter two will focus on theoretical framework, using two theories which are Social Darwinism and the Theory of Intersectionality, and their relation to human dignity and discrimination against disabled persons with regards to gene editing.

Chapter three will discuss the question of the capacity of the foetus as a legal person and therefore a holder of legal rights. The aim will be to examine if the disabled person's foetus has legal rights such as the right to health, life, informed consent and autonomy.

Chapter four will focus on international law and its inadequacies in protecting the rights of disabled persons. It will identify gaps that the law has failed to fill. It will also examine how effective these laws on regulation of gene editing have been and the possibilities of adherence with those laws.

Chapter five will highlight the findings with regards to the previous chapters. It will seek to answer whether gene editing is a discriminatory tool and whether it should be outlawed completely or a regulatory framework that conclusively regulates gene editing in a way that it does not violate the right to human dignity and the right to freedom from discrimination for disabled persons implemented. It will also provide recommendations and conclude the research.

1.15 Timeline/duration

Chapter 1 and Chapter 2 will be done by the end of September.

Chapter 3 and Chapter 4 will be done from the 1st September to 16th September.

Chapter 5 will be done by the end of November.

CHAPTER TWO

2.0 Theoretical framework

2.1 Introduction

This chapter will discuss two theoretical frameworks that are, the theory of Social Darwinism and Intersectionality in relation to gene editing and the right to human dignity and freedom from discrimination. The two theories will be discussed separately and tied together with the two rights in question with regards to disabled persons.

2.2 The theory of intersectionality

The theory of intersectionality coined by Kimberly Crenshaw encompasses viewing a person or a group of people or social issue in the way which they face a myriad of discriminations and disadvantages.⁴³ Intersectionality is defined as the resulting effects of different forms of discrimination overlap, particularly for the marginalised group.⁴⁴ Crenshaw's paper argues that black women face discrimination at a higher level compared to white women being that race and gender biases intersect, hence uniform laws for women would not cater for women of colour being that their experiences are different.⁴⁵ Intersectionality proposes that people have different experiences depending on their overlapping identities which then creates a complexity in discrimination.⁴⁶ Crenshaw asserts that the problem in antidiscrimination laws is treating race and gender as being different and independent in experience and analysis.⁴⁷ She uses the experiences of Black women to show how the former distorts the way courts examine discrimination cases on Black women.⁴⁸ The interests of Black women get lost in the broad categorisation of race and

⁴³ <https://www.ywboston.org/2017/03/what-is-intersectionality-and-what-does-it-have-to-do-with-me> on 24 September 2019.

⁴⁴ <https://www.merriam-webster.com/words-at-play/intersectionality-meaning> on 24 September 2019.

⁴⁵ Crenshaw K, 'Mapping the margins: Intersectionality, Identity politics and violence against women of color' 43, *Stanford law review*,6, 1991

⁴⁶ <https://www.ywboston.org/2017/03/what-is-intersectionality-and-what-does-it-have-to-do-with-me/>

⁴⁷ Crenshaw K, 'Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' 1989 *University of Chicago Legal Forum* 1, 1989, 139.

⁴⁸ Crenshaw K, 'Demarginalizing the Intersection of Race and Sex: A black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' 139.

gender as they are only viewed from the White women's and Black men's experiences.⁴⁹ Crenshaw uses analogy of traffic in an intersection to explain this theory;

*'like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars travelling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in an intersection, her injury could result from sex discrimination or race discrimination [...] But it is not always easy to reconstruct an accident: Sometimes the skid marks and the injuries simply indicate that they occurred simultaneously, frustrating efforts to determine which driver caused the harm.'*⁵⁰

Crenshaw in *Mapping the Margins* discusses Structural intersectionality where women of color are situated at the intersection of race and gender which makes their challenges particularly different from white women and black men considering economic, political and social factors.⁵¹ Women of color experience discrimination differently being that they are from a minority race and lead a life of poverty.⁵² She further discusses Political intersectionality which takes into account that women of color are classified under two distinct groups with conflicting political agendas.⁵³ The focus on feminist and antiracist agendas fails to protect the interests of women of color adequately.⁵⁴ Lastly, she discusses Representational intersectionality which concerns depicting women of color through race and gender narratives and how critiques have marginalised the experiences of women of color.⁵⁵

2.2.1 The relation between human dignity, discrimination and the theory of intersectionality

⁴⁹ Crenshaw K, 'Demarginalizing the Intersection of Race and Sex: A black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' 140.

⁵⁰ Crenshaw K, 'Demarginalizing the Intersection of Race and Sex: A black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics' 149.

⁵¹ Crenshaw K, 'Mapping the margins: Intersectionality, Identity politics and violence against women of color' 43, *Stanford law review*,6, 1991, 1250.

⁵² Crenshaw K, 'Mapping the margins: Intersectionality, Identity politics and violence against women of color' 1245.

⁵³ Crenshaw K, 'Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color' 1252.

⁵⁴ Crenshaw K, 'Mapping the margins: Intersectionality, Identity politics and violence against women of color' 1252.

⁵⁵ Crenshaw K, 'Mapping the margins: Intersectionality, Identity politics and violence against women of color' 1283.

Intersectionality has been used by researchers to show discrimination among people with intersecting identities and this has aided in recognising the rights of the marginalised. The disabled persons are a marginalised group with intersecting identities. Ben Smith notes that the perspective of intersectionality towards identity is to acknowledge the different markers can converge and subsist in an individual which then creates a considerably different experience in comparison to any other independent characteristics involved.⁵⁶ The law then fails a significant number of people by not recognizing intersectionality.⁵⁷ It is therefore vital to consider the disabled persons through an intersectional framework so as to combat the challenges in deficit-oriented practices for people with intersecting identities.⁵⁸

In the case of *Perera v Civil Service Commission (1983)*⁵⁹ the appellant was denied work due to a number of characteristics that are inclusive of nationality, age and his ability to speak English.⁶⁰ Moon notes that the appellant not having one factor did not deny him a job opportunity but it decreased his chances and lack of two factors decreased his chances even more.⁶¹

Similarly, in the case of *Degraffenreid v General Motors Assembly (1976)*, which involved five black women suing for employment discrimination, the court denied the defendants claim of combining race and gender discrimination.⁶² Crenshaw opines that the law has failed by treating black women as purely black or purely women and has refused to recognise specific challenges that black women face.⁶³

Clare is of the opinion that intersectionality explains how gender extends to disability, disability then winds around class, which burdens against abuse, abuse then shifts to sexual orientation, which then forms on race, eventually everything building up into one entity.⁶⁴ Take for example,

⁵⁶ Smith B, 'Intersectional discrimination and substantive equality: A comparative theoretical framework' 16 *The equal rights review*, 2016, 73.

