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HOW TO GET YOUR DREAMLIKE CHILD:

AN OVERVIEW OF ETHICAL THEORIES AND MULTI-LEVEL GOVERNANCE RELATED TO RECENT BIOTECHNOLOGICAL PRACTICES OF CHILD SELECTION AND DESIGN.

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To Edoardo and Clotilde,
my unique,
perfectly imperfect babies.

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PART 2) BIOETHICAL COMMITTEES AND GOVERNANCE

ACRONYMS

AHR = Assisted Human Reproduction

AF = Assisted Fertilization

CNB = Comitato Nazionale di Bioetica (National Committee on Bioethics)

CoE = Council of Europe

CRC = Convention on the Rights of the Child

CRISPR = Clusters of Regularly Interspaced Short Palindromic Repeats

EC = European Commission

GE = Genetic Engineering

GGE = Germline Gene Editing

HE = Human Enhancement

HGE = Human Genome Editing

IBC = International Bioethics Committee

ICB = Italian Committee on Bioethics

IVF = In Vitro Fertilization

MFPR = Multifetal Pregnancy Reduction

NGO = Non-Governmental Organization

OHCHR = Office of the High Commissioner on Human Rights

PGD = Prenatal Genetic Diagnosis

PP = Precautionary Principle

UDHGHR =Universal Declaration on the Human Genome and Human Rights

UN = United Nations

UNESCO = United Nations Education, Scientific and Cultural Organization

UPV CAV-MPV = Uniti per la Vita, Centro Aiuto alla Vita-Movimento per la Vita

WHO = World Health Organization

WTA = World Transhumanist Association

ABSTRACT

This thesis develops around the implications of new biotechnologies applicable in artificial reproduction following the trend toward perfectionism: child selection through prenatal genetic diagnosis (PGD) corresponds to the choice of the embryo based on its characteristics, while child design means the ad hoc creation of that embryo artificially composing or modifying the human genome. Although these practices seem to comply with parental desires, they challenge the essence of humanity. After a general introduction and a description of clinical and social aspects, the first part is devoted to a reflection on the main opposing ethical stances, where bioconservatives and transhumanists clash, represented by Michael Sandel and Julian Savulescu respectively. The second part is instead committed to analyzing how these techniques are handled at global, European and Italian levels. Such study has been carried out by evaluating norms, conventions, official publications, statements and opinions of institutions and bioethical committees at each level. Differently from the open-mindedness promoted by part of the population, governances tend to be cautious and limit the possibility to perform the two practices for the moment. Yet, given their potential benefits to humankind and the increasing social approval, regulations could be influenced by public involvement in discussions.

Keywords: genome editing, enhancement, diversity, human rights.

INTRODUCTION

> "*To be perfect, one lacks only a defect.*"
>
> — Karl Kraus

Nowadays, global society is facing a 'dismissal of human exceptionalism', a cultural oblivion characterized by the loss of uniqueness status of human beings. Such societal change is due to an increasing "convergence between technology and a new understanding of biology" that fosters a disposable world, where "being human becomes an option." (Maccarini, 2021, pp. 1, 3) In fact, the performance culture that represents the ultimate imperative of our society is mirrored by the pressure of global capitalism towards human enhancement. This practice refers not only to a self-improvement of the individual but also to the artificial manipulation of human reproduction, which may lead intended parents to proceed in promoting their offspring's excellence though technological interventions with the scope to create the ideal child.

The aforementioned interference in the life of a child could take many forms and it is important to differentiate its aims: on the one hand, it may be pursued for health-related reasons, to avoid the birth of an individual with severe illnesses or malformations; on the other hand, it is suggested as means to ameliorate the human species by selecting preferable characteristics. As it will be presented further in the following chapters, part of the discourse will be hypothetical since some technologies are not available to be applied to human development yet; nevertheless, it is relevant to evaluate them in their early stages in order to start questioning whether we are comfortable with their implications on human beings, on the conceptual distortion of human dignity they cause and on the concrete consequences on our genome.

Research on the topic will undoubtedly bring about scientific progress we could all benefit from, but – despite the fact that everyone will bear its consequences in the long term – I believe there is not enough public awareness and involvement on the matter. An example is given by the courses in our master program: we study human rights in many fields, focusing on 'categories' of persons considered more vulnerable – in fact, we have classes on women's rights, children's rights, refugees' rights – but no specific teaching on human rights when involved in bioethical debates. In my opinion, this is a lack in the educational offer of the university because these kinds of discussions would be extremely valuable given their complexity and contentious aspects. Given that advancements in biology and medicine are progressing very fast and they affect all of us, I believe we should be furnished with the opportunity to deeply study their relation to human rights, which would be promoted by bioethics. Moreover, despite personal beliefs that any professor may have on the argument, I am sure that university would be a suitable ground to gain an objective teaching and to have a constructive discussion on delicate matters, like the bioethical one that I present here, that is artificial control and influence in prenatal life where many rights may be at stake. This thesis provides an overview of the topic, but it cannot be exhaustive in all aspects because of the novelty and complexity of procedures. This is a hint for reflecting on something that could (maybe sooner than expected) become a reality and which will concern all of us; there are many other important aspects that guarantee peaceful cohabitation into the world to deal with, but hopefully governments and institutions will start getting more and more involved in the issue.

With my dissertation, I aspire to provide a contextualization of practices involved in the artificial design and selection of children, to articulate the feelings of anxiety or excitement they entail, and to analyze how they are regulated in a multi-level dimension, targeting national and international stances. I consider the aforesaid willingness to control and dictate the human nature as detrimental for our conception of human dignity, especially because it is performed on individuals not born yet, thus who cannot express themselves on the issue, and who will be eventually the products of a new market. I based my research mainly on documents I consulted in online database as ResearchGate, ScienceDirect Elsevier, and Springer, then also in the official websites of the institutions I analyzed, and on books of proponents of the interested parties.

My analysis starts with an introductory part on the situation of global society, paying attention to the concepts at the core of my argumentation. Indeed, I will begin with a hint on what pushes us toward a stronger chase for perfection, followed by an overview on two specific clinical and medical practices leading to the selection or design of children. The latter inevitably induce firstly to a reflection about what we consider to be ‘normal’ opposed to what is perceived as a ‘disability’, and then to a focus on the entity of the manipulated embryos and on human identity. These concepts act as valuable support for the understanding of the successive part devoted to the two main perspectives on the issue: on one side there is the so-called bio-conservative group advocated by Michael

Sandel, and on the other side the bio-progressive elite (or trans-humanists) commanded by Julian Savulescu. This theoretical part is successively trailed by an investigation on the viewpoints of ethical committees at global, international and national level, and of legal dispositions where present. In particular, at global level I will examine the positions of the International Bioethics Committee of UNESCO and of the Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing for the WHO; next, I will restrict the field of research to the European level by analyzing the works of the Steering Committee for Human Rights in the fields of Biomedicine and Health for the CoE (former Committee on Bioethics of the CoE), and of the European Group on Ethics in Science and New Technologies for the EU; lastly, I will analyze motions and opinions of the Comitato Nazionale di Bioetica (CNB) – National Committee on Bioethics – in Italy.

PART 1) THEORETICAL DEBATE

CHAPTER I - CONCEPTUAL FRAMEWORKS

1.1 Western societal context

Throughout history, human beings have developed a self-perception characterized by uniqueness that raises humanity above others species, granting some sort of human exceptionalism, not linked "to a specific biological species but to all beings that share that moral equivalence." (Porpora, 2021) It is not only a physical instance but rather it is a deeper matter concerning abstract values, which define the human entity. Nevertheless, these days "advanced societies seem to be more and more dissatisfied with the limitations that are inherent in the so-called human nature." (Donati, 2019, p. 53)

Apparently, our capabilities seem now to be unable to accommodate the performing standards required by society, and we can identify this tendency with the concept of 'performance culture': "the demand to improve performance to do things – faster, more efficiently and effectively – seems to be the ultimate cultural imperative of contemporary global society." (Maccarini, 2019, p. 149) Individuals are questioning their suitability to live up to the increasingly competitive contemporary society, where perfectionism becomes the superlative essence of human life. Day by day, we are all responsible for that and "psychologists point to a swirl of contributing and amplifying factors: the rise of social media and its stylised, cropped versions of other people's lives, tumultuous job markets, an unpredictable economy, standardised school testing at an early age." (New Scientist, 2019) Thus, if on the one hand we could say that human society has improved with modernization, on the other hand this process is guided by the State and the market pressing for human amelioration, hence enhancement.

Speaking of that, it is essential to acknowledge that the market is expanding in fields where it should not belong, like in this case with human standards; as a matter of fact, "we drifted from having a market economy to being a market society (…) in which market values seep into every aspect of human endeavor. It's a place where social relations are made over in the image of the market" but "marketizing a good can change its meaning", (Sandel, 2012, pp. 10, 89) since "when we decide that certain goods may be bought and sold, we implicitly decide that it is appropriate to treat them as commonalities, as instruments of profit to use.” (id, p. 9) Indeed, as the market takes charge of intimate aspects of our lives, we perceive a sort of solicitude to cope with societal expectations, we feel trapped by them. “Today, almost everything is up for sale” (id, p. 3) and there is one possible implication that may alert everyone, that is its repercussions on parenthood and human reproduction. Sure enough, “people who want to choose, in advance, the traits their child will have, and are willing to spend so much money to get a child with certain traits, demonstrate a kind of desire for perfectionism.” (Maccarini, 2021, p. 11)

An interesting point of view on the topic is suggested by Dov Fox, Professor of Law and Director of the Center for Health Law Policy and Bioethics at the University of San Diego. He underlines the hard work of parents for the best of their children as an effort to maintain “a dynamic balance between the extremes of excessive guidance and excessive acceptance” (Fox, 2008); to do so, parents provide their offspring with education or training for an adequate growth, but the aforementioned dynamic can be frustrating when parents decide to interfere in the creation of an unborn child by artificially imposing their preferences for genetic particulars. According to Fox, although

> it is fully plausible that parents who act, before birth, on a preference for a child of a particular type would, once the child comes into being, think about and treat that child with the same affection and caring irrespective of whether she meets her parents’ prenatal expectations, (…) the parent who maintains a dynamic balance between the dispositions of acceptance and guidance will remain open to the possibility that the unwanted workings of a child’s mind and body may reveal themselves constitutive of something valuable, or at least as something meaningfully extraordinary about that particular child-to-be. (ibid)

Once parents actualize their genetic preferences through technological interventions for their future offspring, they develop high expectations that may or may not be corresponded by reality and the degree of dissatisfaction that could be brought about in case their dreams were not realized is actually unpredictable. Furthermore, it has to be kept in mind that self-improvement velocity will likely accelerate, extending the initial gap with respect to un- or under-enhanced individuals; therefore, a deep consideration should be given to the role of freedom of choice.

In a post-human world, where being human "has to be defined and chosen as a particular way of being-in-the-world within a range of possibilities" (Maccarini, 2021, p. 2), we find ourselves overwhelmed by choices. It must be reminded that the freedom to select what we prefer concretely mirrors the right to freedom of thought and the right to freedom of opinion and expression, which are fundamental human rights proclaimed in the Universal Declaration of Human Rights of 1948 (respectively articles 18 and 19). Still, having too many opportunities may become suffocating, albeit apparently exciting; in fact, freedom of choice applied to parental options might challenge its positive aspects. "More options can also translate into more uncertainties, and greater perceived and actual responsibilities for the prospective parents" (Cavaliere, 2018, p. 221) because the effective consequences of such actions will be known only when irreversible, that is when the child will be born.

This is a problem of 'choice overload' meaning that "trying to choose embryos with the 'best' combination of genetic variants could be paralyzing." (Suter, 2018, p. 262) Such mental block is caused by the difficulty to balance the importance to get prenatal information for knowledgeable choices on reproduction together with the anxiety that this news might create. "It may be difficult for individuals to know, in advance, what the information would mean to them, how it might affect their reproductive decisions and planning, or whether it would contribute to anxiety in the pregnancy." (id, p. 274) Weighing costs and benefits of different options is not enough to determine the best option ever since there are also external and environmental factors that could change the intended outcome.

1.2 Clinical practices

To have a clearer idea on what parental choices for the creation of their offspring involves, it is essential to understand which are the incriminated artificial and technological practices for manipulating human reproduction and the scopes of application they have.

In the last decades, scientific research has made progress in leaps and bounds in every field, included that of reproduction: it is enough to consider that in the late 1990s the only solution to a malformed embryo was abortion, since it could have been discovered only later during pregnancy. Back then, the discussion was mainly about genetic tests, intended as a complex of analyses on genes to identify some genetic anomalies in the DNA that could be responsible for severe diseases. So, the scope was about foreseeing a possible predisposition of the individual to future pathologies, that was actually an assumption based on probabilities; for example, there were prenatal genetic screening limited to some illnesses, as for Down Syndrome (CNB, 1999a, p. 12). In response to increasing social demand, prenatal diagnosis spread, and some are still in use today as non-invasive ultrasound or invasive amniocentesis and chorionic villus sampling. Moreover, prenatal diagnoses played an important role conceptually-speaking because they facilitated the idea of the fetus as a patient (CNB, 1992, p. 5), that was absurd until before, thus even the unborn child became a subject in medicine.

Due to its inherent desire to help that works as driving force, "medicine is the major source of enhancement technologies" (Greely, 2008, p. 6) and this is the reason why research is so much promoted and supported. The more it is discovered and the more amelioration of the human condition there is, which could be eased if interventions would be carried out before birth in the earlier stages of life. Nevertheless, "the best human being has not been produced yet" (*The Perfect Human Being Series E12*, 2016) because "genetic enhancement of embryos is, for the present, science fiction." (Steinbock, 2008) Luckily, such manufacture cannot proceed since nowadays applications of genetic modification to design a real person are not allowed, thus the design of babies is so far not possible, or better, we should say not admissible. The shadow of eugenics hovers in such interventions in procreation and to be ethic, "reproductive technology for clinical research (…) needs to have a social value, namely it should be directed at a diagnostic and therapeutic intervention that could lead to improvements in health and well-being" (Cavaliere, 2018, p. 222), while there are uncertainties about the consequences of some practices.

Here, I will focus on two main methods of research somehow linked to assisted – thus artificial – reproduction, whose scope is to "avoid transmitting genetic mutations to the next generations"(Committee on Human Gene Editing et al., 2017): PGD (today) and CRISPR/Cas9 (potentially in the future). However, it must be admitted that in 2018 the Chinese scientist and researcher He Jiankui affirmed that Nana and Lulu were born, being the first twins to be created following germline gene editing (GGE), thus "if these claims are true, GGE has already been used in human reproduction." (Koplin et al., 2020a, p. 49) This experiment has been widely criticized and condemned for "its insufficient safety measures, its scientifically unsound methods, its lack of ethical supervision, and its suspected hidden motivations." (Alonso and Savulescu, 2021, p. 564) "He Jiankui's trial was unethical, not because it involved gene editing, but because it failed to conform to the basic values and principles that govern all research involving human participants" (Savulescu and Singer, 2019, p. 222) and this "is a clear example of an irresponsible use of gene editing technology." (Alonso et al., 2020)

1.2.1 PGD

PGD stands for Prenatal Genetic Diagnosis, and it means testing embryos made through IVF to check whether they present genetic abnormalities in order to allow the transfer in uterus only of those that show a lower risk of developing certain conditions. It "is performed for couples at a high risk of transmitting a known genetic condition to their offspring" and it represents "a well-established alternative to prenatal diagnosis, involving the biopsy and genetic testing of a single or multiple cells from in vitro-obtained oocytes and/or preimplantation embryos." (De Rycke and Staessen, 2017) This method transfers in the uterus only embryos that does not show the considered genetic conditions so as to avoid any other invasive check-up or abortion at a later stage of pregnancy. Even though "theoretically, PGD is applicable for any condition or trait with a known genetic etiology" (Zuckerman and Altarescu, 2019, p. 13), this practice "is not effective when both parents are homozygous for a recessive genetic disorder" (Cavaliere, 2018, p. 216); however, PGD is not legal everywhere, and some States restrict its use to few so-called 'serious' conditions, like Italy for example (ibid). The fact that it concerns the selection of embryos makes people contesting the method because "its scopes are not therapeutic (i.e. PGD does not treat embryos)" (id, p. 218), going against the traditional vision of medicine as a tool to 'cure'.

PGD is sometime interpreted as tool to make a negative selection of children – that is a "selection against disability" (Savulescu and Bostrom, 2009, p. 11) – and destroy the 'potential human beings' believed not to be healthy. At first sight, it seems a somehow ethical action since it is considered to avoid abortion, but it might not be really the case, depending on the perceptions about human identity and personhood, as it will be explained in Section 1.3.

1.2.2 CRISPR/Cas9

CRISPR stands for Clusters of Regularly Interspaced Short Palindromic Repeats and its aim is easily explained by Dr. Jennifer Doudna, who is Professor of Biochemistry, Biophysics and Structural Biology and Biochemist at the University of Berkeley, Nobel Prize in Chemistry 2020 for her development of CRISPR/Cas9 genome editing technique: the scope is "to change the sequence of DNA in cells (…) to correct mutation that otherwise would cause disease. (..) It works by the action of a protein called Cas9 that functions like a molecular skeleton for DNA. (…) It recognizes a particular DNA sequence in a cell that may be not functioning and then disables it by cutting the DNA. We call this *gene editing (...).*" (Vidyasagar and Lanese, 2021) For those who are not of the profession, this technology might sound quite complex, but

> it is currently the simplest, most versatile and precise method of genetic manipulation and is therefore causing a buzz in the science world (…) because any changes made in germline cells will be passed on from generation to generation. (…) In future, CRISPR could be used in embryos to change mutations known to increase the risk of disease. (Edwards, 2021)

CRISPR technology is seen as a potential alternative to PGD because it prevents the occurrence of genetic diseases in future children thanks to a germline modification: changes introduced in the human genome that could be inherited, arising ethical questions for its potentiality to change humanity forever. Apart from 'cleaning' the human genome from potentially ill genes, such technology allows even the up-grade of the genome that is a practice called genetic engineering[1], but "the fear is that germ-line engineering is a path toward a dystopia of superpeople and designer babies for those who can afford it." (Regalado, 2015) In this case, no healing is involved, even though some may consider editing the genome of embryos as 'pre-emptively therapeutic' and consequently it could fall within the traditional ends of medicine (Cavaliere, 2018, p. 220). Nonetheless, we can all acknowledge "the increasing difficulty in distinguishing between therapeutic uses and

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[1] In other words, to be clearer it can be said that genome or gene editing on human beings (HGE) is a form of genetic engineering (GE), which in turn is a form of human enhancement (HE). In this paper, they are used as synonyms.

non-therapeutic (enhancement) uses in the scenario of development of medicine that is increasingly oriented towards prevention." (CNB, 2017, p. 13)

Nowadays, the practice is not legal for embryos to be transplanted by artificial reproduction (even though some experiments were declared effective, as noted above), but a reflection is essential, given the many positive implications it has for scientific research; in fact, thanks to CRISPR technology, overnight the cost of engineering have shrunk, which is a very intriguing factor to promote its development (*L'ingegneria Genetica Cambierà Tutto Per Sempre - CRISPR*, 2016). The economic aspect could be another additional support to favor such manipulation as the preferred way to design children in the future.

1.2.3 To prevent or to cure?

To put it simply, the ultimate goal of these practices can be reduced to ward off the possibility of having a child with disabilities or malformations; notwithstanding, "sometimes, the lines between therapy, prevention, and enhancement are blurred. (…) For this reason, the distinctions between preventing or treating disease and disability (i.e., 'therapy') and the notion of 'enhancement' may not fully capture either public attitudes or public policy options." (Committee on Human Gene Editing et al., 2017, p. 143) Indeed, everyone might weight differently a condition that for some constitutes a disability, while for others it does not, and it must be reminded that "the right reproductive choice for one person might not be the right choice for another." (Suter, 2018, p. 298) One example could be visual field defects because they could be seen as an impairment, while others would not care too much about them; another case is exemplified by the deaf lesbian couple who were willing to have a deaf child because for them deafness was a distinctive quality representing "a cultural identity", rather than a defect (Teather, 2002).

This is to say that general concepts like 'health' or 'disabilities' can be subjective, and the main difference between them lays on the perceptions a person grows with. Indeed, "commentators have noted that the concept of disease is not always objective, but rather it can be the result of social agreement influenced by power and prejudice" (Committee on Human Gene Editing et al., 2017, p. 148), deepening the gap between persons that present traits considered advantageous and those without them or with other traits.

1.3 Ethical considerations

This possible divergence in opinions opens the way for other ethical reflections in line with the development of my argumentation: what is normal? What does it mean to be disabled? Does one of these conditions alter respect for human beings? When does the embryo gain value so as to be considered worthy of respect and protection as a person?

1.3.1 What is 'normal' and what is not?

"Who is entitled to decide what an advantage is? (…) The elimination of disabilities would be a loss of human identity for those who suffer them" primarily (Macpherson et al., 2019), but also for the rest of population since the prospect of choosing gene variability could have "long-term evolutionary implications, if they reduced genetic diversity." (Suter, 2018, p. 296) Most of the beauty in the natural flow of human reproduction is its genetic heterogeneity, where nobody is identical to another person (except in case of homozygous twins). When technology spread in the domain of reproduction, problems of creativity and discrimination arises that are both shaped by social influences: the tendency is to value characteristics according to the trend of the moment with the consequent aforementioned risk of reducing diversity among the designed individual, mirrored by a standardization of individuals. This would divide society, so on one side the ones with trendy qualities, and on the other the rest of population.

Projecting in the long-run, "the anti-equality shadow appears simultaneously, either by genetic enhancement or by embryonic selection technologies, since their application effectively would impose social segregation between the enhanced individuals and the non-enhanced subjects, who would identify themselves with the disabled." (Macpherson et al., 2019) The futuristic world inhabited by individuals having different endowments thanks to enhancement is defined as a *post-human*, and one of the main criticisms targeting such environment lies in the problem of equality among individuals and of opportunities.

Such concern about equality is represented by the dichotomy normal/disabled, or later enhanced/non-enhanced. What is perceived as 'normal' is usually associated with the word 'natural' for the common view that nature produces healthy things, thus is a positive concept; whereas, 'disabled' is detected as something extremely negative that must be settled. Regardless the degree of impairment caused by the malformation, the tendency is to deem persons with disabilities as incapable of doing anything in their lives. Even the wording plays a role in this conception: actually, the expression 'person with disability' should be preferred to 'disabled person', so as to pave the way for a more inclusive contextualization, as it is rightly used in the United Nation Convention on the Rights of Person with Disabilities (2006); indeed, in the former saying we consider first a person that is the subject in question and then we add a specification, which is a characteristic of the individual but not the defining condition; instead, in the latter expression, the characteristic defines the subject, reducing the dignity she is worthy of.

Studies have indicated that "many members of the health professions view childhood disability as predominantly negative for children and their families, in contrast to what research on the life satisfaction of people with disabilities and their families has actually shown" (Committee on Human Gene Editing et al., 2017, p. 126) and this demonstrate where the willingness to promote genetic modifications to boost 'normality' comes from.

Now, in an era of technological development, genetic engineering will inevitably change what we perceive as normal (*L'ingegneria Genetica Cambierà Tutto Per Sempre - CRISPR*, 2016) and enhancement will catch on, upgrading standards about the good qualities for a human being. This is because "the ability to select among so many embryos based on non-medical traits and less serious diseases could gradually, but profoundly, alter attitudes about what is in the future child's best interest." (Suter, 2018, p. 270) Concerning this, another arduous debate could be set up because the 'best interest of the child' is a wide concept, interpretable in many different ways, depending on the context; this thesis does not yearn to satisfy such argument, but I think it is imperative to underline the importance of that notion, which is officially stressed also in the United Nation Convention on the Rights of the Child (1989):

> *3.1 In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the best interests of the child shall be a primary consideration.*

What is best for all children is hard to be defined, and the differences arising between enhanced and non-enhanced individuals could have implications not foreseeable now and they could become evident only when children would grow up. Yet, we can suppose that society will adapt to non-enhanced persons a similar behavior to that applied toward persons with disabilities, because in both cases these individuals do not denote any ‘normal’ factor expected on a human being or the best set of options available to the species. This is also due to the feeling around the fulfilment of human potential, which apparently means welcoming risks to get the best available opportunities. Such disposition to risk can be translated as a moral imperative and consequently those who do not want to follow it might seem to prevent somehow their offspring from achieving the best possible lives.

Although these may seem a scenario that will happen in the long run, the fulfilment of target 3.7 of the Sustainable Development Goals of the 2030 Agenda could accelerate the process: were it the case that “universal access to sexual and reproductive health-care services, including for family planning” would be effectively achieved, it would mean – besides all positive implications on world populations – that AHR would spread, thus PGD could be more easily performed, and child selection would become more feasible. Again, the wave of perfectionism turns, a life that is not as perfect as expected appears less worth living, and potentially “the people who are left behind will be left even further behind”(Greely, 2008, p. 15), which would be devastating for our society and the principles we embrace, and this would be also against the “central, transformative promise of the 2030 Agenda for Sustainable Development” of the United Nations, that is “leave no one behind”, by “combating discrimination and rising inequalities”. (“UNSDG | Leave No One Behind,” n.d.) So, does it mean that there could be different kinds of persons, some of whom deserve more respect than others? Since when a human being can be considered a person worthy of such respect and dignity?

1.3.2 At the origin of the worth of human beings

As said earlier, a post-human world is symbolized by the chances coming from technological advancements supporting enhancement of the human species, meaning “improvements in the capacities of existing individuals or future generations.” (Committee on Human Gene Editing et al., 2017, p. 145) In this kind of environment, our usual perception on society as a whole and on personhood would inevitable face a radical change, and there would be “cultural and structural conditionings that lead to deep transformations in human identity" because the human being would not be suitable enough, rather "post-human persons will represent the accomplishment of humanity's best dreams." (Maccarini, 2019, p. 144)

If it were the case, concepts like 'human rights' and 'equality' would lose value and the same would happen with the notion of 'history': what existed before would lose its special role, and what brought us so far would be just past due to the wrong belief that "the self is detachable from its social and historical roles and statuses", but actually "try to cut myself off from that past (…) is to deform my present relationships." (Sandel, 2009a, p. 223) Such scenario explains how trans-humanism dehumanizes human beings: this movement aims at keeping advantage of progress to ameliorate the human species, while it actually degrades collective society because it is especially "*in* the interpersonal relations, *with* it and *through* it, that we can understand what is *infungibly* human both in the single person and in social form." (Donati, 2019, p. 54) So transhumanism goes a step further than posthumanism in the discussion of human nature, promoting concrete actions to heighten it.

The ethical implications of the disposition to enhance challenge also identity and dignity of the individual. Since identity lacks an exact definition, confusion is fomented on debates about technological intrusion and manipulation of human reproduction; yet, such concept is strictly linked with that of dignity, which – using the words of Habermas – "would confer an infinite value to the fact of being human which would grow to be the foundation for an unconditional respect towards individuals and their human rights." (Macpherson et al., 2019) Consequently, we could think about identity and dignity as constitutive elements for personhood: one may argue that an individual is a person because of the capability to perceive oneself as belonging to the human species, or more precisely to human society because of shared traditions, customs, and ideologies; that is to say, when someone identifies oneself as part of the human group then deserves dignity, and if these two conditions are satisfied then her status as 'person' could be recognized. Additionally, one could feel part of humanity for the physical resemblance to the other individuals, as Margaret S. Archer believes:

> The world being as it is, we humans being biologically constituted as we are and the interaction between the two being ineluctable, is the starting point for our

> development of a sense of self and knowing ourselves to be different – from otherness and others. This sense of self is foundational to the emergence of personhood, but it is a lengthy morphogenetic process. (Archer, 2019a, p. 15)

She argues that the body can be seen as "the necessary but not the sufficient condition for personhood. (…) Hence, personhood is not in principle confined to those with a human body and is compatible with human enhancement", (Archer, 2019b, p. 28) implying that "changes in our bodily constitution do not nullify personhood." (Archer, 2019a, p. 29) Rather, she believes the body to be an "anchorage for selfhood" (id, 12), that is a perception of the self singularly developed by the individual. "Most 'typically human' advanced capacities exist in the normal new-born only *in potentia*" (ibid), thus she cannot be perceived as a fully realized person. As a result, there is ambivalence about the starting point of our worth as persons granted human identity, and therefore of human dignity.

From a genetic point of view, the characteristics of everyone are inscribed in our genome, even though "every individual has a genome different from that of another, if this other is not his/her identical twin; therefore, it can be certainly identified as belonging to the human species and his/her genetic identity is guaranteed from the moment of fertilization. The human genome has been codified after an important international cooperation through the "Human Genome Project", which was launched in October 1990, firstly released in April 2003, and "on March 31, 2022, the Telomere-to-Telomere (T2T) consortium announced that had filled in the remaining gaps and produced the first truly complete human genome sequence." (NHGRI, n.d.) However, genetic identity and individual identity are not necessarily comparable conditions" (CNB, 1996, p. 10) to then collectively join in developing human identity, as socially recognized. Not all scholars agree on the onset for being a fully-fledged person, and there are two main points of view on the matter that can be summarized as follows:

A) "the human embryo is a person right from fertilization" (CNB, 1996, p. 5) because the material and biological nature of an embryo makes her undeniably part of the human species;
B) "the human embryo is not a person since fertilization, but only acquires that status at a later time" (ibid.), when developing distinctive human characteristics (as

previously mentioned by Archer), thus the zygote signs just the first of a long series of modification leading the human being to fulfill the status of person.

Depending on the predilection about these two positions, we will be prone to positively or negatively evaluate the practices of child selection or enhancement; yet, “although the moral status of embryo is significant, there is wide support (…) for the view that at least the early embryo has a lower moral status than a foetus, and much lower than a child and adult.” (De Wer et al., 2018, p. 7) As we have seen, the mainstream seems to favor the idea that, there are technologies that could potentially make the design of children a reality, thus I stress the need for an ethical discussion on the issues and on possible legal implications, because this is missing in our contemporary society. We may be conscious of the probability that this may happen in the future, but we are not enough informed on the current situation of research on the matter, which can actually change our world forever quite soon, undermining our rights and duties as citizens of this world.

In 1974, Robert Nozick started his masterpiece ‘Anarchy, State and Utopia’ by stating that “individuals have rights, and there are things no person or group may do to them (without violating their rights)”. Today we should agree that among such rights there are that to freedom and – by quoting Joel Feinberg neologism – “the right to an open future”: if someone would impose his preferences on my development, my liberties would be lessened (more about this will be presented in Chapter 2). In parallel, this can be translated as the idea that “we don't have the right to use technologies to design our descendants according to our preferences, even with the best intentions.” (Andorno and Yamin, 2019) Developments of new technologies in the field of reproduction urge public awareness because “on balance, like most things, human biological interventions can do some good. They can do some harm [too, so] (…) we need to have a conversation about them. And, ultimately, we need to regulate human enhancements in ways that will maximize their benefits and minimize their harms.” (Greely, 2008, p. 19) We should not worry about disagreements that may arise from public engagement on delicate themes because they would lead to a beneficial and enriching debate for both parties. Moreover, “a politics of moral engagement is not only a more inspiring ideal than a politics of avoidance. It is also a more promising basis for a just society.” (Sandel, 2009a, p. 269)

CHAPTER II - THEORETICAL ARGUMENTATIONS AND OPPOSING VIEWS

Development and education have brought about many innovations, especially in technological and scientific fields that improved both our knowledge on human nature and the constitutional features of our bodies. As anticipated, these discoveries influenced our stances towards the world and our peers. In fact, technological changes caused a modification in our perception of time categories, which implied a transformation also of human identity, given the fact that we – as human beings – develop our identity throughout time. Apart from the boost of a "*performance culture*" previously presented, these interconnected shifts had implications also at societal level: first of all, we are facing a "*social acceleration*" when "all tend to be increasingly rapid and temporary, and time segments increasingly brief" (Maccarini, 2019, p. 150); furthermore, a "*no waiting culture*" stimulates us to overcome temporal limits and challenges "future as historical horizon" (ibid.) because of the tendency to favor actions in the short – rather than long – term.

Fast decision-making capacity, enhanced computational ability, emotional management and concurrent consideration of a plurality of factors are characteristics increasingly more required in human beings; or in other words, we must react as fast as machines keeping a high level of attention to avoid any error. This is obviously impossible, both physically and rationally, but social pressures are leading us toward advancing our nature and our capacities, approaching some sort of perfectionism. Nevertheless, this trend favoring enhancement of the human species does not encounter unanimous acceptance.

Those welcoming human enhancement (HE) are called transhumanists and they affirm its importance by comparing it to a moral obligation that we have toward future generations in particular, but also ourselves. At present, one of the main supporters of such vision is the Australian Julian Savulescu, professor of philosophy who focuses his research on ethics about emerging technologies especially in the field of human reproduction and enhancement, and director of the Oxford Uehiro Center for Practical Ethics. Among his most famous publications, there is 'Human Enhancement' (2009) co-authored with Nick Bostrom, which I took as starting point to summarize transhumanists' position on the issue of designing children; moreover, he is also an active writer of academic articles in the Journal of Applied Philosophy or in the Journal of Medical Ethics, which I also used to better illustrate his opinions.

On the contrary, those against are defined as bio-conservatives, in the sense that they instead favor the preservation of the human species from technological and biological manipulation. The reasons behind their rationale vary, some follow a religious perspective while many others advocate secular arguments. Among the proponents of bioconservative vision there is Michael J. Sandel, who is an American political philosopher and first Anne T. and Robert M. Bass Professor of Government at Harvard University. He stands out for his comprehensive justification on rejection of artificial manipulation of human beings, as he clearly explains in his masterpiece 'The Case Against Perfection: Ethics in the Age of Genetic Engineering' (2007), which I will take as basis for my considerations.

I believe that the debate between Michael Sandel and Julian Savulescu is illustrative to represent the diverging attitudes arising around the new possibilities generated by techno-scientific developments in the field of human reproduction; indeed, they both reflect on the feasibility of selecting or designing the best embryos, the fittest one to bring to life. However, in conducting my research I was surprised to notice that even on a topic so delicate, which evolves around the female figure for obvious reasons, there are few relevant contributions by women on the argument, and I think this displays a meaningful lack in the literature. Moreover, while I was reading materials from both sides, I realize a consistent bibliographical difference between the two approaches: on the one hand, bio-conservatives were quite active at the beginning of 2000s when many books and articles were published denouncing the new technological wave leading to biological enhancement of the species by providing motivations on why such practice should have been avoided (I would bet this was due partly to the dissemination of the 'Transhumanist Declaration' in 2002 that I will mention later on); on the other hand, transhumanists are still very active today in their propaganda for human enhancement, which is usually promoted by criticizing what their opponents affirm, rather than by suggesting sound arguments in favor of their positions. For this reason, I find it necessary for a good understanding of the two viewpoints to first present the bio-conservative position, and then that of transhumanists, although I feel the formers developed as a counterreaction to what is praised by the latter.