⁵⁷ Smith B, 'Intersectional discrimination and substantive equality: A comparative theoretical framework' 84.

⁵⁸ Liasidou A, 'Intersectional understandings of disability and implications for a social justice reform agenda in education policy and practice' 28 *Disability and society*, 3, 2013, 303.

⁵⁹ *Perera v Civil Service Commission (1983)*, Court of Appeal of Britain.

⁶⁰ Smith B, 'Intersectional discrimination and substantive equality: A comparative theoretical framework' 80.

⁶¹ Moon G, 'Multiple discrimination problems -compounded and solutions found?' 3, *Justice Journal*, 2006,89.

⁶² *Degraffenreid v General Motors Assembly (1976)*, United States District court.

⁶³ Crenshaw K, 'Demarginalizing the Intersection of Race and Sex: A black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics'.

⁶⁴ Clare E, *Exile and Pride: Disability, Queerness and Liberation*, South End Press, 1999.

autistic women face oppression based on three different identities; first they are female in a patriarchal society, second, they are disabled in a society that favours ableism and lastly, they are Autistic and are the minority in the Autistic Spectrum Disorder research.⁶⁵ Now, for Autistic women of color the barriers they face are completely different because of their race.⁶⁶

The theory of intersectionality recognizes the inherent differences that exists within a group and takes that into consideration. It is cognizant of the fact that people face discrimination through multiple sources of oppression. Gene editing allows for selection of an offspring based on their gender, race, intellect and ableism. The disabled community is comprised of different persons with different characteristics that include their sex, origin of birth, nationality, race, intellect and have different disabilities. Owing to this, they face discrimination as a result of biases that their potential parents will have in deciding what genetic characteristics that they would desire for their children. Gene editing only seeks to fuel discrimination by allowing selection based on a person's genomes.

Taking into account that there are different types of disabilities, the disparate forms of oppression that disabled persons face are determined by their gender, race, ethnicity, class and political status, it is important to view their experiences independently in order to come up with laws that fully cater to their needs. Human gene editing only promotes discrimination that occurs at different levels and makes the lives of disabled persons more difficult. This reduces their inherent dignity as persons are judged based on their genes and societal standards which make them unacceptable to the community. This paper will attempt to show the various types of discrimination disabled persons face as a result of gene editing and their connection in diminishing their human dignity.

2.3 The theory of Social Darwinism

The term Social Darwinism stems from Darwin's theory of natural selection; he proposes that biological evolution is as a result of living organisms that have favourable traits for survival, to reproduce more than those without, causing the new generations to be more adaptable for survival.⁶⁷ This is in line with the concept of 'survival of the fittest' originating from Herbert Spencer which means that those who are suitably adapted will survive while the weak would

⁶⁵ Saxe A, 'The theory of intersectionality: A new lens for understanding the barriers faced by Autistic women' *Canadian journal of disability studies* 2017, 158.

⁶⁶ Saxe A, 'The theory of intersectionality: A new lens for understanding the barriers faced by Autistic women' 157.

⁶⁷ Darwin C, *On the Origin of species*, (eds), Routledge, London, 2004, 52.

perish, it is the outcome of natural selection.⁶⁸ Galton later then introduced the term eugenics, which is defined as using science in improving the human genome by artificial selective breeding among persons with desirable traits.⁶⁹

Social Darwinism simply means that Darwin's theory of natural selection is applied in society either economically, socially or politically. It is the belief that the struggle for survival between races, individuals and tribes is an engine of social progress.⁷⁰ According to Spencer this social progress is a necessity that human beings must strive for to be perfect in order to survive in their social lives.⁷¹

Some say that this is a misapplication of Darwin's theory of natural selection because it was never to be applied on humans.

2.3.1 The relation between Social Darwinism and human gene editing's impact on disabled persons

The theory of Social Darwinism implies that our biological characteristics influence political and social societies.⁷² The theory arose from Charles Darwin's theory of evolution by natural selection⁷³ in animals and the term 'survival of the fittest' coined by Spencer which meant that those with weak genetic traits would perish and it was not necessary to help them survive.⁷⁴ Social Darwinism has been used by proponents of eugenics to justify prevention of procreation by the unfit which include the disabled.⁷⁵ During Adolf Hitler's regime, Social Darwinism was used to justify the horrible acts of killing Jews and sterilizing Germans with disabilities for the purpose of preservation of the superior race.⁷⁶ Laws that were pro-eugenics were passed worldwide to encourage those with heritable traits to reproduce and to prohibit those who were 'unfit' from

⁶⁸ Howerth I, 'Natural Selection and the Survival of the Fittest' 5 *The Scientific Monthly*, 3, 1917, 253–257.

⁶⁹ Galton J D, Galton J C, 'Francis Galton: and Eugenics today' *Journal of Medical Ethics*, 1998, 99.

⁷⁰ Greene J, 'Darwin as a social evolutionist' 10 *Journal of the History of Biology*, 1, 1997, 1.

⁷¹ Harris M, *The Rise of Anthropological Theory: A History of Theories of Culture*, New York, Crowell, 120-12.

⁷² Halliday R, 'Social Darwinism: A Definition', 14, *Victorian Studies*, 4, 1971, 389-405.

⁷³ Darwin C, *On the Origin of Species*, 1 ed, Routledge, London, 2004.

⁷⁴ Dennis R, 'Social Darwinism, Scientific Racism, and the Metaphysics of Race', 64, *The Journal of Negro Education*, 3, 1995, 243-252.

⁷⁵ Oxford bibliographies, 26 May 2016 <http://www.oxfordbibliographies.com/view/document/obo-9780199756384/obo-9780199756384-0166.xml> on 21 September 2019.

⁷⁶ Bachrach S, 'In the name of Public Health-Nazi Racial Hygiene' *New England journal of Medicine* 2004, 351:417-420.

reproducing.⁷⁷ This was because their genes were deemed inferior. German doctors were obligated to euthanise or rather kill the ‘incurably sick’ without their consent. Gene editing with the aim of cancelling out disability genes is not far from the practices along euthanasia during the Nazi era.