2.1 Bio-conservatives

‘Bioconservativism’ is a school of thought that embraces biology and conservativism as basis for the defense of human dignity against artificial manipulations of the human nature that scientific progress has made available in recent years. In fact, advancements and discoveries in the medical field would permit the design of future persons – namely children – by editing the human genome according to preferences of the intended parents. Bioconservative exponents represent a heterogeneous group, which encompasses thinkers with different moral and political background; what they have in common is the belief that the possibility to act and shape the biological constitution of a person by third parties in light of their desires would transform our perception towards one another, thus changing societies, and above all degrading human dignity. Some thinkers focus on the resulting being that would be produced in the sense of a ‘different human being’ – as feared by Francis Fukuyama–, or how relationships would change, and reflect on the possible implications this would have on human rights and freedom, that is on the “dubious ends” caused by these practices, as Leon Kass would define them; while others are not so keen on the ends, rather they concentrate instead on the burden of responsibilities that parents take upon themselves – as Jürgen Habermas discusses – without considering the moral implications of their choices. I briefly expose their opinions in order to provide a wider overview on the different positions that are conglomerated under the concept of bioconservativism.

2.1.1 Francis Fukuyama

According to Fukuyama, parental selection of children based on genetic characteristics would create a subgroup of “children of choice”: these children would perceive themselves as different from other children, because “they may come to believe increasingly that their success is a matter not just of luck but of good choices and planning on the part of their parents, and hence something deserved.” (Fukuyama, 2002) Such genetic overclass could have implications on human dignity, as conceived nowadays, since the power to enhance may influence the meaning and relevance of human being due to the fact that genetic manipulation would lead us into a post-human world “in which any notion of ‘shared humanity’ is lost, because (…) we no longer have a clear idea of what a human being is.” (ibid) Moreover, to modify human nature is a risk in the sense that it could erase those constitutive elements that enable us to connect with one another, as members of the same species; indeed, he rightly affirmed that we cannot foresee whether such changes in human beings would reduce or increase social inequalities. For Fukuyama, "we do not have to regard ourselves as slaves to inevitable technological progress when that progress does not serve human ends. True freedom means the freedom of political communities to protect the values we hold most dear, and it is that freedom that we need to exercise with regard to the biotechnology revolution today." (ibid.) From his point of view, we should not blindly accept genetic enhancement because it would create a new class of human beings that could ruin the social equilibrium that we hardly keep nowadays, with the endless efforts to lessen inequalities.

2.1.2. Leon Kass

Even Kass is concerned about the safeguard of humanity in light of the "growing powers to manipulate human bodies and minds, not merely to heal disease but to satisfy desires." (Kass, 2009, p. 271) Kass questions the possibility to restrict our greed for biotechnological discoveries, narrowing the scope of action of scientific research; indeed, he affirms that "yes, there *are* things we should *not* know; yes, we probably should seriously entertain proposals for setting at least *some* limits on *certain* forms of dangerous knowledge" (id, p. 272) and among these things I infer we could insert human genetic enhancement. Indeed, he fears that the intrusion of biotechnologies would cause a reduction in the "naturalness" and worth of human procreation.

Kass holds the idea that genetic manipulation and potentially also genetic engineering allowing parents to choose their offspring would negatively influence parental attitude far from "unconditional acceptance toward critical scrutiny" (Kass, 2004, p. 98), thus redefining what is considered as an acceptable birth and consequently transforming child-parents' relations: "A child who is designed to certain specifications might be viewed as more of an artifact" or "as a means to the parents' ends" (id, pp. 109, 95), since they would be *made* suiting parental preferences, thus becoming the concrete satisfaction of their desires. Furthermore, given the fact that the medical reasons behind child selection – which could be undergone through PGD as in the example provided by Kass (id, p. 95) – could shift toward other intentions closer to enhancement, the scope of such practices results unclear; actions promoting the birth of children chosen according to qualitative desired traits would entail some uncomfortable consequences as “turning procreation into a form of manufacture; promoting a new eugenics, where parents and society seek only the “best” children; (…) and binding the next generation to a genetic fate that suits the will of the present one.” (id, p. 109)

2.1.3 Jürgen Habermas

A similar focus on the selection and design of children who become products of parental choices is promoted also by Habermas in his masterpiece “The Future of Human Nature”, where he suggests reflecting upon implications of these kinds of decisions that parents may underestimate. Indeed, he recognized that “what hitherto was “given” as organic nature (…) now shifts to the realm of artifacts and their production” (Habermas, 2001, p. 12) because of new possibilities to mold human genome and select desired traits. But this modification of the usual order of things obfuscate the distinction between “the naturally grown and the made” (id, p. 42), since biotechnologies are becoming more and more involved in interventions affecting human nature. However, Habermas stresses an ambivalence on such practices when he affirms that “birth (…) being a natural fact, meets the conceptual requirement of constituting a beginning we cannot control.” (id, p. 58) The presumption to master something, which is by its nature not dependent on our will, is an intrusion that forces us to open our mind to moral reflections on our behavior.

Human reproduction is reliant on human body because it provides a fertile ground for developing life, but so far human beings do not have any chance to influence the formation of the new individual; on the contrary, newly developed practices for genome modifications and PGD allow for a selection of offspring, but for Habermas “the fact that we make a highly momentous distinction between life worth living and life not worth living *for others* remain disconcerting.” (id, p. 69) Such decision changes self-understanding of the resulting child, and it would also prevent symmetry of responsibility and relationship “among free and equal persons”, who actually become “the programmer and the product thus ‘designed’.” (id, pp. 14, 65) Parental choice on whether to bring a new person to the world or not is shaped by an ideal on the potential *essence* of the being provided by prenatal tests (suggesting possible predispositions, rather than certainties) that become a sort of quality control on the product/child; according to Habermas, such power to select turns out to be similar to a eugenic choice, though. Moreover, he maintains that “the parents’ choice of a genetic program for their child is associated with intentions which later take on the form of expectations addressed to the child, without, however, providing the addressee with an opportunity to take *a revisionist* stand.” (id, p. 51) Therefore, genetic programming of offspring is deleterious for the child-to-be, in line with Habermas argumentation. In fact, he believes that “eugenic interventions aiming at enhancement reduce ethical freedom insofar as they tie down the person concerned to rejected, but irreversible intentions of third parties, barring him from the spontaneous self-perception of being the undivided author of his own life.” (id, p. 63)

2.1.4 Michael Sandel

After this brief summary on the main points illustrating the opinions of some of the most famous promoters of bioconservativism, I will now focus my in-depth analysis on the viewpoint of Michael Sandel, who I deem takes a wider position on human selection and enhancement, encompassing the above-mentioned concerns in a single explanation, that it is worth examining.

Michael Sandel, in my opinion, can be considered the spokesperson for bioconservatives because his explanations are inclusive of all the others above mentioned. His background in politics and philosophy contributes to his high competence when dealing with issues hitting society from a moral point of view, and in fact he gives a far-reaching answer to the need to reject the possibility of enhancing humanity through the selection of which children would be born or even their a priori design. As concisely anticipated, bioconservatives discredit biotechnological interference in human reproduction that exceeds treatment of illnesses and aims at an ad hoc continuation of humanity, based on several accounts; as a matter of fact, the main worries linked to practices like child selection and child design concern both the single involved individual and parents, but also society.

The risk of creating two classes of human beings would modify our perception of personal success and compare persons to products of manufacture, where those more successful are the ones better made. Moreover, contemporary society on the one hand fosters a type of attitude that decreases parental unconditional acceptance of how their offspring would grow, and on the other hand it oppresses parents with overloaded responsibilities they do not recognize because they are blinded by the opportunities of freedom of choice;

therefore, they wish the use of such techniques would be limited. As I will present hereafter, Sandel incorporates all these points in his justification in favor of bioconservativism, which are clarified in his masterpiece “The Case against Perfection: Ethics in the age of Genetic Engineering.” (2007)

2.1.4.1 Moral repercussions on human behavior

Sandel enquires into the skepticism that many persons show toward technological innovations targeting human beings, and he rightly concludes that “when science moves faster than moral understanding, men and women struggle to articulate their unease. (…) This is why the genomic revolution has induced a kind of moral vertigo.” (Sandel, 2007, p. 9) (Sandel, 2009b, p. 71) Common individuals that are not accustomed to the scientific world, thus those who are not familiar with all the progress achieved in recent years on possibilities to artificially establish in advance the outcome of human reproduction, are usually surprised by that. Contrasting feelings related to these innovations prompt ourselves to update our ideas about, or to start reflecting upon, the moral essence of human nature and the position of human beings in relation to the world around. Yet, as Sandel remind us, we are not used to these kinds of questions interrogating our morality, which provoke a sort of rational disorientation to us. To better understand this point, it is useful to evaluate it when concretely applied to the matter of our concerns, that is to say, human enhancement through child design and selection.

> No one objected that height, intelligence, and athletic power are disabilities that children should be spared. And yet something about the ad leaves a lingering moral qualm. Even if no harm is involved, isn’t there something troubling about parents ordering up a child with certain genetic traits? (Sandel, 2007, p. 3)

Sandel acknowledges parental duty to stimulate and encourage children’s excellence, but he also recognizes that nowadays this translates into research for perfection. This attitude goes well beyond usual efforts of parents towards the education of their offspring, namely “it highlights a problem with the trend toward hyperparenting.” (Sandel, 2009b, p. 81) In other words, parents get too entangled in perfecting their children. As a consequence, we should all ponder over high-pressure child-rearing practices that are spreading in contemporary societies, whose aftermath has the potential to disrupt the freedom of their children. Indeed, “the hyperparenting familiar to our time represents an anxious excess of mastery and domination that misses the sense of life as a gift" (Sandel, 2007, p. 62), thus a new life coming into the world loses the incredible and marvelous mysteriousness and unpredictable characteristics that parents would get to know throughout her child's growth.

"To appreciate children as gifts is to accept them as they come, not as objects of our design, or product of our will, or instruments of our ambition. (…) We choose our friends (…) But we do not choose our children. (…) That is why parenthood, more than other human relationships, teaches what the theologian William F. May calls an 'openness to the unbidden'." (Sandel, 2007, p. 45) Many times, Sandel talks about the "mystery of birth" because it is an event that normally is out of our reach. In fact, human reproduction through sexual intercourse is at the mercy of natural genetic lottery, so nobody can know in advance how the child would be, but parents are nevertheless willing to welcome him or her because what they value the most is the creature they conceive. Sandel affirms that "in a social world that prizes mastery and control, parenthood is a school for humility. [Because] … we care deeply about our children, and yet cannot choose the kind we want." (id, p. 86) Such humility carries out the real meaning of an 'openness to the unbidden' above mentioned, which is however not easy to put into practice. Indeed, parental love is believed to have two displays, one is of acceptance and the other is of transformation: "accepting love affirms the being of the child, whereas transforming love seeks the well-being of the child. Each side corrects the excesses of the other." (id, pp. 49-50)

Notwithstanding, human enhancement fosters the latter to eclipse the former; when parents surrender to the tantrum of designing their offspring, the balance between these two expressions of parental love is thrown off. Despite the fact that "central to the norm of parental love is the idea that one's children are inalienable" (Sandel, 2012, p. 72), the manipulation of future offspring impairs parenthood in the sense that it damages parental love equilibrium. Sure enough, Sandel fears that the ethics of giftedness – that should be characteristic of parenthood – risks to be dislodged by techniques like genome editing to choose the child who will be born, and its implications could be seen on both the side of the child-to-be and that of mothers and fathers willing to control their reproductive flow. On the one hand, to design a child is to influence her life in line with the designer's view of what are better endowments, which can be disquieting because "by choosing a child's genetic makeup in advance, parents deny the child's right to an open future. A similar objection can be raised against any form of bioengineering that allows parents to select or reject genetic characteristics." (Sandel, 2009b, p. 72) So, based on these statements, Sandel wants us to recognize the limits we may set on other human beings not born yet, invading and intimate sphere of autonomy of a third person, and violating a priori her freedom to choose for herself. On the other hand, "if the genetic revolution erodes our appreciation for the gifted character of human powers and achievements, it will transform three key features of our moral landscape – humility, responsibility and solidarity" (Sandel, 2007, p. 86), which I have partly anticipated already.

In the case of hyperparenting, humility fails to stand out, and solidarity decreases because the differentiation among human beings diminishes that feeling of common fate joined by humanity as a whole. Then, with respect to responsibility, we face its explosion, which brings with it habits of control that in turn increase the weight of being responsible for our decisions, and we cannot escape it; this is because "we attribute less to chance and more to choice. Parents become responsible for choosing, or failing to choose, the right traits for their children. (…) A domain once governed by chance has now become the arena of choice" (Sandel, 2007, pp. 87–88) but this is an unprecedented situation, so we might feel empowered by new biotechnologies, while at the same time our morality hardly copes with this accountability.

Insomuch as these three core components of our morality are ruined by biotechnological progress, Sandel suggests to tackle such instrumentalizing tendency in order to be able to deal with an emerging challenge, that is "how to take advantage of the great breakthroughs in biotechnology and in genetics for human health and well-being, without allowing those technologies, those tools, to define our purposes for us." (*The Perfect Human Being Series E13* , 2016, pt. min 0:55-1:16) Moreover, he underlines a prevailing bias for overreaching that is constantly expanding in today competitive society, which boosts a societal organization that views losers simply as unfit. This ideology foments what Sandel calls a "tyranny of merit", in which the fear of falling and losing status quo pushes parents to "become intensely involved with their children's lives" according to "the idea that our destiny is in our hands, that our success does not depend on forces beyond our control, that it's up to us (…) [It is a] promise of mastery." (Sandel, 2020, pp. 12, 34) Needless to say, this promise is alluring at first sight, but its consequences may not be so as well.

Legitimately, Sandel infers this to be “a way for privileged parents to have the kind of children they want and to arm them for success in a competitive society.” (Sandel, 2007, p. 78) Apparently, it should be what every parent would aspire to for his children, but actually this reaction to societal pressure turns children into commodities, it makes them “product of deliberate design” (id, p. 75). Literally, selecting or rejecting an embryo following PGD, or even artificially building up the genome of offspring, are costly procedures that parents decide to undertake to get the ideal child; in other words, children become objects to commission. However, our morality does not admit that – or at least, it should not – because human beings are not things.

“The reason human beings must not be treated as things or used merely as means to an end is that they are inviolable. They are, to borrow Kant’s language, ends in themselves, worthy of respect.” (Sandel, 2007, p. 114) Therefore, children cannot be molded to satisfy the desires of others. Nonetheless, some argue that a child is not a real child until birth, and this paves the way for two similar yet peculiar questions that I earlier disclosed, and which even Sandel poses himself:

> At what point do we acquire this inviolability? When does human life become worthy of respect? The answer could not depend on the age or development stage of a particular human life. Infants are clearly inviolable. (…) Every human being – each one of us – began life as an embryo. If our lives are worthy of respect, and hence inviolable, simply by virtue of our humanity, it would be a mistake to think that at some younger age or earlier stage of development we were not worthy of respect. Unless we can point to a definitive moment in the passage from conception to birth that marks the emergence of the human person, we must regard embryos as possessing the same inviolability as fully developed human beings. (ibid.)

This ‘equal-moral-status position’ “rightly rejects the utilitarian view of morality, which weight costs and benefits without regard for the inviolability of persons” and it deals with “‘human life’ in the sense of being human rather than bovine and living rather than dead. (…) Every person was once an embryo, and there is no nonarbitrary line between conception and adulthood that can tell us when personhood begins.” (id, p. 115)

This issue around the moral status of embryos and the starting point that makes life gaining worth and respect is very debatable, as presented in Chapter 1.3.2, and it is exceptionally pertinent when dealing with artificial manipulation of human reproduction, so the position of Sandel on the matter is remarkable. Although he criticizes the comparison between embryo and human being, he denies the belief according to which the latter is seen as a mere thing since this would imply to miss "its significance as potential human life" (id, p. 125); as a matter of fact, he declares that a warrant for respecting the integrity of an embryo is not limited to the consideration of it as a human being since embryos should not be "objects at our disposal" anyway. (ibid) Some forms of respect should be given regardless their qualities, and once managed this issue, he provokes our thoughts by stating that "if it's true that the developing fetus is morally equivalent to a child, then abortion is morally equivalent to infanticide." (Sandel, 2009a, p. 251) So, in this line of reasoning, rejecting a fetus because PGD showed a predisposition to genetic diseases – that is to say, child selection – would mean killing a child.

Such assertion has a magnitude on the way in which Sandel discusses these kinds of biotechnological practices on children with regard to HE and GE; furthermore, such stand entails an even increased burden of responsibility on parents that could compromise the freedoms of individuals involved. What he is willing to make us understand is that these techniques might be appealing, but we are not totally aware of their moral and psychological surroundings, and probably we could not even imagine their significance until it would be to late – be it the case for these procedures to widespread.

2.1.4.2 Is GE really a form of freedom?

When it comes to freedom, individuals in Western societies consider it as a right, a human right, something that grants you to do whatever you want. Many may also think HGE and GE to be the latest expressions of such liberty because the manipulation of our genetic make-up empowers us to create somebody as we want; yet, Sandel brings us back down to earth confining such illusion when he reminds us that freedom of choice is not "an adequate basis for a just society." (Sandel, 2009a, p. 220) The unease felt by part of the population with regard to these methods must not be put aside for favoring their expansion because this would damage our social environment, in the sense that respect would not be guaranteed to all of us but just to part of citizens. Kant thought us that our liberty ends when that of another person starts, and Sandel embodies this principle when he criticizes the power of our will in persuading our actions.

Sandel considers enhancement in the form of genetic engineering as the most extreme example of the ethics of willingness which triumphs over giftedness: “genetic engineering to create designer baby is the ultimate expression of the hubris that marks the loss of reverence for life as a gift.” (Sandel, 2007, p. 127) Producing a child with intended distinguishing features concretely realizes a misinterpretation of parental love since it recollects only its transformative side, with the presumption to avoid possible suffering. Actually, “to appreciate children as a gift or blessing is not to be passive in the face of illness or disease. Healing a sick or injured child does not override her natural capacities but permit them to flourish.” Simply, “in caring for the health of their children, parents do not cast themselves as designer or convert their children into products of their will.” (id, pp. 46, 49) Applying medical means for non-medical scope is for Sandel an exaggerated impulse that parents indulge, while all the alternatives offered by artificial human reproduction to get the desired child are examples of procreative practices “in which the old eugenics meets the new consumerism.” (id, p. 72) Noticeably, the gaze of Sandel encompasses the issue from a broad perspective, taking into account for his analysis also historical and social trends.

“The shadow of eugenics hangs over today’s debates about genetic engineering and enhancement” (id, p. 68), and one of the reasons is that manipulating the genetic makeup of children with the intention to improve them is reminiscing of the morally repulsive practices that Nazism promoted for perfectioning the human species. There are other ways in which parents can mold their children, so using irreversible artificial techniques increases the “danger of creating two classes of human beings: the enhanced and the merely natural” (id, p. 15); while on the contrary, “from the liberal-eugenics standpoint, (…) neither the education nor the genetic alteration violates the child’s autonomy, or ‘rights to an open future’.” Still, Sandel underlines that “whatever its effect on the autonomy of the child, the drive to banish contingency and to master the mystery of birth diminishes the designing parent and corrupt parenting as a social practice governed by norms of unconditional love.” (id, pp. 78, 82)

Sandel targets “eugenic parenting” as objectionable firstly because he takes in Hannah Arendt views according to which “human beings are born, not made” (ibid), and secondly because of the entrancement of this attitude of domination toward the world, which imposes a biotechnological and economic intrusion in the creation of an individual, missing the meaning of achievements and capabilities as gifted characters. Indeed, he strongly believes that “as the role of enhancement increases, our admiration for the achievement fades” (Sandel, 2009b, p. 78) because the credit for accomplishments would not be of the person who reached the goal but rather it would come from third parties. GE shifts the merit from the person who demonstrates some values to that who decided her genetic makeup, and this disposition brings about a sad conclusive observation:

> It is tempting to think that bioengineering our children and ourselves for success in a competitive society is an exercise of freedom. But changing our nature to fit the world, rather than the other way round, is actually the deepest form of disempowerment. (...) We should do what we can to create social and political arrangements more hospitable to the gifts and limitations of imperfect human beings. (Sandel, 2007, pp. 96–97)

2.2 Transhumanists

Transhumanism emerged as gradually as scientific and technological discoveries throughout the last century, and I think it is useful to recollect some of the most significant and formalizing events that signed the history of this movement (“Transhumanism,” 2022):

- In 1998, the World Transhumanist Association (WTA) was founded by Nick Bostrom and David Pearce as an international NGO connecting people sharing the same beliefs on bio-technological development and on public policies concerning it.
- In 2002, the WTA adopted the Transhumanist Declaration, officially stating the aim of transhumanism and their wish for the future management of issues regarding technological development linked with scientifical progress and health.
- In 2008, following some years of political turmoil partly associated with the WTA, a rebranding was promoted, and the association changed its name to “Humanity+”, which continues to advocate for safe and ethical use of technology, life extension, expanding human capabilities, improving human beings.

On Humanity+ website two official definitions of transhumanism are presented:

> (1) The intellectual and cultural movement that affirms the possibility and *desirability of fundamentally improving the human condition* through applied reason, especially by developing and making widely available technologies to eliminate aging and to greatly enhance human intellectual, physical, and psychological capacities. (2) The study of the ramifications, promises, and potential dangers of technologies that will enable us to *overcome fundamental human limitations*, and the related study of the ethical matters involved in developing and using such technologies. [emphasis added]

As we can notice, the scope of action is wide and varied, but the focus can be summarized as enhancing the human being so as to surmount our limits.

To grasp the key points of transhumanist's argumentations, I believe it is worth reading the co-authored book "Human Enhancement" (2009) by Nick Bostrom and Julian Savulescu. They, together with other relevant thinkers, philosophers, bioethicists, and professors, discuss the recent trend toward species amelioration provided by new biotechnological developments. The possibility to manipulate human genome through GGE techniques led to the acknowledgement that "human enhancement has moved from the realm of science fiction to that of practical ethics" (Savulescu and Bostrom, 2009, p. 18), thus it is essential to reflect upon its implications on human society as a whole, and throughout the book, we can gain an interesting overview of the reasons they promote to favor practices such as 'child design' and 'child selection', given the fact that the concept of HE stands as basis for both approaches.

Mastering human nature is something desirable in transhumanists' eyes based on the ideas that "if it wasn't good for you it wouldn't be enhancement. In terms of human functioning an enhancement is by definition an improvement on what went before. (…) If it were wrong to interfere with nature we could not, among many other things, practice medicine." (Harris, 2009, pp. 131, 134) These affirmations demonstrate how transhumanists perceive a sort of linear continuum in scientific progress: once, research permitted the evolution of medicine to treat illnesses and save lives; now, science is taking a step forward, beyond medicine, to improve healthy lives. This raises the fear of a possible growing inequality among human beings, but for transhumanists "concerns about equity do not speak to why improvement is wrong." (Caplan, 2009, p. 200) As we have seen, it is already workable to have genetically superior children through artificial reproduction compared to those conceived naturally, thanks to the selection of embryos following PGDs, and so far, no social distinction between children is made based on the way they have been conceived. Still, considering life as a gift that parents give us, "wouldn't we all prefer parents who try to make the gift as good as possible, rather than leaving everything to chance?" (Singer, 2009, p. 279)

HE allows parents to furnish their offspring with better characteristics that would benefit them in contemporary competitive society. Nevertheless, even before the advent of such revolutionary innovation, parents already tried to better their children and to educate them according to the values they deem more important. Furthermore, parental education is widely accepted even though parents valorize different features as beneficial in life; consequently, this "acceptance of reasonable pluralism about the good life implies that there are different reasonable views of what a good person and a good life would be" therefore "selection need not assume that we know what the perfect child would be, only that we know what would make a given child, or any child, better, what would likely give it a better life." (Brock, 2009, pp. 272, 271) So, there is nothing new with HE, rather – if anything – "the problem is bad parenting, not bad technology" (Caplan, 2009, p. 208) from transhumanists' point of view.

When we reflect upon affective relationships that everyone undertakes in life, "there is a sense in which any decision made by prospective parents, and in particular by a prospective mother, that is intended to affect the nature of the child that will be born can be considered selection" (Brock, 2009, p. 252): even the choice of a partner becomes a sort of selection because we consider that person to be more valuable that others for his/her characteristics, which we would potentially like to pass on to our descendants. As seen already, some worry that parents in similar context would choose similar traits to enhance, thus reducing the diversity that makes us unique; yet, transhumanists do not feel it to be a good reason to prevent the spread of HE because for them "we would face a serious loss of genetic diversity only if the genetic supermarket was very widely used for a long time in a way that tended to focus on a small number of genotypes. Before this had had any real impact, we could observe what is happening, and stop" (Singer, 2009, p. 284) so this would not represent any such risk.

According to transhumanism, the alarm about the possibility to change the identity of a person by modifying her genome is deceptive because it is not only our genome that make us the person we are, but also and especially the environment in which we grow up. There are not fixed set of traits that are universally accepted as defining characters for human beings, and the specificity of human nature cannot be demonstrated on these grounds, thus “there is no basis for the claim that change, improvement, and betterment always represent grave threats to our essential humanity.” (Caplan, 2009, p. 202) Indeed, if the conviction is that to preserve humanity and the human species the genome cannot be modified, then “cloning on a universal scale would be the best way to achieve that (clearly dubious) objective. Only if all future reproduction were by cloning (monozygotic or identical twinning) or somatic cell nuclear transfer would the human genome be ‘‘preserved’’ intact”. (Harris, 2009, p. 135) This would be rightly objectionable, though.

Lastly, some are unease with the fact that decisions on design or selection of children could be applied at early stages of life or even before the beginning of life – whatever it be – and this depends on our perception of personhood. Yet, in the transhumanist argumentation, these kinds of choices evolve around “an actual fetus not yet a person and a different possible fetus and possible person. It is the choice between one actual being and another possible being, neither of which are actual persons.” (Brock, 2009, p. 253) Plus, there is another point in favor of HE that involves its potential hereditariness: the chance to undergo a change in the germ line means that it would be no more necessary to repeat such alteration in future individuals, which would be beneficial both for human beings and for society as a whole. Indeed, “just as societies now spend money on education, especially in science and technology, in the hope of gaining an economic edge by having better-educated people than other nations, so too some nations will seize on genetic enhancement as a way of achieving the same goal” (Singer, 2009, p. 288); it would become an easier and quicker way to improve ourselves, gaining competitiveness at social level, which would be an additional advantage according to transhumanists.

2.2.1 Julian Savulescu

As already noted, Savulescu is one of the most engaged supporters of the transhumanist view, promoting species amelioration through the selection or design of future individuals. He is deeply convinced that we have a moral obligation to enhance humanity, and he underlines this commitment in many of his articles. As a matter of fact, he stresses our duty to "try to ensure that our children have the best lives possible and the best advantage when they start life" (Savulescu and Sparrow, 2013, p. 40) because "if it were the case that social justice could be more effectively achieved if certain members of society were enhanced (perhaps so that they had equal access to opportunities afforded to those with higher capacities), then it might again be a requirement to enhance them in the interest of justice." (Pugh et al., 2013, p. 343)

The social justice at which Savulescu aspires reminds us of a situation where improving some human beings would make them fit for the world and let them gain competitive advantages so as to reach equality compared to those individuals that are naturally superior. According to him, it is not just a question of physical capabilities but also of morality, and since "a great moral improvement in short time seems necessary for us to handle responsibly the enormous powers of modern scientific technology, it is imperative to put a lot of effort into research on biomedical means of moral enhancement." (Persson and Savulescu, 2019, p. 13) Indeed, our duty to enhance implies that "research into gene-editing is not an option, it is a moral necessity" (Savulescu et al., 2015, p. 476), otherwise there won't be any chance for equality and justice.

2.2.1.1 Stances on biotechnologies

To achieve that kind of justice, Savulescu promotes techniques like HGE, and in particular GGE because the possibility to control human genome "has enormous potential both as a research tool and a therapeutic intervention" (Gyngell et al., 2017, p. 498), which is additionally favored by its rapid increased use in laboratories, where this technology is studied and tested either as "a conventional medical technology" or as "a potential human enhancer" (Alonso et al., 2020, p. 259).

If we focus on CRISPR example of HGE, that is its most famous application, we can infer that this biotechnology is a step further than mere medicine because it has been "amplified not only to cut, but also to add genes" (Alonso and Savulescu, 2021, p. 563) so the modification does not aim only at preventing a disease, but also at getting specific wished characteristics. In fact, HGE is advantageous because instead of requiring a pharmaceutical company or a lab to conduct the procedures and alter the genome, "we could get the body to manufacture it, this would be even better." (Alonso et al., 2020, p.

263) This is the reason why Savulescu states that "CRISPR genetic editing technology constitutes an intervention that enhances and takes some human capabilities beyond their normal parameters. This would mean that CRISPR would leave the medical paradigm, or at least the therapeutic paradigm" (id, p. 269), according to which changing our genes would constitute a profound variation of the self. Precisely, Savulescu strongly opposes such paradigm: he believes that traits' design does not determine any substantial change for the individual since this would happen only in case it could provoke a valuable modification in human identity, and "it would be identity-altering [only] if it caused a different chain of psychological connectedness and continuity on a psycho logical or narrative account of identity." (Alonso and Savulescu, 2021, p. 565) So, from this viewpoint, designing children cannot be attacked as a practice that influences the resulting offspring in terms of identity and personality, and no harm can be said to be inflicted.

On the contrary, the increased effectiveness of GGE with respect to conventional methods for the selection of traits, and the possibility to affect the genome once for all instead of operating in every generation, allows to "lower the total frequency of disease-causing genes in the gene pool, and therefore the incidence of such diseases in future generations" (Gyngell et al., 2017, p. 501), benefitting them. In fact, Savulescu foresees that "advanced and precise gene editing techniques could virtually eradicate genetic birth defects, thereby benefiting nearly 8 million children every year." (Savulescu et al., 2015, p. 476) This reduction of genetic mutations appears as an obvious advantage of the application of new biotechnologies in human reproduction, leading to a revolution in GE, which is furthermore beneficial in people's eyes because GGE and CRISPR techniques "allow couples to have a genetically related child without passing on genetic disease, including circumstances where it is not possible to select an unaffected embryo using a preimplantation genetic diagnosis." (Koplin et al., 2020a, p. 49) Thus, these procedures have all what it takes to become the best alternative in reproduction when the intended parents hope to have the healthiest children.

Nevertheless, there are some imaginable side-effects when applying GGE that trigger some opposition based the fear for them to happen. "Given the limitations of our knowledge of human genetics, there is a possibility that the intended genome edits themselves may cause unanticipated harms" and "genetic variants used to decrease risk for some diseases may inadvertently increase risks for others, potentially rendering the recipients of these changes (and their descendants) vulnerable to future health threats." (Koplin et al., 2020a, p. 50) In fact, "the most obvious safety concerns regarding GGE stem from what are called 'off target' mutations – unintended changes to the genome." (Gyngell et al., 2017, p. 504) Savulescu acknowledges them as likely limits perceivable by society and in order to solve such worries he suggests ensuring none come into existence following GGE, boosting protection of future generations from the transmission of these safety risks by limiting the practice at research stage so that embryos are not "allowed to develop to the point that they are the subjects of morally weighty harms." (id, 505) Nevertheless, he believes it to be "unlikely that a small number of germline mutations pose a serious enough risk to future generations that we ought not to pursue GGE. Mutations are constantly being introduced in the human germline and many human activities increase the rate at which they occur" (ibid) as for example delayed maternity and paternity, when ovum and sperm are 'old'.

Bearing these concerns in mind, Savulescu suggests that "at present, gene editing should only be used for research, so that the technique can be refined" and its accuracy be improved, or even to allow the "development of alternatives to CRISPR". (Alonso et al., 2020, p. 268) Furthermore, "given the current rate at which the technology in this field is improving, genomic researchers may soon be able to prevent serious harm at a cost that is comparatively small and reasonably bearable." (Koplin et al., 2020b, p. 10) Therefore, the anxiety we could feel towards clinical performances for the design of human beings will soon be blown away thanks to new discoveries coming from research. GE is already a reality, and its spread will probably become unavoidable in the near future, so Savulescu insists on the fact that it is better to start confronting and trying to get comfortable with it.

2.2.1.2 Non-identity problem

Despite Savulescu's reassurance and explanation, GE techniques take with themselves a dilemma, the so-called 'non-identity problem', which is considered "one of the most difficult problems in procreative ethics (or the ethics of future generations)." (Alonso and Savulescu, 2021, p. 563) It deals with the hypothesized implications of GE on the individuality of human beings, which are hard to demonstrate. "Briefly, the non-identity problem points towards the difficulty of explaining why it is wrong to bring people into existence who will experience harm if (a) the harm is not so bad that it renders life not worth living, and (b) this harm could be avoided only by bringing a different person into existence instead." (Koplin et al., 2020a, p. 55)

The non-identity problem became famous in 1980s thanks to the work of moral philosopher Derek Parfit, and also Savulescu presents an analysis on the question. He discusses the non-identity problem specifically linked to the experiment performed by He Jiankui in 2018, briefly presented in chapter 1.2. The opinion of Savulescu on the test undergone by the Chinese scientist is somehow controversial, because he criticizes the lack of safety measures and ethical supervision, but he thinks that "we must conclude that Jiankui did not harm them in any way. Given that their lives are worth living, bringing them to existence did not harm them. Properly speaking, from this perspective, bringing them to existence could not have harmed them if their lives are worth living, as the only alternative would be to have never existed." (Alonso and Savulescu, 2021, p. 570) As a matter of fact, Lulu and Nana were born only because of the clinical interventions on their genome, therefore, without such performances they could have never existed; the necessary interconnection between the two facts (birth of twins and CRISPR application) make it hard for us to determine whether their lives, although being artificially designed, were "saved, harmed or cured". (id, p. 564) Usually, these kind of ethical concerns are about practices that violate the integrity and rights of existing people, whereas in this case GE biotechnologies "cannot benefit or harm any individual, as they are the cause of their very existence." (id, p. 565)

Many efforts to find a solution for this problem have been attempted: some deny "the idea that harm and moral wrongness must necessarily be person-affecting" while focusing on the consequent benefits because failing to create a possible better world would be wrong; or vice versa, some others sustain the 'person-affecting clause' according to which using HGE to create an individual causes that person not to be "treated up to the appropriate standard (…) as an end in itself" (id, p. 566), a lack of respect for its rights. However, despite these attempts, the non-identity problem is far from being solved and it will remain so because its recurring application will even increase in the future due to promising escalation of HGE use.