Proponents of gene editing on the human genome have relied on Social Darwinism to substantiate the modification of human genes stating that those with weaker genes should be edited out. The term has also been used to restrict the ‘unfit’ from reproducing.⁷⁸

In the United States eugenics was a form of social progress, being that they enhanced the genetic components of humans, hence improving the human species.⁷⁹ In *Buck v Bell*(1927), the decision of the Supreme court was that sterilizing a ‘feeble minded’ woman was justified being that it was for the good of the rest of the world and there was no need to populate the earth with unfit persons.⁸⁰

It has been stated in the UN International Bioethics Committee of October 2015 that the ethical concerns that were in classic eugenics must not be obscured and likened to the 20th Century modern eugenics ethics, nonetheless, gene editing opens doors for discrimination and stigmatisation of disabled persons.⁸¹ This is especially true with disabled persons who become disabled later in life as a result of accidents, injury and war, thus, they will not be able to correct their genes pre-birth. They will therefore face discrimination and stigmatisation in the new reformed society full of able or ‘normal’ people.

Eugenics has just evolved into Social Darwinism and especially now that human gene editing has acquired a tool, that is CRISPR-Cas 9, which makes ‘perfecting’ the human race easier. Scientists will be playing the role of God by relying on the theory of Social Darwinism, they will be essentially implying that there are some people who are typically not worthy of living and therefore we should get rid of them. Gene editing poses moral and ethical questions of the authority of the one determining that certain people are ‘unworthy’ of life due to their genetic composition and the reasons for killing them. Human beings lose their dignity in defining them as carriers of genes rather than the essence of human nature. This study aims to critic this theory in justifying editing

⁷⁷ Baruch S, Huang A, Pritchard D, Kalfoglou A, Javitt G, Borchelt R, Scott J, and Hudson K, ‘Human Germline Genetic Modification: Issues and Options for Policymakers’ Baltimore: Genetics and Public Policy Center, 2005, 34.

⁷⁸ <http://www.oxfordbibliographies.com/view/document/obo-9780199756384/obo-9780199756384-0166.xml> on 21 September 2019.

⁷⁹ Kevles J, *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, Harvard University press, 1995.

⁸⁰ *Buck v Bell*, (1927) The Supreme Court of the United States.

⁸¹ Conti A, ‘Drawing the line: Disability, Genetic intervention and Bioethics’ *Laws* 3, 2017, 3-5.

out disabled persons. It argues that the scientific world should allow nature to take its own course rather than trying to force artificial selection by editing out disability traits.

CHAPTER THREE

3.0 Rights of the foetus

3.1 Introduction

This chapter will focus on the rights of prospective children with regards to gene editing. It will investigate the extent to which fetuses have been considered to have human rights. The rights to be discussed are inclusive of legal entitlements to health, life, autonomy and informed consent.

3.2 Legal personality of the foetus

First, we must discuss the capacity of a foetus as a legal person so as to determine whether they are capable of having rights that are protected by the state. In the classical case of *Roe v Wade* (1973) the court was of the opinion that the term person, as enshrined in the Fourteenth amendment was not inclusive of the unborn.⁸² This implies that the foetus has no constitutional rights.⁸³

On the other hand, the Universal Declaration of Human Rights under Article 3 recognises each and every person is entitled to life.⁸⁴ Article 6 (1) of the ICCPR also provides for the safeguarding of human life.⁸⁵ Article 6(5) further prohibits pregnant woman from being sentenced to death.⁸⁶ It could then be presumed that the life of the unborn is protected from the provision of prohibition of a death sentence on a pregnant woman.⁸⁷ The Convention on the Rights of the Child in its preamble conveys that a child because of his physical and mental infantilism, requires exceptional

⁸² *Roe v Wade* (1973), The United States Supreme Court.

⁸³ Chen W, 'Human germline gene editing: engineering an unstoppable train' 28, *Southern California Interdisciplinary Law Journal*, 2, 2019, 547.

⁸⁴ Article 3, UDHR.

⁸⁵ Article 6 (1), ICCPR.

⁸⁶ Article 6 (5), ICCPR.

⁸⁷ Submission of the pro life campaign to general discussion on article 6 (right to life) of the International Covenant on Civil and Political Rights, <https://www.ohchr.org> >HRBodies>CCPR>Discussion>ProLifeCampaign_ on 7 September 2019.

protections and care, comprising proper legal rights, prior to and after birth.⁸⁸ It would then be right to assume that because the fetus gains legal personality due to its right to life and essentially being a human being, it is therefore competent of legal rights. Meyer contends that future people can be bearer of rights.⁸⁹ He is of the opinion that rights are attributed to persons by reason of them being human regardless of the type of human they are.⁹⁰ He argues that causing harm to an unborn child today adversely affects the interests and infringes on the rights of future people.⁹¹

3.3 Right to consent

With regards to the issue of consent, Shawna Benston expresses that the discussion of consent should start with the cognizance that coming generations are not able to give consent to acquiring genetic characteristics gotten through natural birth or through gene modification technology.⁹² The foetus has no way of giving consent to editing of its own genetic makeup.

Article 6 of the Convention on Human Rights and Biomedicines provides that when a person is not able to consent to medical interference, it should directly benefit him or her.⁹³ The Universal Declaration on Bioethics and Human rights under Article 7 stipulates that medical practice should only be undertaken on a person who is unable to consent if it is in his or her best interest.⁹⁴ Article 5 of the declaration provides that for persons not able to exercise independence, concrete actions should be undertaken to safeguard their rights and freedoms.⁹⁵ Additionally, future generations should be protected when applying science to human life and this includes their genes.⁹⁶

⁸⁸ Preamble, Convention on the Rights of the Child.

⁸⁹ Meyer H, 'Past and Future; The case for a threshold notion of harm' *Rights culture and the law, Themes from the legal and political philosophy of Joseph Raz*, Oxford University Press, 2003, 145.

⁹⁰ Meyer H, 'Past and Future; The case for a threshold notion of harm' *Rights culture and the law, Themes from the legal and political philosophy of Joseph Raz*, Oxford University Press, 2003, 146.

⁹¹ Meyer H, 'Past and Future; The case for a threshold notion of harm' *Rights culture and the law, Themes from the legal and political philosophy of Joseph Raz*, Oxford University Press, 2003, 145.

⁹² Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' *Laws*, 2016, 5, 5.

⁹³ Article 6, Convention on Human Rights and Biomedicine.

⁹⁴ Article 7, Universal Declaration on Bioethics and Human Rights.

⁹⁵ Article 5, Universal Declaration on Bioethics and Human Rights.

⁹⁶ Article 16, Universal Declaration on Bioethics and Human Rights.

Paul Knoepfler opines that parents who decide to make alterations to their children's genes for non-therapeutic reasons have dictated the kind of future the child will have without their consent.⁹⁷ The question should not be consent but whether that consent is material to medical practice especially because it is for the benefit of the child.⁹⁸ Foht argues that using CRISPR to edit out those mutations is a preventative measure to protect the child that embryo develops to be.⁹⁹ It is assumed that parents are the most appropriate decision makers for their children before they attain independence being that they have more interest in the life of the child.¹⁰⁰ However, this has been contested in issues where the parents have decided that no life is better than living with a certain condition.¹⁰¹ Equally salient to note is that some people living with different disabilities have published articles taking the position that they would not alter their conditions if given the chance.¹⁰²

Moreover, we must question whether the foetus can exercise his autonomy rights. Jurgen Habermas argues that once a person discovers that their characteristics were pre-natally determined by someone else, it will affect the person's perception on what their independence and equal membership in society entails.¹⁰³ Joel Feinberg argues that children have autonomy rights that could also be held in trust by their parents for as long as they push towards the chances of the child's fulfilment.¹⁰⁴ In this regard, it is implied that some genetic interventions are permissible while others are not.¹⁰⁵ Children's anticipatory right to autonomy is violated when their

⁹⁷ Knoepfler P, *GMO Sapiens: The life-changing science designer babies*, (eds) WSPC, 2015.

⁹⁸ Foht B, 'Gene editing: Old moral questions' *The New Atlantis*, 48, 2016, 7.

⁹⁹ Foht B, 'Gene editing: Old moral questions' *The New Atlantis*, 48, 2016, 7.

¹⁰⁰ Ormond E, Mortlock P, Scholes t, Bombard Y, Brody C, Faucett E, Garrisson N, Hercher L, Isasi R, Middleton A, Musunuru K, Shriner D, Virani A, Young E, 'Human germline genome editing' 101, *American journal of human genetics*, 2, 2017, 167-176.

¹⁰¹ Botkin J, 'The legal concept of wrongful life' 259, *JAMA*, 10, 1988, 1541-1545.

¹⁰² Hayden C, 'Should you edit your children's genes?' 530, *Nature News*, 7591, 2016, 402-405.

¹⁰³ Habermas J, '*The Future of human nature*' (eds) Polity press, 2003.

¹⁰⁴ Feinberg J, 'The Child's Right to an Open Future' In W. Aiken and H. LaFollette, *Whose Child? Children's rights, parental authority and state power*, Rowman & Littlefield, 1980, 124-53.

¹⁰⁵ Nuffield Council on Bioethics, *Genome editing and human reproduction: social and ethical issues*, July 2018, 69.

opportunities are limited.¹⁰⁶ The child's ability to choose for themselves is extinguished as the parent ultimately decides the future of the child.

3.4 Autonomy rights

Some cases of fetal harm show the extent of minor's autonomy.¹⁰⁷ The question that follows is whether a child can claim damages for defects caused by CRISPR.¹⁰⁸ Article 8 of the Universal Declaration on the human genome stipulates that one is entitled to reparation for any harm caused as a result of interference in their human genome.¹⁰⁹ In the case of *Smith v Brennan* (1960), the court posits that a minor can bring a case forth for damages caused to him pre-birth regardless of the status of the minor as a person, at the time the injury was caused.¹¹⁰ The facts of this case were that the plaintiff sustained injuries in a car accident that occurred during the time he was in his mother's womb, which caused him to have deformities after birth, ensuing from the defendant's negligence.¹¹¹ Consequently, the New Jersey Supreme court held the driver liable.¹¹²

3.5 Right to health

Furthermore, the ICESR recognises the right to health of every person and requires state parties to ascertain that they prevent and treat diseases.¹¹³ Article 25 of the CRPD also recognises that states are obligated to ensure that disabled persons are afforded the right to health without discrimination.¹¹⁴ From this we could infer that the foetus has a right to gene editing¹¹⁵ to prevent

¹⁰⁶ Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' *Laws* 2016, 5, 1-5.

¹⁰⁷ Cunningham A, 'A cleaner, CRISPR Constitution: Germline Editing and Fundamental Rights' 27 *William Mary Bill of Rights Journal*,3, 2019, 877.

¹⁰⁸ Cunningham A, 'A cleaner, CRISPR Constitution: Germline Editing and Fundamental Rights' 27 *William Mary Bill of Rights Journal*,3, 2019, 877.

¹⁰⁹ Article 8, Universal Declaration of Human genome and human rights.

¹¹⁰ *Smith v Brennan* (1960), Supreme Court of New Jersey.

¹¹¹ *Smith v Brennan* (1960), Supreme Court of New Jersey.

¹¹² *Smith v Brennan* (1960), Supreme Court of New Jersey.

¹¹³ Article 12, International Covenant on Economic, Social and Cultural Rights.

¹¹⁴ Article 25, CRPD.

¹¹⁵ Chen W, 'Human germline gene editing; engineering an unstoppable train' 28, *Southern California Interdisciplinary Law Journal*, 2, 2019, 547.

genetic diseases that may be detected during the fetal stage. However, disability is not a disease per se. For some disability is seen as a character trait of a person rather than inability, for instance deafness has been considered a cultural trait rather than a disability.¹¹⁶ Noelle opines that one should have a right not to have their genes altered and to inherit genetic characteristics that have not been artificially modified.¹¹⁷ Nonetheless, it is unlikely that the courts would uphold this right¹¹⁸ due to lack of case law to support the entitlement to healthy birth,¹¹⁹ also the life of the baby is not at risk meaning that it would not be in the state's interest to interfere as its interest is in promoting life,¹²⁰ it would also impose a huge burden on the medical field¹²¹ and the courts would consider the resulting effects of genetically editing out certain characteristics on society in the treatment of existing persons with disabilities.¹²² Benston posits that autonomy rights and right to health are related.¹²³ One has the right to choose the best healthcare.

3.6 Right to life

Article 10 of the CRPD stipulates that all persons have a right to life and that the enjoyment of this right by disabled persons should be in the same way as others.¹²⁴ Rosamund posits that in English law the foetus is not legally entitled to life.¹²⁵ Notwithstanding, English courts have made efforts to compensate for damages caused to the foetus by third parties.¹²⁶ Article 2 of the ECHR stipulates

¹¹⁶ Jones A, 'Deafness as culture: A psychosocial perspective' 22, *Disability Studies Quarterly*, 2, 2002, 51-60.