2.2.1.3 Embryos and moral status

Savulescu recognizes that people could oppose the facility with which he advocates in favor of human enhancement for example by selecting the best embryo based in its genetic makeup because their "intuitions about selecting embryos are polluted by their intuitions about whether it's right or wrong to kill an embryo." (Savulescu and Sparrow, 2013, p. 37) This resistance depicts the moral relevance that people give to possible but not yet existing persons, making it hard for them to accept practices that would harm embryos. On the contrary, Savulescu sustains that, at their stage of development, "embryos have no right to worthwhile life. (…) Embryos do not have ends, so it cannot be wrong to treat them merely as entities that do not have ends." (Persson and Savulescu, 2010, pp. 53, 55) Therefore, based on this premise, another important aspect to reflect on, which is pivotal when dealing with implications of biotechnological applications that aim at creating a human individual, is the question on the status of embryos. As previously described in chapter 1.3.2, there is no unanimous consent about the beginning of personhood and worth of an individual; to recall, some believe that an embryo has already a value in itself because it should be considered a person since fertilization, while some others claim that this is not possible because the human being acquires necessary characteristics for personhood only after birth, and gradually.

Usually, transhumanists tend to favor the second interpretation; indeed, as anticipated, Savulescu points out that "genomic intervention (…) deals with possible persons rather than existing persons" (Gyngell et al., 2019, p. 516) because it operates in anticipation of somebody, since its scope is the creation of an ad hoc individual. On this account, he proposes that "the moral status of embryos be downgraded, so that it would not be wrong to create any number of embryos in order to have a healthy child" (Persson and Savulescu, 2010, p. 57), that is one of the main reasons for parents to choose biotechnological interventions when applying for AHR. He affirms that "the moral status of embryos must be lower than that of babies" (id, p. 52) because he denies that embryos are conscious human beings, thus they cannot have any rights since these are obtained after birth, which is the turning point that makes an individual gain a right to worthwhile life.

A similar concern regards the risk of harm that might be inflicted on embryos, but Savulescu thinks "it is doubtful that the embryo is the type of entity that can be harmed, or at least, harmed in a morally significant way. The embryo does not have experiences or desires, and on some accounts of wellbeing, entities that lack experiences and desires have no wellbeing and thus cannot be harmed.” (Gyngell et al., 2017, p. 504) Actually, this argumentation sounds as a contradiction because the scope of genetic intervention is exactly the wellbeing of the individual, so it would be nonsense to deny any state of wellness only because at an early stage of life; it might be argued that psychological wellbeing is hard to define for embryonic life but physical wellbeing is far from being nonexistent in that period of life. Anyway, if it cannot be said that an act harm that being or entity, such act cannot be accused as morally bad. In other words, for Savulescu, there is nothing wrong in selecting an embryo at the expense of another one because its low moral status – and shortage of psycho-physical involvement in real life – somehow prevent it from feeling harmed. Those who challenge this denial, as for example opponents of abortion (which constitutes one of the way to undertake embryo selection), turns to the potentiality to develop necessary capabilities to be guaranteed full moral status for embryos or even before conception, claiming that “an unfertilized human ovum together with a human sperm have the potential to become a human adult” (Savulescu and Clarke, 2021, p. 6) but Savulescu responds by affirming that “embryos that will not be implanted can be said to have no actualizable potential” (Persson and Savulescu, 2010, p. 57), so for him, they cannot have a moral status anyway.

As we have seen, the discussion about moral status presents a layered version of it, sometime promoting its reduction and sometime its expansion. “The phrase ‘full moral status’ (FMS) suggests a threshold level above which moral status cannot rise. However, (…) it seems possible that a being or entity could have a higher moral status than the moral status of ordinary adult humans.” (Savulescu and Clarke, 2021, p. 3) An example would be an enhanced person (post-human), whose morality has been artificially improved through the design of genetic make-up. Different degrees of moral status to be accorded differently to people – intended as ordinary members of a species – makes Savulescu wonders why those who lack such capacities should be granted moral status at all. He assumes that even humans will benefit from the creation of post humans: “All things being equal, post-humans with more highly developed moral capacities than humans possess will be more likely to treat other beings, including humans, in morally appropriate ways than will humans.” (id, p. 12) Nevertheless, he also admits that “there are reasons to be concerned about the consequences for us of creating post-humans with higher moral status than we possess." (ibid.) Indeed, he reflects on the bias humans have for their counterparts to detriment of other species, like animals, because believed to have lower moral status; thus, he compares this tendency with the behavior that post-humans may develop toward normal humans, and he concludes that, "by parity of reasoning, we can infer that they may well regard themselves as being entitled to kill and eat us, to conduct harmful experiments on us, and to sacrifice the lives of many of us in order to save the life of one of them." (id, p. 13) So, for Savulescu, we should create enhanced individual who would potentially erase us because we are not enhanced. To me, this seems nonsense, though.

As we can gathered, this uncertainty about moral status and possible implications cause moral confusion that we are unable to solve, and besides, a common mistake exacerbates our unease: for Savulescu it is wrong to "speak of 'future generations' as if they were now identifiable individuals who will exist in the future." (Savulescu, 2014, p. 177) According to him, we erroneously give too much worth to future generations even though their existence depends on our choice nowadays, so currently they are not concrete individuals worthy of respect and protection, who can express themselves on matter concerning them.

> It would be absurd to claim that we shouldn't develop any risky novel technologies because it 'affects the next generation without their consent'. The central question with GGE, as with all interventions that create risks for individuals who cannot consent, is not whether the individuals who would be exposed to the risks would consent to them, but whether they will also (expectably) enjoy benefit that outweigh the risks. (Gyngell et al., 2017, p. 507).

Savulescu is aware of the importance and untouchability of consent as necessary requirement for any intervention on someone else's life; however, he reminds us that "future generations are also unable to consent to any of the myriad decisions we routinely make that affect the world future generations will be born into", (Koplin et al., 2020a, p. 50) even without manipulating their genome. That is why he criticizes those countries which outlaw practices like CRISPR, because he holds them responsible of preventing the advancement of societal wellbeing.

2.2.1.4 Psycho-social repercussions

For Savulescu, there is no reason why a country should ban this kind of biotechnology because an official forbiddance could have negative consequences for society:

> If CRISPR is only accessible to a few, if access to this technology is not guaranteed to the entire population, the consequences could be the creation of a new elite that is not only economically more powerful, but also biologically superior. (…) CRISPR would be the tool to break the existing genetic class differentiation. From this point of view, CRISPR would be a tool of social therapy, not enhancement. (Alonso et al., 2020, p. 271)

Thus, on this view, although governments should be free to disapprove practices of genetic engineering aimed at altering and improving the social pool, it should still allow it for the sake of its citizens, in order to protect and promote equality for all. What is more, when we look back to evolution or to past innovations, we realize that this could really be seen as the continuum of the evolutionary flow:

> humanity has already experienced some drastic changes through history, changes that have modified its biological constitution. Inventions such as the wheel, writing or more recently internet, have had very significant consequences on a biological and social level. (…) They also were not distributed in a fair way right from the start. But preventing some people from accessing transformative technologies by over-regulating them can inadvertently lock in current inequalities, and prevent the worst off from improving their lot. (id, pp. 271-272).

From an historical point of view, many of the new technologies developed in the past could have been described as tools to enhance, whereas today these are of common usage without even considering them as made for enhancement. Savulescu admits that the speed at which these innovations emerge and are employed in everyday life actually influences our appreciation toward them, and "it could be defended that CRISPR and gene editing in general will only need a period of normalization" (id, p. 265) so that people get used to them and get aware of the benefits they bring about. These biotechnologies are already part of human knowledge, thus they cannot be neglected; rather, we should collectively discuss and tackle the issue from an ethical perspective. Indeed, Savulescu proposes to "reject prejudice against gene editing in favor of sound scientific information and fine-grained ethical analysis." (id, p. 272) In his opinion, "we need a mature ethics that enables us to use powerful science such as gene editing, while also preventing abuse. What we do not need is more unwarranted nightmares of doom that unjustifiably prevent many people from benefiting of great improvements in their health. Caution is necessary" (id, p. 273), meaning that an equilibrium should be met between being too permissive or excessively reluctant about biotechnological applications. "Perhaps the best we can hope for is harm reduction and a regulated market to make important enhancements (…) part of a basic healthcare plan so that the benefits of gene editing are distributed equally." (Savulescu and Singer, 2019, p. 222) However, this equality could be achievable only if all members of society agree to have enhanced children, thus only through artificial reproduction, which to me is quite unlikely.

Despite the ethical, social and political turmoil that genetic engineering techniques have triggered, Savulescu reminds us that "CRISPR technologies have started a revolution that could bring enormous benefits to humanity" (Alonso et al., 2020, p. 260); now, it is up to everyone involved with it to decide whether this increase in action power will magnify the easiness of harming people or the spread of advantages coming from it. On this question, Savulescu promotes a version of the "welfarist" approach: "the goal of HETs [Human Enhancement Technologies] should be to enhance quality of life and well-being, not just for individuals but also for the communities they participate in, applying principles of equity and social cohesion." (Bavelier et al., 2019, p. 2) With these argumentations, Savulescu tries his best to convince us on the need for such innovations, underlining their task as tools for social and biological justice. Indeed, he stresses the fact that we need to employ the available scientific knowledge not only to prevent illnesses, but we must also "try to make people's lives go better, not just healthier." (Savulescu and Sparrow, 2013, p. 57)

Nevertheless, as already noted above, health-related aspects play an important role in the promotion of GE, and – aware of this – Savulescu strengthens his reasoning by emphasizing the aid that the associated practices determine: "advanced gene editing techniques could reduce the global burden of genetic disease and potentially benefit millions worldwide" (Savulescu et al., 2015, p. 478) because an healthy individual will pursue an active life, both in terms of work and socialization; therefore, even those around him will benefit from his enhancement. Again, for this reason, parents would likely design their offspring since in contemporary society "starting or growing a family is an immensely significant decision; technology which could help individuals who make that decision realize their goal would be invaluable" (Afnan et al., 2021, p. 10) because it would allow them to have a child already 'fit for the future'.

Moreover, to seek endorsement for his stances, Savulescu claims that "there is no clear or morally relevant distinction between using CRISPR to alter (…) our children, and other medical interventions that have similar effects when the goal is treating or preventing disease." (Alonso et al., 2020, p. 267) He perceives as unreasonable any motivation against these two objectives, which can be tackled with the same means; in fact, he goes on appealing to the increasing blurred line between procedures intended as therapy and those seen as enhancement, given the fact that "what is considered 'normal' or 'medically advisable' depends on subjective judgments or cultural norms that change over time." (id, p. 261) Thus, we should just let these new biotechnologies bloom and wait for our morality to get accustomed to them.

Human genetic enhancement "cannot be good or bad absolutely. We can speak of whether a particular application of a technology is good or bad, or whether their availability has good or bad effects on society—but technologies themselves are not the type of object to which the property of 'good' or 'bad' attaches." (Gyngell et al., 2019, p. 519) Consequently, we should not ask whether – for example – CRISPR is good, but rather we should analyze the context and values that make us appreciate or despise its use, and when we will do so, Savulescu believes we will agree on the moral obligation to design children so as to permit everyone to live their best lives.

2.3 Female critiques

As anticipated, the literature about these topics is neither exhaustive nor inclusive, in the sense that there are very few female authors. Yet, I will conclude this first part on the theoretical background of child design and selection providing a brief recap on two criticisms developed by two women against both factions: firstly, bioconservative stances will be opposed by Frances Kamm, an American philosopher and professor, specialized in normative and applied ethics, who analyzes the ideas of Sandel and highlights some critical aspects; then, transhumanism will be challenged by Susan B. Levin, a professor of bioethics and ancient Greek philosophy, who criticizes the essence of Savulescu's thoughts.

2.3.1 Frances Kamm on Sandel

Kamm develops an interesting yet intricate rebuttal of the arguments promoted by Sandel, focusing on his rejection to "mastery the mystery of birth" and enhancement because of the fear of their consequences on human relations. Indeed, she opposes his bioconservative strict position on enhancement, whereas she shares his position against a "genetic supermarket" because she agrees that "such a consumer model is out of place when creating persons." (Kamm, 2009, p. 113) because people are not products to be sold, "they are not commodities, but rather beings worthy of concern and respect in their own right." (id, p. 114) Yet, she does not see any reason to consider morally wrong to design a person. Indeed, she holds illogical the idea of immorality linked to enhancement on the grounds of an unequal moral status of individuals, depending on whether their genome has been manipulated or not; instead, she feels that equal moral status is just provided by the virtue of being human beings.

Furthermore, Sandel is against genome manipulation to treat illnesses because it "typically involves desiring mastery (…), and attempting to master the mystery of birth (if not by the pursuit of enhancements)" (id, p. 95) which is bad. Yet, Kamm believes that "these bads can be outweighed by the good of curing diseases" (ibid.) because "if mastering nature were bad, one would have to show not only that the goods of enhancement are not as important as the goods of treatment but that they are not good enough to outweigh or transform the bad aspects of mastery." (id, p. 102) Moreover, she separates the desire to master and the actual mastery of birth because she affirms that "a desire for mastery is not inconsistent with an openness to the unbidden that Sandel emphasizes" which "does not, however, necessarily imply a willingness to accept whatever comes even if it is bad." (id, p. 94) Indeed, a person might not accept something positive happening to her just because it is not in line with her hopes. According to Kamm, there is the need for "much more argument to show that there is some duty owed to nature which we offend against when we change natural capacities" (id, p. 107), while the argumentations supported by Sandel are not enough.

2.3.2 Susan B. Levin on Savulescu

Levin accuses Savulescu to have utilitarian ideas on enhancement because he feels it as the best way to maximize social welfare and 'harm-avoidance'. Yet, she reminds us that "there are conditions traditionally viewed ad disabilities, whose status is now subject to challenge. (…) There is thus no limit on what could be viewed as harmful." (Levin, 2016, p. 58) On the matter, she demarcates that "actual accounts of well-being just are controversial, being wrapped up, for instance, with notions of worthwhile aims. As expected given their handling of well-being— beyond the abstract, indefinite goal of maximizing certain goods, particularly cognitive ability—advocates fail to defend any such vision." (id, p. 62) Indeed, because of their open definition of harm, everything could count as something to be avoided, leading enhancement closer to eugenics.

As a matter of fact, Levin recalls the similarity of the transhumanists with earlier eugenicists, who "were openly utilitarian, trumpeting a moral requirement to maximize populational welfare through bioenhancement and corresponding sociopolitical mandates." (Levin, 2021, p. 17) She warns against their approach to science, especially for "their unsubstantiated commitment to genes' strong causal role" linked to complex traits like intelligence, and she believes that "even if science and technology could do exactly what transhumanists say, we should have serious qualms about signing on. (…) Transhumanists extend medicalization to our very humanity, seen as a "disability" that science and technology not only can, but, morally speaking, must, address." (id, p. 18)

Levin criticized Savulescu's commitment to transhumanism because this actually belittle our value as human beings and our capabilities, which should always be upgraded according to him. Supporting this idea, transhumanist "proponents frequently contend that technological advances will augment autonomy indirectly by expanding the range of options among which individuals may choose, at least in the realm of procreative decision-making." (Levin, 2016, p. 53) Nevertheless, Levin stresses that it is actually the opposite because children would be deprived of the right to an open future and to self-determination, and even parental autonomy would diminish: social expectations would overpower them, shaping their decisions on the creation of their offspring. Then, transhumanism will spread the idea that "those who opt for enhancement are better parents, while those who would be content with unenhanced progeny are objectively worse” (id, p. 56) because they do not try to improve the wellbeing of their children, but actually this belief is very prejudicial and reduce the value of parents to one single decision.

Furthermore, for Levin, the wide range of application of enhancement that Savulescu opens to every aspect of humanity is unsustainable not only in terms of parent-child relations, but also economically given the scarce available resources, and socially because transhumanism aims at imposing its view as the only right one to follow. Savulescu calls for public discussion on the matter to praise his position, whereas Levin underlines the importance of a more extensive public confrontation to raise awareness on what biotechnologies are capable to do.

2.4 Conclusive theoretical thoughts

What is unknown brings about worries, and it is even more the case for new biotechnologies affecting human beings, which are still to be perfected. Given his background in medicine and neuroscience, Savulescu talks about these new methods of artificial reproduction, while Sandel avoids this specialized and detailed discussion to focus on their repercussion. Indeed, Sandel rightly fears the division of human beings into two classes, and also Savulescu depicts such possible scenario; yet, if the former is aware that this separation would be detrimental for our society because it would erode principles like equality and solidarity, the latter accepts it even in light of future domination by the products of our actions, that is enhanced individuals. With respect to future generation, Savulescu is somewhat egoistical because he denies the importance to pay attention toward future generation when applying techniques like CRISPR, while lots of people hold it as prerequisite, as we will see in the next chapters.

Furthermore, it is true that there are many things that humanity could improve to have better lives, as progress in the past has shown us; yet, past melioration was on objects, rather than on subjects and therefore the issue now is more complex because genetic engineering and selection would involve not only human beings and their bodies, but there would be implications also for human rights and human dignity. Moreover, transhumanists’ ideas of wellbeing and harm are too wide that there will always be space for betterment: although they fairly explain that we will face a loss of diversity consequent to the possibility to select traits of offspring only in the long-term, child selection and design would be infinitely perpetuated to avoid upcoming diseases or to fit to new social trends, so the troublesome possibility of traits homogenization would instead become real.

PART 2) BIOETHICAL COMMITTEES AND GOVERNANCE

As demonstrated, opinions about practices like child selection or child design vary enormously, and there is no right or wrong position. This open interpretation of how things should go allows for opposing stances, and here my goal is to examine whether these theoretical frameworks are somehow mirrored by multi-level governance, or rather a favored viewpoint is pursued. I will begin with a global perspective provided at macro-level by organizations such as UNESCO and WHO, to then move to the European level, and to end with the Italian stand on the matter.

CHAPTER III – AT GLOBAL LEVEL: UNESCO & WHO CASES

From a worldwide perspective, I focused on the western world, and I decided to consider two institutions that are reliable and competent on issues related to the well-being of humankind in the entirety of its complexity, namely the United Nations Educational, Scientific and Cultural Organization (UNESCO) and the World Health Organization (WHO). But before going into their specific stances, I deem it essential to delineate the legislative global environment, which is surprisingly puny. At global level, no binding universal legal instrument tackling and governing techniques like genetic engineering for human enhancement or child selection has been drafted:

> There is no single international human rights instrument or law with regard to parenthood and reproduction (including ART) in which the rights, interests and welfare of all affected parties – in particular (…) future children – are explicitly articulated, acknowledged, and balanced against each other as well as against other accepted values. (UNESCO IBC, 2019, para. 93)

Although I assume this is due to the relative novelty of procedures, evidently universal guidelines on the matter will soon be necessary; otherwise, uninhibited behaviors will bring about the risk of a deleterious global competitiveness for genetic engineering, neglecting basic human rights and fundamental freedoms, which are essential values for a peaceful cohabitation in contemporary society. This was clear already in 1993, when the World Conference on Human Rights was concluded with the formulation of the Vienna Declaration and Programme of Action, which stated that "everyone has the right to enjoy the benefits of scientific progress and its applications. (…) [But] certain advances, notably in the biomedical and life sciences as well as in information technology, may have potentially adverse consequences for the integrity, dignity and human rights of the individual." (OHCHR, 1993, para. 11) Such awareness was accompanied by a call for international cooperation with the aim to ensure respect and protection for human dignity and rights in this area of universal concern. This has not been completely achieved yet, but things are going in the right direction.

3.1 Legal instruments:

3.1.1 UN CRC

Given the fact that the core of my arguments evolves around the figure of future children, I felt the need to start by analyzing the Convention on the Right of the Child (CRC), drafted and adopted by the United Nations (UN) in 1989, which is the most ratified international convention so far. Article 1 defines a 'child' as "*every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier*." Interestingly enough, it underlines a deadline to be considered a child, but it does not provide any specific indication for the beginning of childhood, except for a reference in its preamble, where the Declaration of the Rights of the Child (1989) is recalled stating that "the child, by reason of his physical and mental immaturity, needs special safeguards and care, including appropriate legal protection, *before* as well as after birth." (italics added) Nevertheless, in the General Comments drafted by the Committee on the Rights of the Child, the subjects are always children already born, so it cannot be assumed that unborn children are granted the same rights. As a matter of fact, even the General Comment No. 7 (2005) entitled "Implementing child rights in early childhood" does not explicitly sign any starting point for childhood, but it maintains that "in its consideration of rights in early childhood, the Committee wishes to include all young children: at birth and throughout infancy (…)" (para. 4) so, the phase before birth is not to be included.

Although "the Committee recommends that States parties establish systems of early identification and early intervention as part of their health services, together with birth registration and procedures for following the progress of children identified with disabilities at an early age" (Committee on the Rights of the Child, 2007, para. 56), and even if it "recognizes that most mortality, morbidity and disabilities among children could be prevented if there were political commitment and sufficient allocation of resources directed towards the application of available knowledge and technologies for prevention, treatment and care" (Committee on the Rights of the Child, 2013), no remarks are made about prenatal life and related researches for illnesses or disabilities. In fact, according to the Committee on the Rights of the Child, "childhood is a period of continuous growth from birth to infancy, through the preschool age to adolescence" (ibid.); yet, such definition is inconsistent with the above-mentioned child-related needs, quoted by the Office of the High Commissioner for Human Rights (OHCHR). Indecisiveness in defining a basic concept like 'child' makes discussing about child design and selection even harder and more delicate.

3.1.2 Right to health

Child design and selection as ways toward health protection and promotion are debated because health is a long-range right. WHO was the first institution to affirm the right to health in an official document, its Constitution. From that moment on, the right to "the highest attainable standard of health" has been proposed again and again, starting with the 1948 Universal Declaration of Human Rights (UDHR) that "mentioned health as part of the right to an adequate standard of living (art. 25)." (Bayefsky, 2000, p. 1) In the 1966 International Covenant on Economic, Social and Cultural Rights (ICESCR) also emphasized that:

> *The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for: (a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child.* (art.12)

Despite being more than 50 years old, these words can still be applied to the current situation because progress has eased this task, but it has also provided new means to achieve it. Yet, on the one hand, stillbirth rate and infant mortality have been reduced (at least in advanced countries), while on the other hand the concepts of 'healthy development' and 'child' can be trigging: if a child is to be considered so only after birth, then PGD could not be justified in the name of health because embryos and fetuses are not part of the 'child'-group, whereas PGD is actually permitted with the excuse to select 'healthy' *child-to-be*. The lack of clarity on terms allows for flexibility on their utilization, which is not of help to get harmonizing legislation around the world. Similarly, CRISPR-

Cas9 aims at developing the healthiest child, although intended to be applied in an entity not considered a child yet. Furthermore, health became one of the grounds against which no discrimination should be raised, and base for rights protection by States.

> Obligations to protect include, inter alia, the duties of States to adopt legislation or to take other measures ensuring equal access to health care and health-related services provided by third parties; to ensure that privatization of the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services; to control the marketing of medical equipment and medicines by third parties. (Committee on Economic, Social and Cultural Rights, 2000, para. 35)

These features are key aspects when applied to child design and selection because usually these are attainable only artificially. Thus, considering that for the moment CRISPR-Cas9 is not available for human reproduction, and only PGD is allowed in some States, the private sector is the only supplier (unless a country will decide to provide them for free or will be sponsored by an insurance). Therefore, although their basic justification is to guarantee healthy offspring, it is hard to believe child design and selection will be considered as real options to respect the right to health.

This right has a specific article even in the 2006 Convention on the Right of the Persons with Disabilities (CRPD) that it is worth the mention, since often child design and selection are invoked to avoid having child with disabilities. Article 25 affirms that:

> *States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. (...) In particular, States Parties shall: (...) b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimize and prevent further disabilities, including among children and older persons*;

so, based on these words, it might be gathered that living persons with disabilities must be granted medical support, while in contrast concepts like “early identification” and “prevention of further disabilities among children” might be abused to promote medicalized interventions. I think it will be necessary for UN to comment on these points because new biotechnologies will soon ease these processes and the risk is that practices not permitted now will actually take advantage of such openness in interpretation to find entitlement.

As analyzed above, the possibility to choose your own offspring (be it by designing them or selecting the embryo that will be implanted) is becoming more and more tempting, given the trend in today society to seek perfectionism everywhere. Indeed, the likelihood of new biotechnologies to spread to the human sphere is increasing, awarding them social consent, so rights connected to them should be revised and updated in order to prevent doubts on their permissibility. Furthermore, given that "all human rights are universal, indivisible and interdependent and interrelated" (OHCHR, 1993, pt. I, par.5), it is paramount to reflect on the right to health in its widest scope of application, that is even before birth; as noted, child design through enhancement would hardly be involved but we should not exclude the possibility for the contrary in the future. The malleability of the issue allows for unpredictability, so again public discussion is important to shape future regulations on the matter, in light of respect for human dignity.

3.1.3 UNESCO declarations

Differently, if we consider non-binding instruments like declarations rather than conventions, UNESCO drafted several relevant documents, which are listed below in a chronological order, underlining the most pertinent articles and key aspects:

- 1997, Universal Declaration on Human Genome and Human Rights (UDHGHR)
    - Article 1 "*The human genome underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity*"
    - Article 2 *"(a) Everyone has a right to respect for their dignity and for their rights regardless of their genetic characteristics.*
      (b)That dignity makes it imperative not to reduce individuals to their genetic characteristics and to respect their uniqueness and diversity."
    - Article 8 "*Every individual shall have the right, according to international and national law, to just reparation for any damage sustained as a direct and determining result of an intervention affecting his or her genome."*

    - Article 12 *"(a) Benefits from advances in biology, genetics and medicine, concerning the human genome, shall be made available to all, with due regard for the dignity and human rights of each individual*."
- 1997, UNESCO Declaration on the Responsibilities of the Present Generations towards Future Generations
    - Article 3 "*The present generations should strive to ensure the maintenance and perpetuation of humankind with due respect for the dignity of the hu-man person. Consequently, the nature and form of human life must not be undermined in any way whatsoever*."
    - Article 6 "*The human genome, in full respect of the dignity of the human person and human rights, must be protected and biodiversity safeguarded. Scientific and technological progress should not in any way impair or compromise the preservation of the human and other species*."
    - Article 11 "*The present generations should refrain from taking any action or measure which would have the effect of leading to or perpetuating any form of discrimination for future generations*."
- 2003, UNESCO International Declaration on Human Genetic Data
    - Article 1 *"(a) The aims of this Declaration are: to ensure the respect of human dignity and protection of human rights and fundamental freedoms in the collection, processing, use and storage of human genetic data, (...) in keeping with the requirements of equality, justice and solidarity, while giving due consideration to freedom of thought and expression, including freedom of research;"*
    - Article 3 "*Each individual has a characteristic genetic make-up. Nevertheless, a person's identity should not be reduced to genetic characteristics, since it involves complex educational, environmental and personal factors and emotional, social, spiritual and cultural bonds with others and implies a dimension of freedom*."
    - Article 7 "(*a) Every effort should be made to ensure that human genetic data and human proteomic data are not used for purposes that discriminate in a way that is intended to infringe, or has the effect of infringing human rights, fundamental freedoms or human dignity of an individual or for purposes that*

lead to the stigmatization of an individual, a family, a group or communities."

- 2005 UNESCO Universal Declaration on Bioethics and Human Rights
    - Article 2 "*The aims of this Declaration are : (...) (c) to promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law; (...) (g) to safeguard and promote the interests of the present and future generations; (h) to underline the importance of biodiversity and its conservation as a common concern of humankind*."
    - Article 3 "1. *Human dignity, human rights and fundamental freedoms are to be fully respected. 2. The interests and welfare of the individual should have priority over the sole interest of science or society*."
    - Article 10 "*The fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably*."
    - Article 11 "*No individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms*."

As we can notice, many points are repeated and I purposedly quoted them again because they stress key aspects for the discourse on child selection and design. The 1997 UDHGHR signed the first official attempt to protect and promote respect for the human genome that becomes common basis to pool all human beings under a single social class. Such inclusion occurs regardless of any blemish that a person may have in people's eyes, which actually represents the first pretext for exclusion in a society that seek perfectionism in all spheres and stages of life. Indeed, uniqueness is glorified, together with the safeguard of human rights and dignity. In this declaration, no specific mention is given to future generations but such lack has been filled by the other declaration of the same year; as a matter of fact, the ad hoc declaration on the Responsibilities of Present Generations towards Future Generations clearly stated the necessity to pay attention to implications of new technologies and scientific discoveries in the long run, with the imperative to make them cope with the respect of human rights, human dignity and fundamental freedoms (art. 3). From its words, some sort of antagonism can be gathered towards invasive practices implemented thanks to scientific progress, in favor of preserving the human genome as it is. In fact, its manipulation could hamper equality while creating an excuse for discrimination based on genetic make-up, potentially having negative consequences for future generations. Thus, in this line of thought, performing child selection and child design should be avoided.

Similarly, declarations in the new millennium resemble aspects of the previous ones, so evidently the impact of these documents was not as strong as intended – although aware of their not binding characteristics –, and it was necessary to reaffirm some principles again: like for example, the need not to reduce people to their genetic make-up, while supporting the relevance of distinctiveness of human genome (2003 decl. art.3); or the fact that no discrimination should be caused based on human genome, because it would amount to human rights violation (2003 decl. art. 7a – 2005 decl. art. 11). Moreover, particular consideration is suggested towards future generations, highlighting the essential nature of equality among individuals, keeping in mind that they represent a category of persons who cannot consent on procedures applied to them before birth. Indeed, no legal instrument can "protect the unborn child from being genetically tested." (UNESCO IBC, 2015, para. 16)

All these issues around child selection and design will be amplified soon, due to the rapid advancements in genetics that deepens the confines of ethical reflections, which are "never-ending commitments. Probably some revision of existing declarations should also be considered. The cogency of the principles is untouched. [In contrast,] the scope of possible application is changing and widening every day" (id, para. 127), thus updated stances on the matters are needed. Thankfully, UNESCO has a powerful ace up the sleeve, which is "the only global forum for reflection on bioethics" (UNESCO, 2019): the International Bioethics Committee (IBC).

3.2 IBC

The IBC is an ad hoc body that works for ensuring respect for human dignity throughout scientific developments and its meetings are usually convened once a year by the UNESCO Director-General to discuss the most recent controversies. Since its creation in 1993, the IBC has drafted four relevant reports dealing with issues related to the manipulation of human genome and interventions on human reproduction:

1. The Report of the IBC on Pre-implantation Genetic Diagnosis and Germline Interventions (2003) underlined the fear of such practices to be contrary to human dignity because they could foster negative positions towards people with disabilities, keeping in mind consequences on future generations and the impact they could have on self-perception too. In particular, "there have been exceptional requests by couples who themselves are affected by a genetic disease (deafness, dwarfism by achondroplasia) to perform PGD and select embryos carrying the same mutation for transfer to the uterus. In this way an affected baby would be conceived on purpose with the idea that such a child would better integrate in the family. The International Bioethics Committee of UNESCO (IBC) considers such an approach to be unethical because it does not take into account the many lifelong and irreversible disadvantages that will burden the future person." (UNESCO IBC, 2003, para. 59) Still, here we should notice how subjective can be the interpretation of disability as disadvantage: the connection is immediate for the majority of society, while for a minority represented by people with disabilities it is not always so.
2. The Report of IBC on Updating its Reflection on the Human Genome and Human Rights (2015) has been needed due to the enormous advances made in scientific and technological fields, making it easier and cheaper to perform analyses or modifications in the genetic make-up of an individual, therefore increasing the risk for human rights violations to occur. The IBC solicits the international and local communities, and all citizens and experts of civil society "to consider the human genome as one of the premises of freedom itself and not simply as raw material to manipulate at leisure. At the same time, considering that scientific advancements in this field are likely to offer unprecedented tools against diseases, it is crucial to acknowledge that these opportunities should never become the privilege of few. What is heritage of humanity entails sharing both of responsibilities and benefits." (UNESCO IBC, 2015, para. 128) Moreover, following this ideology of sharing as moral imperative, it pushes for a "moratorium on genome editing of the human germline (…) [because] the concerns about safety of the procedure and its ethical implications are so far prevailing." (id, para. 118)

3. The Report of IBC on Assisted Reproductive Technologies and Parenthood (2019) deals with issues related to techniques like PGD and CRISPR-Cas9, aware that they are not only means to overcome infertility but also instruments to satisfy parental desires. From its evaluation, it transpires a cautious stance towards these methods because of the responsibilities they hide and the fact that the principle of the best interest of the child is extremely hard to define in the context of ART.
4. The Report of the IBC on the Principle of Protecting Future Generations (2021) provides a deep overview on the most relevant aspects of techniques linked to human genome manipulation and study, and on the possibility to introduce hereditary modifications thanks to recent scientific and technological developments. Indeed, "the IBC strongly recommends that the international community acts with extreme caution in applying gene editing on the human genome. In particular, germline editing introducing heritable modifications that would be transmitted to future generations requires specific precautions because it raises serious ethical concerns. Given current knowledge, the IBC considers it irresponsible to clinically apply gene editing on the human embryo, zygote or germline." (UNESCO IBC, 2021, para. 216)

These reports target many features that are worth of an analysis, such as the position of the IBC with respect to the above-mentioned techniques, their multiple impacts, the needed attention towards future generations, and implications in the field of human rights.

3.2.1 IBC on genetic technologies

IBC acknowledges the fact that the emergence of PGD or CRISPR-Cas9 techniques "not only served to treat infertility, but also created a space for fulfilling wishes and overcoming some of the biological constraints on procreation" (UNESCO IBC, 2019, para. 1) for example by according to parents the possibility to select desired traits of their offspring. It also admits that "major technical hurdles remain" (id, par. 59), so their use is not really risk-free. Additionally, beside these concrete hazards, it must be taken into account even the possible contributions of these techniques in the increase of social "disparities between those who can access treatment and those who cannot" (UNESCO IBC, 2021, para. 159), and of discrimination because "there will likely be differences between genetically modified humans and genetically unmodified humans" (id, para.161). In this way, the application of these methods in ART could bypass their initial task of handle and cure infertility, becoming the cause of development of two classes of human beings based on their economic resources that would be against the principles stated in the UDHGHR, more precisely:

> *12. (a) Given the fact that the technology has not yet been mastered, seeking specific cognitive, physical or emotional capacities by choosing the traits to be transmitted opens a new era of genomic manipulations; this could be considered a kind of eugenic drift, deliberate modification of the human species or transhumanism. Furthermore, one could speak of an attack on human dignity.* (ibid.)