¹¹⁷ Lenoir N, Respect for life and the law of the living, in Noble D, Didier V, (eds), *The Ethics of life*, (eds) UNESCO, Paris, 1998.

¹¹⁸ Chen W, 'Human germline gene editing: engineering an unstoppable train' 28, *Southern California Interdisciplinary Law Journal*, 2, 2019, 547.

¹¹⁹ Barrett K, 'Prosecuting Pregnant Addicts for Dealing to the Unborn' 1991.

¹²⁰ Carbone, 'Legal Applications of the "Best Interest of the Child" Standard. Judicial Rationalization or a Measure of Institutional Competence?', 134 *PEDIATRICS*, 111 ,2014.

¹²¹ <https://www.forbes.com/sites/arneweitraub/2017/12/01/gene-therapy-is-booming-but-how-will-we-manage-the-costs/#220ec1c1604d> on 4 November 2019.

¹²² Shapiro M, *Bioethics and law: cases, materials and problems*, 2ed, 2003, 468- 471.

¹²³ Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' *Laws* 2016, 5, 1-5.

¹²⁴ Article 10, CRPD.

¹²⁵ Scott R, 'The English Fetus and the Right to Life' 11, *European Journal of Health Law*, 4, 2004, 347.

¹²⁶ Scott R, 'The English Fetus and the Right to Life' 11, *European Journal of Health Law*, 4, 2004, 349.

that everyone has a right to life.¹²⁷ However, in *Paton v U.K (1980)* the Commission rejected the argument that the term ‘everyone’ in article 2 of the Convention was inclusive of the foetus.¹²⁸ Additionally, it was the Commission’s opinion that the right to life of the foetus cannot be separated from the mother’s since their lives are interconnected.¹²⁹ In the case of *Vo v France* (2004), the court rejected the notion of a foetus as a person and accordingly it is not legally entitled to life and if the foetus has a right to life it will be limited according to the interests of the mother.¹³⁰ Recognising the right to life of the foetus would conflict with the pregnant woman’s rights.¹³¹ Nevertheless, Judge Traja’s opinion in the case is that life exists before birth, within the framework of Article 2 of the ECHR and therefore must be protected.¹³²

Chen is of the opinion that the framework used in wrongful life cases could be used to assess the damage caused by differences in medical costs where the child is born healthy with a mutation and where a child is birthed without a mutation.¹³³ In the case of *Kealey v Berezowski* (1996), Justice Lax posits that wrongful life claims include those where pregnancy is planned with the help of a physician but a defect still arises.¹³⁴

3.7 Conclusion

In conclusion, there is great ambiguity on whether a foetus has legal rights therefore an uncertainty on whether a claim can be brought claiming that the foetus has any of the rights discussed above. The life of the foetus is not guaranteed in any legal instrument as the wording indicates human or persons. The foetus is not stated to be inclusive in the latter terms. And in any case, this right may

¹²⁷ Article 2, ECHR.

¹²⁸ *Paton v U.K*, European Commission on Human Rights, Judgement of 13 May 1980.

¹²⁹ *Paton v U.K*, European Commission on Human Rights.

¹³⁰ *Vo v France*, ECtHR, Judgement of 8 July 2004.

¹³¹ *Vo v France*, ECtHR.

¹³² *Vo v France*, ECtHR.

¹³³ Chen W, ‘Human germline gene editing; engineering an unstoppable train’ 28, *Southern California Interdisciplinary Law Journal*, 2, 2019, 546.

¹³⁴ *Kealey v Berezowski* (1996), Ontario Court of Justice.

be subject to limitation by the mother's rights. However, case law shows that one can claim damages in case the foetus suffers injury while in the mother's womb.

CHAPTER FOUR

4.0 International laws with regards to the right to human dignity and freedom from discrimination of disabled persons in gene editing technologies

4.1 Introduction

This chapter will investigate the international legal system for the purpose of finding out whether it is sufficient to protect and uphold the rights of disabled persons in relation to the constantly evolving biomedical technology particularly CRISPR-Cas9.

CRISPR-Cas 9 enables scientists to modify the human genome by adding, deleting and altering genetic material on it.¹³⁵ Changes made on the genome of a human being are permanent and can be passed onto future generations which could alter the human species in entirety.¹³⁶

There are no specific international laws or norms regulating genome editing however, legal provisions that cater to scientific research and modification on human genes do exist.

National/Municipal regulation in regard to this does exist, however it will not be practical since people will go to countries that permit it and it is therefore critical to have international laws governing it.¹³⁷ Previously, there has emerged a form of 'reproductive tourism' where people migrate to areas where medical interventions are not banned which arises from not having a uniform ban on reproductive technologies.¹³⁸ National boundaries have little effect in the scientific arena and therefore having regulation in certain nations on CRISPR will be ineffective.¹³⁹

Shawna Benston's article states that the considerations on whether CRISPR should be regulated must be centered on willful disability alleviation, non-intervention and deliberate initiation of

¹³⁵ <https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting>

¹³⁶ <http://www.dicyt.com/news/gene-editing-is-a-new-challenge-for-ethics-and-the-law>

¹³⁷ International summit on gene editing, Committee on science, technology, law policy and global affairs, December 1-3.

¹³⁸ Spar D, 'Reproductive tourism and the regulatory map' 352 New England journal of medicine, 6, 2005, 531-533.

¹³⁹ Harris L, 'Recognizing and legitimizing the transnational scientific governance of human gene editing, 11, McGill Journal of Law and Health, 2, 2017, 102-103.

disability.¹⁴⁰ This is because some people will choose to use this technology for their benefit while others will not, and the ones who opt out of editing their genes face stigmatization.¹⁴¹ She then questions what the right way to use CRISPR-Cas 9 without diminishing the value of persons who have not used the technology would be.¹⁴² She further states that tensions may arise among certain rights such as the right of the child to an undetermined future, entitlement to those already living with disability and potential differently abled persons to adequate accommodations and the right to privacy in marriage and family.¹⁴³

4.2 International laws and case law on application of genetic technologies

First, Article 1 of the Universal Declaration of Human Rights provides that every person is equal in dignity and human rights.¹⁴⁴ The Convention on Human Rights and Biomedicine then goes on to explicitly set forth that human beings should be treated equally in the use of biology and medicine for the purpose of protecting human dignity.¹⁴⁵ Secondly, Article 15 of the same stipulates that persons should be protected during scientific research on biology and medicine.¹⁴⁶ The same article also recognises the freedom of scientists to conduct research as long as human rights are protected.¹⁴⁷ Furthermore, Article 12 of the Universal Declaration on the Human Genome and Human Rights declares that freedom to conduct research is connected to freedom of thought.¹⁴⁸ It is also important to note that Article 21 further asserts that the body of a person shall not be used for financial gain.¹⁴⁹ The Universal Declaration on the Human Genome and Human Rights stipulates that the right to dignity and human rights of persons should be respected despite one's genetic characteristics and that implies that people should not be reduced to their genetic

¹⁴⁰ Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' *Laws* 2016, 5, 1-5. Gene editing can be used to edit out disability hence intentional reduction of disability, it can also be used to create disability or engineer it on oneself that is, intentional inducing of disability and on the other hand, one may opt not to interfere with genetic constituents altogether.

¹⁴¹ Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' 1-5.

¹⁴² Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' 1-5.

¹⁴³ Benston S, 'CRISPR, a Crossroads in Genetic Intervention: Pitting the Right to Health against the Right to Disability' 1-5.

¹⁴⁴ Article 1, UDHR.

¹⁴⁵ Article 1, Convention on Human Rights and Biomedicine.

¹⁴⁶ Article 15, Convention on Human Rights and Biomedicine.

¹⁴⁷ Article 15, Convention on Human Rights and Biomedicine.

¹⁴⁸ Article 12(b), Universal Declaration on Human Genome and Human Rights.

¹⁴⁹ Article 21, Convention on Human Rights and Biomedicine.

constituents as envisioned in Article 2.¹⁵⁰ The Article also notes that there are unique aspects of a person and that uniqueness and diversity should be respected.¹⁵¹

Equally important, is Article 4 of the declaration which reiterates that in its natural occurring state the human genome should not be used for commercial purposes.¹⁵² As illustrated in the *Howard Florey\Relaxin patent (2002)*¹⁵³ case concerning a patent application for a hormone called relaxin that allows the uterus to relax during birth, the opponents proclaimed that it was an infringement of human dignity to isolate a pregnant woman's gene for financial gain.¹⁵⁴ On the other hand, the response was that there was consent from the parties and lots of substances that were life-saving were acquired in the same way.¹⁵⁵ The question then becomes whether consent is a justifiable reason to allow trade in human genes and if allowing the free market to prevail would not infringe on the right to human dignity. In addition, who is to give consent and also what then for the future generations who have not consented to have their genes edited. Moreover, Article 12 of the Declaration seeks to address the inequalities that may occur as a result of lack of financial resources by declaring that benefits of advancement in medicine, genetics and biological technology shall be availed to all taking into account the dignity of persons.¹⁵⁶ Conversely, if the law did not provide for equality, private interests among the scientists and corporate bodies in the race to commercialise gene editing, may only allow access of the technology to only a few which contradicts with benefit sharing.¹⁵⁷ Additionally, the United States Supreme Court held that patenting of the human gene is not permitted because DNA is a product of nature.¹⁵⁸ However, in Europe patenting of DNA is not seen as being contrary to public order and would therefore be permitted.¹⁵⁹

¹⁵⁰ Article 2, Universal Declaration on Human Genome and Human Rights.

¹⁵¹ Article 2, Universal Declaration on Human Genome and Human Rights.

¹⁵² Article 4, Universal Declaration on Human Genome and Human Rights.

¹⁵³ Howard Florey/Relaxin patent (2002), European Patent Organisation.

¹⁵⁴ https://www.wipo.int/wipo_magazine/en/2006/02/article_0009.html

¹⁵⁵ https://www.wipo.int/wipo_magazine/en/2006/02/article_0009.html

¹⁵⁶ Article 12, Universal Declaration on Human Genome and Human Rights.

¹⁵⁷ Mulvihill J, Capps B, Joly Y, Lysaght T, Zwart H, 'Ethical issues of CRISPR technology and gene editing through the lens of solidarity' *British medical Bulletin*, 2017, 21.

¹⁵⁸ Joly Y, Tonin PN. Social, ethical and legal considerations raised by the discovery and patenting of the BRCA1 and BRCA2 genes. *New Genetics Society* 2014; 33:167–80.

¹⁵⁹ Plomer A, Torremans P, *Embryonic Stem Cell Patents*, Oxford University, 2009.

Furthermore, Article 6 of the same prohibits discrimination along the lines of genetic characteristics of people.¹⁶⁰ Similarly, the additional protocol to the cloning of human beings provides that creation of identical human beings in genetic characteristics is equated to instrumentalization of human beings.¹⁶¹ From the above discussion, it is conclusive that international instruments which concern biomedicine and genetics seem to imply that the protection of embryos and prevention of commercialisation equals dignity.¹⁶² In addition, Article 11 of the Universal Declaration on Bioethics and Human rights avers that violation of dignity occurs when there is discrimination.¹⁶³

In *Ghaidan v Godin-Mendoza* (2004) the court's decision was that treating a person as if they are less valued constitutes a violation of their human dignity.¹⁶⁴ In another case, *Purhoit and Moore v Gambia* (2004) it was held that each and every human being is guaranteed the right to human dignity exempt discrimination.¹⁶⁵ In the Convention on the Rights of Persons with disabilities, discrimination is defined as any differentiation or excluding of the disabled with the result of not recognising their human rights, or effecting the enjoyment of rights, equally with others.¹⁶⁶ Article 11 of the Universal declaration prohibits practices that are against human dignity.¹⁶⁷

Moreover, Article 10 expresses that studies on the human genome and its application should not be preferred over human rights.¹⁶⁸ Article 2 of the Convention of Human Rights and Biomedicine also notes that the interests of society should be secondary to that of the human being.¹⁶⁹ Further, the convention in Article 13 asserts that modifications on the human genome are prohibited unless they are for therapeutic, preventive and diagnostic purposes.¹⁷⁰ In addition, Article 12 affirms that tests carried out to determine if there are any genetic diseases should only be for health purposes.¹⁷¹ Body enhancements are not included in the laws. Presently, gene editing technologies present the

¹⁶⁰ Article 6, Universal Declaration on Human Genome and Human Rights.

¹⁶¹ Additional protocol to the convention on human rights and dignity of the human being with regard to the application of biology and medicine, on the prohibition of cloning human beings.

¹⁶² Beyleveld D and Brownsword R, 'Human dignity, human rights and human genetics' 61 *The Modern law review*, 1998, 665.

¹⁶³ Article 11, Universal Declaration on Bioethics and Human Rights.

¹⁶⁴ *Ghaidan v Godin-Mendoza* (2004), United Kingdom Supreme Court.