The IBC is clear on the matter: there is still a lot of work and research to do before such innovations could be applied safely and with full knowledge of the facts, plus it explicitly refers to a transhumanist stance on the issue, which recalls the praised mastery of birth and enhancement. Thus, following this mindset as it is put into words, any kind of artificial selection or decision on human genome is seen negatively so far and should not be welcomed. Indeed, "due to uncertainties on the effect of (…) modification on future generations, such interventions have been strongly discouraged or legally banned in many countries" (UNESCO IBC, 2015, para. 46) and the IBC officially affirms that – in specific – "heritable genome editing for reproductive purposes" must be prohibited "because it is currently unsafe." (UNESCO IBC, 2021, para. 211)

Doubtlessly, for the IBC, when it comes to practices affecting genetic make-up, "safety is the unquestionable condition for application to human beings. This is all the more so when the object of investigation is an intervention which is likely to have significant effects on the life of individuals who could be considered 'designed on demand' by someone else without their consent, and transmit their genome modifications to future generations." (UNESCO IBC, 2015, para. 105) Therefore, techniques to design children and select their characteristics can be detrimental for future offspring because of the complexity of human genome, plus "modifications are likely to have unforeseen and irreversible consequences on individuals and their descendants." (UNESCO IBC, 2021, para. 161) IBC is conscious about the fact that currently "there is not enough knowledge to interpret all the information into reliable predictions about a person's health and susceptibility to genetic disease" (id, para. 47), thus such lack of scientific knowledge should facilitate prudence as regards child design or child selection. Indeed, "the spread of a desired genetic variant among the population (…) may have a great impact on biodiversity" (id, para. 26), which is something to protect instead, as underlined in the 1997 Declaration on the Responsibilities of the Present Generations towards Future Generations article 6, and in the 2005 Universal Declaration on Bioethics and Human Rights article 2.

The fast-evolving environment in which science and medical practice develop poses several new challenges, like the fact that "genetic analyses are becoming cheaper, faster, more comprehensive (…) [so that] genetic tests are being offered more and more for non-medical purposes and the boundary between medical and non-medical use is blurring." (UNESCO IBC, 2015, para. 10) This is quite alarming for the IBC which defends the difference between these two uses of new technologies as crucial; as a matter of fact, it believes that their applications especially in non-medical fields should consider the respect of human rights and dignity as necessary and compulsory (id, para. 122). Such specification about non-medical purposes in the employment of genetic-related practices can be seen in connection with the challenging expansion of the market in this field, which unquestionably denigrates the effort in support of human rights and dignity asked by the IBC.

Indeed "several aspects of medicine (…) respond to the logic of demand and supply" (UNESCO IBC, 2015, para. 28), like its application beyond medical reasons. This constitutes a worry for the IBC that "encourages international society to take appropriate measures to prevent the premature commercialization of clinical applications" of practices targeting human genetic make-up (UNESCO IBC, 2021, para. 216). Moreover, IBC is aware of the gluttony caused by advanced knowledge on human genome and the economic benefits it could generate, so it stressed the fact that "the human genome is not patentable on the basis of public interest considerations." (UNESCO IBC, 2001, p. 1) Finally, one last provocative issue related to the non-medical function of human genome manipulation is linked to the possibility of enhancement, in the sense of altering traits or capabilities. In this case, techniques like CRISPR-Cas9 could be employed in a healthy embryo or even zygote to ameliorate its already 'normal' genetic make-up, which would have a particular impact at social level.

3.2.2 IBC on social impacts

According to the IBC, one of the arguments “against genetic enhancement of normal human characteristics is that it would profoundly affect our self-perception as ‘persons’ – that is as autonomous beings. Instead we might consider ourselves to be mere ‘things’ or biological artefacts designed by others.” (UNESCO IBC, 2003, para. 98) Such degradation of the personal status would on the one hand make people lose connection with the rest of society, intended as a group of human beings sharing psycho-physical and social characteristics; on the other hand, the manufacture of human genetic make-up that potentially may be passed on to future generations would make them “not appreciate the values of fairness and efforts to the same extent as the present generation.” (UNESCO IBC, 2021, para. 160) For this reason, IBC calls for a reflection on the permission to produce inheritable genetic modifications and on the necessity “to draw the line between treatment and enhancement” (ibid.), that is between medical and non-medical purposes.

Apart from the devaluation at personal level and of social values, even the IBC recognizes that the main risk of allowing enhancing techniques is the creation of two classes of human beings, with negative influence “on the perception of disability and on societal solidarity with disabled people and women who give birth to them.”[2] (UNESCO, 2019, para. 22) Furthermore, such risk is not restricted to child design, but it also concerns child selection since “effects of discrimination and stigmatization can also occur with regard to prenatal and preimplantation genetic testing.” (ibid.) This would entail some sort of disrespect for care of people with disabilities since the possibility that “prevention as social objective (…) would imply a discriminatory practice that sends the message that these people are unwelcome in society.” (UNESCO IBC, 2015, para. 88) These issues open the way for the recurring question on the social status of embryos/zygotes/fetuses that even the IBC takes on in its 2015 report, when it reminds us that “the destruction of embryos implied in some of these techniques revives the well-known controversy on the principle of respect of human life.” (UNESCO IBC, 2015, para. 106) Mindful of the

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[2] Here, I keep the quote as it is because I deem it important to notice that UNESCO makes a terrible mistake, neglecting the 2006 Convention on the Rights of Person with Disabilities, which calls for a shift in the common saying, asking for a more inclusive language: ‘person with disability’ should be preferred to ‘disabled person’.

complexity on the topic, the IBC affirms that, “here, consensus is impossible to attain.” (ibid.)

Unanimity is continually challenged because innovations can clash with the common understanding. Still, changes produced by scientific and technological progress cause an uncontrolled tendency “to imagine that everything that is technically possible should be achieved” (UNESCO IBC, 2015, para. 28), disregarding the potential impacts that could be generated. Such viewpoint recalls the moral imperative to enhance praised by Savulescu, and it can be ascribed to the emerging concept of ‘technological imperative’:

> new technologies are inevitable and essential, and they must be developed and accepted for the benefit of society. Technological imperative in health care, and specifically in infertility care represents the tendency to prioritize the development and use of new technologies regardless of their costs [and unknown risks]. (…) The emphasis on technical innovation as a solution for the existing problems in the society and particularly fertility problems, as well as the constant media reference to its successes and rapid innovations have created a general social acceptance of the new technologies. Repeated publicity has a great power of persuasion (…). (UNESCO IBC, 2019, paras. 69–70)

Indeed, the more something is underlined and inculcated in people’s mentality, the more people will be convinced that such thing is good; therefore, “the widespread use of genetic screening (…) may foster a culture of ‘perfectionism’ or ‘zero defect’ and even renew some ‘eugenic trends’, with the consequence that it could become more and more difficult to accept imperfection and disability as a part of normal human life and a component of the diversity we are all called on to acknowledge and respect.” (UNESCO IBC, 2015, para. 125) The danger is about a blind acceptance of biotechnological imperialism on delicate aspects of life, like human reproduction. Warned of this, the IBC recommends to raise awareness on the issue, and to “involve and inform all members of society about all plans, risks and measures to be implemented in terms of the impact of advances in the life sciences.” (UNESCO IBC, 2021, para. 214) It is essential to make society reflects upon practices linked with child design and selection because it would be unjust to carelessly let science and technology drive and mastery our biological future in its most intimate sphere, that is by manipulating human genome.

3.2.3 IBC on ethical impacts

As already mentioned, for the present generation it is difficult to feel connected to the future ones because they are not real now, thus objections have been raised regarding our responsibility towards them. To summarize very precisely in one sentence this standpoint, it can be said that “since there is not yet anyone to be harmed (as future human beings are not born yet), then it is impossible to commit wrongful actions.” (UNESCO IBC, 2021, para. 146) Based on this account, no adverse affirmation could be made against child design and selection; nevertheless, an ethical problem may still emerge: future offsprings are “individuals who cannot give consent to be genetically tested” in the present (UNESCO IBC, 2015, para. 16); in fact, consent is one of the most challenging ethical issues resulting from the fast technical progress that we are facing in genetics nowadays and given its deep controversial character I will not discuss it here, but I consider it worth the mention.

Current technological “developments have led to several ethical questions at least in [other] three domains: they have increased human responsibility, they have shed new light on the relation between the individual and society and they have bought more freedom and constraints.” (UNESCO IBC, 2019, para. 61) In my opinion, these three areas of concern are interconnected because responsibility entails freedom and constrains, which are essential aspects to consider and remember when creating social bonds. Biotechnological intrusion in an intimate sphere of life like reproduction puts in the hands of those performing the procedure the power to choose for the life of future individuals, and such privileged authority must encompass accountability for actions undertaken. Therefore, on the one hand freedom is enlarged for scientists – who can experiment new practices and make research on them – and for parents – who can decide a priori characteristics for their offspring; on the other hand, it can be argued that this increased liberty brings about limitations to those resulting from it, since core aspects of their lives are influenced and manipulated by preferences of third persons. Moreover, restrictions are usually applied also by norms regulating procedures because governments tend to have a careful stand on these ever-changing, fast-evolving matters. Then, it follows that the relation between individual and society is modified too, and according to the Universal Declaration on Bioethics and Human Rights article 3.2, the interest of the individual should prevail over that of society, which is not always so easy to guarantee.

Since nobody can put himself out of society and aware that our actions have – direct or indirect – consequences on the community around us, some suggest we should hold future generations in high regard because of the increasing possibility for our action to have an impact on them out of proportion, in line with the Declaration on Responsibilities of the Present Generations toward Future Generations (art. 11); as a matter of fact, "future generations can also be seen as the disadvantaged and vulnerable, since they may suffer the negative consequences of current actions/decisions without being able to express their interests." (UNESCO IBC, 2021, para. 183) Yet, the proposal to care for them has been objected based on the impossibility for future generations to "behave in a reciprocal way towards us", namely they cannot have any special consideration for us. However, the IBC underlines that "moral obligations are often endorsed towards people who cannot be reciprocal, such as babies" (UNESCO IBC, 2021, para. 145) therefore "since moral obligations do not necessarily demand reciprocity, it is possible to conceive of moral obligations towards future generations" (ibid.) Indeed, IBC affirms that "the present generation should be encouraged to develop a moral obligation or social responsibility for the well-being of future generations on ethical grounds." (id, para. 151), rather than for blindly accepting whatever progress enables scientists to do as suggested by transhumanists.

Several ethical questions have been raised toward upcoming generations after the possibility to select their characteristics spread out: the chance to select traits and profiles would make them gain different values since embryos or fetuses with 'good profile' would be favored against others. In this way, a wave of discrimination towards some features would rise; therefore, future individuals who will not be the result of artificial reproduction where genetic make-up can be drawn a priori may face prejudices or feel inferior compared with their enhanced peer. In this scenario, it is evident that no equality can exist, which is actually one of the key points stressed in article 1 of the 2003 International Declaration on Human Genetic Data and article 10 of the 2005 Universal Declaration on Bioethics and Human Rights. Thus, the basis for a peaceful cohabitation on this world would fade, and for this reason, the IBC stresses the need for special attention for future generations.

3.2.4 IBC on future generations

> The precautionary principle is considered one of the main ethical and legal instruments aimed at protecting current and future generations from serious negative consequences of current rapid developments in science and technology. In essence, it requires decision- makers to adopt measures to avoid, reduce or minimize danger to current and future peoples, communities or the environment (if the stakes are high but the scientific evidence about such dangers is insufficient or inconclusive). (…) However, when used to protect the welfare and rights of future generations, the principle must be supported by other moral values and considerations. (UNESCO IBC, 2021, paras. 103, 136)

This is due to the unique character of future generations; indeed, IBC considers the term 'future generation' as "an empty name as there is no one currently to who it refers to" (id, par. 137). Child design is one of those techniques applied now but whose consequences will become real in the future, for which knowledge on its hazards is not exhaustive, so in this case it should be imperative to follow the precautionary principle (PP).

At present, it is not possible to foresee all feasible implications and have a reciprocal relationship with future generations, and "since our actions determine the existence and identity of future people, the concept of harming or benefiting such individuals leads to well-known philosophical paradoxes and problems, such as the 'non-identity problem' discussed by Parfit (1984)", (UNESCO IBC, 2021, para. 139) already presented in chapter 2.2.1.2. In order to guarantee some sort of equity in health and 'health as human rights', the IBC notes that the PP is a necessary support for HGE, so as not to ignore potential risks and respect intergenerational justice, keeping in mind that both "present and future generations should be considered as a continuum of the human species." (UNESCO IBC, 2021, para. 151)

> The notion of justice between generations, defended by philosophers from completely different backgrounds, demands respect for the living conditions of future individuals who should be free to develop their potentialities without being biologically conditioned by the particular conceptions of 'good' and 'bad' human traits that were dominant at the time they were conceived. Neither PGD nor

> genetics in general should become instruments for “intergenerational tyranny”. (UNESCO IBC, 2003, para. 97)

Nevertheless, it is arduous to effectively talk about ‘tyranny’ because it presupposes someone accountable for it, whereas “it is challenging to identify agents (persons or institutions) most likely to take on responsibility for future generations.” (UNESCO IBC, 2021, para. 101) As noted by the IBC, such liability is abstract in the sense that it is a prior precaution applied toward someone who is not born yet, and exactly for this reason it is so important. Intergenerational responsibility is crucial “for justice between all peoples to keep in mind that the respect for dignity of every human being entails the duty to refrain from making her or him a mere instrument for the fulfilment of the wishes and preferences of others.” (UNESCO IBC, 2015, para. 33) It can be gathered that designing the genome of a child is contrary to her or his dignity; still, “science and technology are sectors that can be of use to social justice and future generations. The aim is not to give up on scientific progress, but to carry it out with thoughtful reflection about its consequences (…) [because] promoting technological advances without reflecting on their impact on future generations may threaten the foundations of the future.” (UNESCO IBC, 2021, paras. 130, 174) Unleash scientific research and its subsequent implementations would make several new practices applicable without due concern to long-term consequences. Moreover, when dignity is belittled, neither equality nor social justice have a place.

Everyone would benefit from progress, but nobody would bear the accountability for its negative and maybe even unpredictable side-effects, which should then be repaired as stressed by article 8 of the 1997 UDHGHR; nevertheless, blindly accepting emerging technological practices makes all of us somehow responsible for them, since “protecting the interests of future generations must be considered as a collective and shared responsibility that involves stakeholders at various levels, including civil society. Everyone needs to be aware of their roles as stewards of the world and to take care of the world on behalf of future generations.” (UNESCO IBC, 2021, para. 204) Today we do not know who will come into existence tomorrow, but we know for sure that somebody will be born; yet, a common feeling of care towards them spreads in our society, thus “the idea of protecting future generations suggests that they might have a right to be protected.” (id, para. 9)

3.2.5 IBC on rights

As always, protection and promotion of rights represent a controversial topic, and their potential role becomes even more relevant in delicate issues like child selection or design. On the one hand, IBC believes that progress in human genetics brings about benefits which should be at the basis of universal human rights like the right to health. On the other hand, when it comes to interventions in the genome of future individuals, neither the linkage between such practices and health nor the absence of discrimination are to be taken for granted. Indeed, nowadays germ-line interventions go beyond the right to health because they allow for enhancements too. This enlarges the spectrum of rights involved in the issue:

> while some people claim that parents have the right to make far reaching choices concerning their offspring, including the use of genetic information obtained from the early stages of pregnancy, others hold that they should refrain from genetic testing of their future children if it is not necessary for their health. Some people underline the responsibility of parents to strive for the best possible health of their children even by intervening in their genes, whereas others stress the right of every human being to have an unmanipulated genetic make-up, so that nobody is due to choices of other human beings with respect to their biological starting configuration. (UNESCO IBC, 2015, para. 32)

The discussion goes on with the faction affirming the parental right to know whether their children could develop some diseases, versus those believing this would be against the best interests of the child. When it comes to children, consensus on best practices is hardly achievable. We could sum up the dispute by saying it evolves around the differentiation between rights of parents and rights of children. Or better, at the heart of the discussion there is a dubious point on “whether future generations may have ‘rights’. The intricate interconnectedness and interdependence of reality brings us back to the concept of ‘social justice’, referring to every member’s duty to contribute to the common good of the community, as well as to the community’s responsibility towards all its members.” (UNESCO IBC 2021, para. 183) Nonetheless, “there is a conceptual difficulty in accepting the whole of humankind as the subject of rights, because the concept of a ‘right’ has always implied the existence (not the future existence) of some individual entity (not a collectivity).” (id, para. 185) In fact, often the denial of possible rights granted to future generations lays on the stance that only existence guarantees rights, and future generations actually represent future collectivity rather than a single person now. On the matter, the IBC asserts that “the rights of future generations should be recognized and protected by the present generation, who should act as trustees of the available assets and natural resources. If faced with the legal critique that non-existing people cannot have rights, a solution would be to focus on the duties and obligations of the present generations towards future generations” (id, para. 151), as previously discussed.