¹⁶⁵ *Purhoit and Moore v Gambia*, African commission on human rights, communication no 241/01, 2003.

¹⁶⁶ Article 2, Convention on the Rights of Persons with Disabilities.

¹⁶⁷ Article 11, Universal Declaration on Human Genome and Human Rights.

¹⁶⁸ Article 10, Universal Declaration on Human Genome and Human Rights.

¹⁶⁹ Article 2, Convention of Human Rights and Biomedicine.

¹⁷⁰ Article 13, Convention on Human Rights and Biomedicine.

¹⁷¹ Article 12, Convention on Human Rights and Biomedicine.

fear of having eugenics repeat itself since it can be used for modifying and enhancing the human body and not only for treatment.¹⁷² Article 28 of the convention provides for a public debate on developments in biology and medicine.¹⁷³ This is to ensure that there is public participation when it comes to scientific developments in human life. The convention on the rights of persons with disabilities in its preamble stipulates disabled persons should be afforded an opportunity to take part in decision-making on policies affecting them.¹⁷⁴

The declaration on bioethics and human rights also takes cognizance that harm to individuals who participate in gene editing should be minimized.¹⁷⁵ Article 8 of the Universal Declaration provides for damages that may occur as a result of interference in the human genome.¹⁷⁶ Article 24 of the Convention sets out that persons who suffer damage have the right to compensation.¹⁷⁷ Moreover, Article 23 provides that where there is infringement of rights adequate judicial protection should be provided.¹⁷⁸ It is clear that the law presumes that there may be consequences after scientific intervention in humans and avails remedies for such cases. It is however impossible to compensate for irreparable harms such as mutations, defects and diseases that may occur as a result.

4.3 Inadequacies of these regulations

First, it is important to note that if the regulation process is made too stringent or if it takes a precautionary approach can limit or slow progress of biological advancements and those that may need it will be at a loss.¹⁷⁹ Charo argues that regulation should be set in place when there is a high level of risk which would then allow biological products accessible to the market at a faster rate.¹⁸⁰ The down side of international instruments is that they lack the enforceability factor and also they will not be applicable to States that have not ratified them.¹⁸¹ Charo also notes that the United States, even though they regulate before biological or medicinal products enter the market, it

¹⁷² Lenaola I, Mutugi M, *Bioethics of Medical advances and genetic manipulation: legal, philosophical and moral perspectives*, longhorn publishers, Nairobi, 2019.

¹⁷³ Article 28, Convention on Human Rights and Biomedicine.

¹⁷⁴ Preamble, Convention on the Rights of persons with Disabilities.

¹⁷⁵ Article 4, Universal Declaration on Bioethics and Human Rights.

¹⁷⁶ Article 8, Universal Declaration on Bioethics and Human Rights.

¹⁷⁷ Article 24, Convention on Human Rights and Biomedicine.

¹⁷⁸ Article 23, Convention on Human Rights and Biomedicine.

¹⁷⁹ Charo A, 'Legal and regulatory context of Human Gene editing' 32 *Issues in science and technology* 3,2016, 39-44.

¹⁸⁰ Charo A, 'Legal and regulatory context of Human Gene editing,' 39-44.

¹⁸¹ Charo A, 'Legal and regulatory context of Human Gene editing,' 39-44.

becomes harder to control the actions of practicing physicians once the product enters the market.¹⁸²

States should come together after consultations and debate together with specific interest groups and come up with laws on what is permitted and what is not under gene editing. This universality of laws will prevent people from going to other countries and accessing the technology to modify their genetic characteristics locally in those countries that favour gene manipulation for purposes other than medical treatment. Extensive research should be carried out before allowing gene modification on the body of a person this is due to the fact that CRISPR-Cas 9 is done on the human germline which makes it heritable unlike in the somatic sense where it would be used for therapeutic purposes such as identifying genetic diseases and treating them.¹⁸³ Another consideration would be whether this technology would be available to all, keeping in mind that there are third world countries and the research will mainly focus on ‘western’ medicine.¹⁸⁴ In the International summit, Nigeria expressed its interest in gene editing due to the large number of people suffering from sickle cell in their country of which, unfortunately they do not have the technology.¹⁸⁵

The international instruments discussed above could possibly regulate gene editing but there would be grey areas such as what forms of gene editing should be permitted and what constitutes a disability that should be cut out or altered. There are ethical concerns that people and States generally are most concerned about, which could prevent the technology from ever coming into use notwithstanding that it would be beneficial to the human species.¹⁸⁶ Francis Fukuyama opines that while most people are occupied with surveilling ethical stances, advantages and disadvantages of numerous technologies, practically no one has been paying attention to what

¹⁸² Charo A, ‘Legal and regulatory context of Human Gene editing,’ 39-44.

¹⁸³ Newson A, Wrigley A, ‘Being Human: The Ethics, Law and Scientific Progress of Genome Editing’ 87 *Australian Quarterly* 1, 2016, 7-8.

¹⁸⁴ International summit on gene editing, Committee on science, technology, law policy and global affairs, December 1-3.

¹⁸⁵ International summit on gene editing, Committee on science, technology, law policy and global affairs, December 1-3.

¹⁸⁶ Bennet B, ‘Expanding Horizons: Scientific frontiers, legal regulation and globalization’ 19, *Indiana Journal of Global Legal Studies* 2, 2012, 526.

types of institutions would be required to permit societies to supervise the rate and range of development of technology.¹⁸⁷

Bennet points out that in order to capture the inadequacies in our laws with regards to technology, the way these technologies relate to each other need to be looked at and also for efficiency, laws need to adapt to changing times.¹⁸⁸ Han Somsen argues that regulation should be founded on honour for human rights and not on local morals and should avoid being precautionary.¹⁸⁹ In that regard, some have argued that people's fears are based on a moral fallacy and that scientific technology should be governed by what is in reality and the data presented.¹⁹⁰ It is however important to recall the history of the role of genetics in eugenics and the harms it caused to the dignity of persons.¹⁹¹

4.4 Conclusion

In conclusion, the laws with regards to biotechnology and human genes discussed above have attempted to regulate the scientific advancements inconclusively. The regulators need to come up with laws that are specific to gene editing particularly CRISPR-Cas 9 because of its ability to spread worldwide due to its affordability. Undoubtedly, for these laws to be effective they need to be ratified by all countries to avoid conflict of laws and also require an enforceability mechanism which may include sanctions. At this point in time we see that there are different laws and different approaches to gene editing technologies. Some countries seem to favour the technological advancements whereas some do not tolerate interventions on the human gene. It is true that there are risks that come about when gene editing is allowed on the human gene however, it may be advantageous because it could cure diseases such as Huntington's. To sum it up, states need to come together and come to an agreement on where the line on gene editing should be drawn after carrying out extensive research and come up with effective rules to govern the ways this technology will be used to prevent misappropriation.

¹⁸⁷ Fukuyama F, *Our Posthuman Future: Consequences of biotechnology revolution*, Farrar, Straus, and Giroux, London, 2002.

¹⁸⁸ Bennet B, 'Expanding Horizons: Scientific frontiers, legal regulation and globalization,' 524.

¹⁸⁹ Somsen H, 'Regulating human genetics in a neo-genetic era' in Murphy T, *New Technologies and Human Rights*, Oxford Publishers Online, 2009.

¹⁹⁰ Rushton J, Jensen A, 'James Watson's most inconvenient truth: Race realism and moralistic fallacy' 71, *Medical hypothesis* 2008, 629-640.

¹⁹¹ Rushton J, Jensen A, 'James Watson's most inconvenient truth: Race realism and moralistic fallacy' 630.

CHAPTER FIVE

5.0 Research findings, conclusion and recommendations

5.1 Introduction

This chapter will discuss the research findings from the discussions in the previous chapters, come up with a conclusion and provide recommendations.

5.2 Discussion of findings

This study's aim was to determine whether the practice of gene editing is discriminatory towards the disabled persons, predominantly a violation of their right to human dignity and freedom from discrimination. This chapter will discuss the research findings as per the research questions posed in Chapter One.

Does the foetus have legal rights? Chapter 3 discusses the rights of the foetus. It seeks to determine whether the foetus has legal rights. Case law seems to reject the idea that an unborn child can have the right to life. In the case of *Roe v Wade* (1973)¹⁹² an unborn child was not included in the definition of a person. Similarly, in *Vo v France* (2004)¹⁹³ the court implied that the right to life of the child would be determined by the mother's interests since their lives are intertwined. The mother has the right to abort her child if her life is in danger. Statutes advocate for the protection of the right to life but do not explicitly state whether the foetus has a right to life. The foetus is nowhere mentioned in the legal instruments. However, case law has shown that one can claim damages from injuries caused in utero. Undoubtedly, if there is no specific right to life for the foetus then there is no right as a legal person for the foetus. Consequently, no guarantee for the legal protection of dignity and freedom from discrimination of the foetus.

Do the laws adequately protect the rights of disabled persons when it comes to gene editing? As discussed in Chapter 4, there are no laws in Kenya to regulate gene editing. There are no laws that specifically regulate gene editing even on the international realm. However, there are international instruments on applications of scientific biological modifications on human beings that could be

¹⁹² *Vo v France*, ECtHR.

¹⁹³ *Roe v Wade* (1973), The United States Supreme Court.

relied on in protecting human rights with regards to gene editing. The instruments seek to protect the dignity of persons by placing it at the center of regulation. They prohibit commercialisation of the human genome for the purpose of safeguarding human dignity. They also reject modification towards body enhancement and only permit it in cases where it would benefit the health of persons. All these instruments do not prohibit gene editing particularly CRISPR neither do they try to regulate it. For this reason, it would be easy for anyone to go around the law and edit on the human genome and not face consequences. These loopholes need to be filled in order to adequately protect disabled persons against violations of human dignity and freedom from discrimination with regards to CRISPR application. Additionally, according to Chapter Four the enforceability of international instrument becomes difficult due to the lack of an enforceability mechanism. There is also the fear that robust regulation may slow down development and prevent people from benefiting from gene editing. These fears have to be put aside for the sake of preventing consequences and to allow enough research to be carried out on safe gene editing.

Is gene editing discriminatory? To answer the main question for this study, the hypothesis is confirmed that gene editing to some extent is discriminatory despite being beneficial. CRISPR-Cas 9 is meant to alter and modify genes. Editing of genetic characteristics of disabled persons proves the societal construct that the lives of disabled persons are not worth living and that they are defective. It allows society to form beliefs that there are perfect and imperfect humans. Parents will discriminate their unborn children according to their genetic traits just as unborn children with Down Syndrome are aborted due to their condition. According to Chapter Two we see similarities in Social Darwinism and gene editing using CRISPR as it is a form of artificial human selection. Statutes concerned with biomedicine and genetics aim to protect the dignity of persons in the face of scientific inventions. However, the dignity of persons is still undermined when it comes to gene editing since a person's value is measured by the quality of their genetic characteristics. Eventually, human beings will be treated as a vessel of commerce as people will be trading genes. Disabled persons already existing at a time when everyone is seeking perfection by editing their genes, will face stigmatization in institutions just because they are different. On the other hand, CRISPR promises benefits that could solve health problems that are crippling the world. The right to health cannot be denied to any person. The purpose of law is to protect citizens and not to prevent development by denying access to certain resources. However, it is the responsibility of states to conduct comprehensive research on the dangers and benefits of CRISPR before allowing

it to be used on human beings. Furthermore, they need to ensure its use will not lead to discrimination of certain people and that every person will be able to access it.

5.4 Conclusion

This research concludes that gene editing violates the right to human dignity of disabled persons and their freedom from discrimination by its very nature. For gene editing to work there has to first be a distinction between abled and disabled humans for it to be used on a person. After that distinction is when people will opt to use it to correct the deformity or rather alter the gene. The tool CRISPR is designed to further differentiation on the basis of genes. Thus, its nature is obviously based on discrimination of human beings. It has also been likened to eugenics which could cause consequences of widespread discrimination towards disabled persons. Additionally, the legal instruments in place do not anticipate the violations of rights in cases of misuse of CRISPR gene editing that may arise, neither do they seek to protect the unborn or future generations. The current laws may be open to abuse considering the lack of gene editing specific regulations. Therefore, there is need for regulation on the use of CRISPR. On the other hand, it is well noted that the benefits of gene editing could also preserve the lives of human beings. However, the risks seem to be more perilous and should not be ignored.

5.5 Recommendations

This research recommends that States come up with an international treaty or standards for CRISPR technology to protect the interests of persons inclusive of the unborn. These standards should be common to all countries so as to prevent unethical uses of this technology. The dignity of persons should be at the core of these standards. States should implement laws that hinder discrimination of disabled persons and also those who choose not to use gene editing on their offspring. Further research should be carried out on this technology to determine the safest ways to conduct medical interventions on human beings using CRISPR.

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