3.3 WHO

The World Health Organization deals with issues closer to child design rather than child selection since it discusses about genome manipulations. It expresses itself only recently, through an ad hoc committee established in December 2018 called ‘Expert Advisory Committee on Developing Global Standards for Governance and Oversight of Human Genome Editing. This multidisciplinary panel is composed of 18 specialists from all over the world with the task to examine challenges related to both somatic, germline, and heritable HGE by reviewing the existing literature on the matter, so as to make advice and recommendations to governmental mechanisms. The decision to set up this cabinet arrives because “the recent application of tools, such as CRISPR-Cas9 (…), to edit the human genome with the intention of treating or preventing disease and the gaps in our scientific understanding, in addition to some of the proposed applications of human genome editing, raise ethical issues that have highlighted the need for robust oversight in this area.” (WHO 2021a, p. vi)

Given the recent establishment of the committee, the literature by WHO on child design and selection is not so expansive, but in July 2021, the Expert Advisory Committee published a relevant document entitled ‘Human Genome Editing’, divided into three parts: ‘HGE position paper’ summarizes key points; ‘HGE framework for governance’ discusses about the meaning of “good governance” on the issue by designing some concrete examples; ‘HGE recommendations’ lists guidelines that should be followed. Based on these works, I will now illustrate WHO’s position on the matter.

3.3.1 WHO on new biotechnologies

In the Position Paper, it can be read that according to the Expert Advisory Committee, “the COVID-19 pandemic has clearly demonstrated the importance of using new tools and methods to combat serious diseases and highlighted the potential benefits of human genome editing research. It also reminds us of the need to develop technology carefully, with robust testing and quality assurance measures in place to maximize benefit and minimize harm.” (p.vi) Thus, for HGE it is essential to balance openness to new biotechnologies with rigorous safety measures. The committee recognizes somatic and heritable HGE as acceptable practices but it also underlines that other alternatives exist and should be considered first, since “the possibility that human genome editing might be used for the enhancement of human traits is very controversial.” (WHO 2021a, para. 53)

Aware of the fact that “the success of a single editing event is best achieved in early stage embryos, as any edits propagate through the entire organism” (Taylor and Galichet, 2021, p. 7), the Expert Advisory Committee highlights benefits coming from somatic editing at fetal stage that could not be achieved with conventional methods (WHO 2021a, para. 41). Yet, it does not openly promote such technology, given its complex moral and economic implications, which instead push for more public engagement:

> the Committee believes it is essential that all people have an influence in public deliberations about whether, and if so how, human genome editing technologies should be used and to what ends. Public empowerment would strengthen the conditions for autonomy and agency by having members of the public actively involved in discussing and debating the what, whether and why of human genome editing. As such, it would help shape the research and policy agenda so that these reflect public values, perspectives, experiences, interests and priorities. (WHO 2021c, p.16)

Societal concerns about practices linked to genome manipulations vary depending on the context, both geographically and culturally. Nevertheless, the Expert Advisory Committee suggests some principles and ethical values to keep in mind while making decisions, like for example: openness, transparency, honesty and accountability; responsible stewardship of science; inclusiveness; caution; non-discrimination; equal moral worth; global health justice. (WHO 2021a, pp. 13–14) The wish is for these virtues also to potentially become “a firm foundation for the work of future experts committee and other applicable units.” (WHO 2021c, p. 19) Were it the case, a common base for global guidelines on HGE application could be achieved.

Nevertheless, despite this hopeful gaze at the future, the Expert Advisory Committee discusses some possible negative situations that might hamper the benefits coming from new biotechnologies, among which there is “unscrupulous entrepreneurship and clinics expanding assisted reproduction.” In this scenario the first challenge has been highlighted also by UNESCO, that is that “differentiating between different uses of a technology” becomes more difficult and there is already evidence about unscrupulous clinics which have pursued practices actively evading domestic laws, favored by the disharmony of international regulations. This situation highlights potential commercial interests in packaging HGE, leading to another major problem, namely influencing policies: “given the potential financial returns from leading the field in advanced assisted reproduction services, commercial interests may override health and ethical interests in pursuit of heritable human genome editing.” (WHO 2021a, p. 52) That is to say, it will likely happen “that commercial companies and professional GLGE [Germline Gene Editing] ‘enthusiasts’ may want to exploit prospective parents’ dreams (or their fears to lag behind) by selling them this technology as a means to at least improve their chances of having a ‘perfect child’.” (De Wer et al., 2018, p. 12) So, earnings could easily persuade policymakers to soften laws or turning them in their favor in order to boost economic improvement.

3.3.2 WHO on good governance and recommendations

The tempting profit from genome manipulation make good governance even more needed, in order to try to guarantee what affirmed in the preamble of the 1946 WHO Constitution: “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition”. If modifying genetic make-up followed the rule of the market, then such practice would go beyond its medical end, neglecting its primary aim to provide health, thus official guidelines are necessary to avoid that.

> Inspired by the description of governance by the United Nations Educational, Scientific and Cultural Organization (UNESCO) the Committee understands

> governance to include the norms, values and rules of the processes through which public affairs are managed so as to ensure transparency, participation, inclusivity and responsiveness. Governance also represents the structures and processes that are designed to ensure accountability, transparency, responsiveness, adherence to the rule of law, stability, equity and inclusiveness, empowerment, and broad-based participation. Governance is not limited to formal mechanisms such as legislation, regulations or judicial opinion but includes informal mechanisms such as ethical, social and professional norms or other influences that guide its development. (…) Good governance is an iterative, ongoing process that includes mechanisms for regular revision in light of technical, practical and ethical developments and changes in societal views and values. Ideally, good governance is proactive, not only reactive. (WHO 2021a, para. 14–15, 17)

Therefore, the concept of good governance is very intricate, and it encompasses many features by connecting values and principles. Moreover, it should "develop policies on its permissibility or impermissibility and ensure that any permitted procedures are safe (for all those involved) and effective." (id, para. 41) In order for good governance to be successful, it must "consider both the desires of prospective parents to have genetically connected offspring and the risks to future offspring, as well as possible effects on society, particularly in light of these alternatives" and "learn lessons from past experiences in the use of reproductive technologies, including the scale of patient demand, the equity of access, the safety of the procedures, the effectiveness of governance systems and the effects on society generally." (id, para. 46) Without these features, governance loses part of its power to impose its authority in a democratic way.

For these reasons, the Expert Advisory Committee advises WHO to (i) develop models of best practice of inclusive multidirectional, multistakeholder dialogue, and supporting materials, that can be applied to human genome editing; and (ii) explore how best to include in decision-making under-represented groups that are interested in human genome editing. (WHO 2021b, p. 5) The first point implies that collective wellbeing in health terms should prevail in HGE innovations, rather than individual benefits, whereas the second one involves adequate protection and equity of access. Furthermore,

> as an organization dedicated to advocating for and ensuring the health and well-being of all people and all nations, WHO, led by its Director-General, has an essential role to play in helping negotiate and promote norms and regulations that can ensure our most important values will guide the application of genome editing technologies. Indeed, WHO and its Director-General are uniquely positioned to articulate global ethical values and principles, exercise moral authority and thereby lead through moral suasion. (WHO 2021c, p. 3)

In particular, the Director-General should assure HGE be pursued only “in jurisdictions with domestic policy and oversight mechanisms.” (id, p. 12) This aspect is quite relevant because it entails that it would not be legal anymore to go abroad to do something that in your home country is forbidden, and in this way even respect for human rights is ensured, by keeping new biotechnological methods connected to their original medical scopes and to safe environments. As a result, child design is not blatantly criticized or outlawed but regulations are highly requested.

3.4 UNESCO & WHO side by side

It could be said that UNESCO and WHO, through their ad hoc committees (IBC for the former, and Expert Advisory Committee for the latter), show affinity from an ideological point of view. In fact, their works are basis for reflection and source of inspiration for one another. It is reassuring that these two institutions share a common overview on new practices available in artificial reproduction, and that they are up with the times, even discussing procedures that could be potentially applied to human beings in the future that are now being studied, tested, and analyzed. Although WHO is more open to scientific and technological progress, they both stress the need for a cautious approach to new technologies applicable in artificial reproduction. Indeed, they fear the power of earnings in influencing decision on their permissibility, with annexed risks to mitigate the differentiation between medical and non-medical fields of action, and to affect human biodiversity that would be lessen in favor of current ideal of perfection.

I would say that, up to now, the main difference lays on literature because UNESCO has debated more than WHO on issues linked to human enhancement, persons with disabilities, the status of embryos and fetuses; nevertheless, neither of the two provide exhaustive indications on the matters. So, in conclusion, as debated at the beginning of the chapter, universal cooperation on genetic engineering has not been fully realized so far, but thanks to shared positions, it can be gathered that there is hope for some sort of harmony in regulations and guidelines in promoting and accepting biotechnological developments in the field of child design at global level.

CHAPTER IV – AT EUROPEAN LEVEL: CoE & EU CASES

I will now tighten the field of business to a meso-level, that is the European one. I focus on the standpoints of the Council of Europe (CoE) and of the European Union (EU) because they both provide interesting insights on HGE methods, and related governance and ethics. As written on the website of the CoE, "the Council of Europe and the European Union share the same fundamental values – human rights, democracy and the rule of law – but are separate entities which perform different, yet complementary, roles." As a matter of fact, the CoE is composed of 46 countries, 27 of which are also constituents of the EU. These two institutions have drawn up two important documents for the protection and promotion of rights: the European Convention on Human Rights by the CoE in 1950, and the Charter of Fundamental Rights by the EU in 2000[3]. Nevertheless, the former is too old to target genetics as possible base for discrimination, given that studies on genetic make-up and transmission of genetic traits spread years later; differently, in the latter, genes and related biotechnological practices are considered.

4.1 Human rights

4.1.1 Rights in the CoE

As anticipated, the European Convention on Human Rights is not of help when dealing with child selection and design; however, in 1997 the CoE drafted the Convention on Human Rights and Biomedicine, which is usually called 'Oviedo Convention' and is the only legally binding instrument specific for human rights in the field of biomedicine. Indeed, it is "a unique reference framework to that end. The Oviedo Convention represents the outcome of an in-depth discussion at European level, on developments in the biomedical field, including in the field of genetics." ("Genome editing technologies," 2021)

Among all articles, I deem the following ones as more relevant in the discussion about child design and selection:

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[3] The Charter "acquires a legally binding character" in 2009 with the Treaty of Lisbon , thanks to which the EU gains "full legal personality" and "which gives the Charter the same legal value as the Treaties." ("The Treaty of Lisbon | Fact Sheets on the European Union | European Parliament," n.d.)

Article 1 lays the basis for every operation affecting human beings and their genomes: "*Parties to this Convention shall protect the dignity and identity of all human beings and guarantee everyone, without discrimination, respect for their integrity and other rights and fundamental freedoms with regard to the application of biology and medicine*." Here, discrimination is a general word but in article 11 it is specified also that "*Any form of discrimination against a person on grounds of his or her genetic heritage is prohibited*."

Article 2 underlines the primacy of the human being, mirroring the analysis made at global level: "*The interests and welfare of the human being shall prevail over the sole interest of society or science*." Such affirmation is not an obvious one because some claim it rightful to select embryos or design children that do not present diseases seen as a load to society, but this would be against the dignity of and respect for some minorities, as in the case of the deaf couple presented in chapter 1.2.3.

Articles 12 and 13 go at the heart of the issue because they deal with practices related to child design and selection. Article 12 is about predictive genetic tests: "*Tests which are predictive of genetic diseases or which serve either to identify the subject as a carrier of a gene responsible for a disease or to detect a genetic predisposition or susceptibility to a disease may be performed only for health purposes or for scientific research linked to health purposes, and subject to appropriate genetic counselling*." Such statement justifies practices like PGD because undertaken with the intent to avoid the growth of fetuses that appear to have ill genes. Then, article 13 is about intervention on the human genome: "*An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants*." Through these words, it can be gathered that methods like CRISPR-Cas9 should not pave the way for enhancement and germline modification must not be performed.

Last but not least, article 28 focuses on public debate: "*Parties to this Convention shall see to it that the fundamental questions raised by the developments of biology and medicine are the subject of appropriate public discussion in the light, in particular, of relevant medical, social, economic, ethical and legal implications, and that their possible application is made the subject of appropriate consultation*." Unfortunately, nowadays I do not see any effort to publicly debate over designing children, whereas I deem it every day more necessary, since progress evolves fast in this field.

4.1.2 Rights in the EU

Differently from the Oviedo Convention, the Charter of Fundamental Rights (hereafter, the Charter) has a specific right focusing on biomedical applications that must conform to ‘the right to the integrity of the person’. Article 3.2 affirms that

> *in the fields of medicine and biology, the following must be respected in particular: the free and informed consent of the person concerned, according to the procedures laid down by law, prohibition of eugenic practices, in particular those aiming at the selection of persons, the prohibition on making the human body and its parts as such a source of financial gain.*

Interestingly, this article officially bans ‘selection of persons’ because it is considered a ‘eugenic practice’, but ‘in the field of medicine and biology’ the outcome of PGD is actually ‘select persons’. Discarding embryos that do not fit parental desires is a first attempt to select a child, although at a stage of life not clearly considered real life. As explained in chapter 1.2.1, PGD “technology is currently legal in many European countries (…), but in some countries it remains restricted to so-called ‘serious’ conditions (e.g. in Italy and Germany), and in others is completely banned (e.g. in Poland).” (Cavaliere, 2018, p. 216) The problem of incompatibility between what imposed by the Charter and what permitted by single States may rise depending on the interpretation given to the word ‘person’. As previously noted, personhood is a very complex concept and vary even within our society, therefore the ambiguity highlighted with regard to the beginning of childhood makes it tolerable to authorize PGD in a country even if such country is party to the Charter.

Besides article 3, the Charter promotes other rights that are useful in the controversy about child design and selection. First of all, article 1 signs the inviolability of human dignity, which “must be respected and protected”, and then article 21.1 declares that “*any discrimination based on any ground such as sex, race, colour, ethnic or social origin, genetic features, language, religion or belief, political or any other opinion, membership of a national minority, property, birth, disability, age or sexual orientation shall be* *prohibited*." It explicitly introduced that discrimination can be based also on genetic characteristics and disabilities, and interestingly, one of the main criticisms against child design and selection is raised because these practices are indeed seen as discriminative with respect to persons with disabilities. Thus, they are believed to disregard the dignity of human beings.

Furthermore, it is relevant to notice that, for the EU, also Directive 98/44/EC gives the task to evaluate "all ethical aspects of biotechnology" explicitly to the EGE (art. 7) and it also has something to say on child design; in particular, article 6 runs as follow:

> *1. Inventions shall be considered unpatentable where their commercial exploitation would be contrary to ordre public or morality; however, exploitation shall not be deemed to be so contrary merely because it is prohibited by law or regulation.*
> *2. On the basis of paragraph 1, the following, in particular, shall be considered unpatentable: (...) (b) process for modifying the germ line genetic identity of human beings*.

Although it just deals with its patentability so as to prevent exclusive economic exploitation of the practice, in line with UNESCO IBC, it does neither ban nor accept GGE, but this is the only explicit position officially expressed by the EU on the matter.

4.2 CoE (CDBIO)

On behalf of the CoE, already in 1982 the Parliamentary Assembly stated that "human dignity implies "the right to inherit a genetic pattern which has not been artificially changed"." (De Wer et al., 2018, p. 9) So, although biotechnologies like Crispr/Cas9 had not been discovered yet, fears about possible modification of the human genome existed. Then it shifted its attentions to other issues, but quite recently, in 2017 the Parliamentary Assembly expressed its concerns about new GE techniques in biomedicine and made official recommendations on their use, such as:

> 1. urge member States which have not yet ratified the Oviedo Convention to do so without further delay, or, as a minimum, to put in place a national ban on establishing a pregnancy with germ-line cells or human embryos having undergone intentional genome editing;

> 2. and, in addition, develop a common regulatory and legal framework which is able to balance the potential benefits and risks of these technologies aiming to treat serious diseases, while preventing abuse or adverse effects of genetic technology on human beings;
>
> 3. foster a broad and informed public debate on the medical potential and possible ethical and human rights consequences of the use of new genetic technologies in human beings;
>
> 4. instruct the Council of Europe Committee on Bioethics (DH-BIO) to assess the ethical and legal challenges raised by emerging genome editing technologies, in the light of the principles laid down in the Oviedo Convention and the precautionary principle;
>
> 5 recommend that member States, on the basis of the public debate, the DH-BIO assessment and the common regulatory and legal framework devised, develop a clear national position on the practical use of new genetic technologies, setting the limits and promoting good practices. (Parliamentary Assembly, 2017, sec. 5)

A practical response to these recommendations came from the former Committee on Bioethics of the CoE (DH-BIO) which expresses opinions on HGE technologies on behalf of the CoE, and which from January 2022 is called Steering Committee for Human Rights in the fields of Biomedicine and Health (CDBIO). More specifically, the committee launched the Strategic Action Plan (SAP) on Human Rights and Technologies in Biomedicine for the years 2020-2025, which is “designed to protect human dignity, human rights and individual freedoms with regard to the applications of biology and medicine” taking the Oviedo Convention as base. (“SAP,” n.d.) As a matter of fact, SAP “puts particular emphasis on addressing the challenges posed by new technological developments and by the evolution of established practices in the field of biomedicine.” (DH-BIO 2019, 6)

To do so, it defined four thematic pillars on which developing its work: the first one is governance, that lets weave together human rights and public dialogue in biomedicine to guarantee transparency and democracy; the second is equity in healthcare, to oppose disparities in access and giving due consideration to more vulnerable people; thirdly, physical and mental integrity of persons, also improving children participation in decision-making process; lastly, the fourth pillar is about strategic cooperation and communication with other intergovernmental institutions involved in bioethics. In this regard, "to raise awareness of human rights principles and the challenges raised by developments in the field of biomedicine, it is important for the work of the Committee on Bioethics to be widely communicated and rendered more visible to all stakeholders. This will facilitate an increased understanding of the contribution of the Committee on Bioethics, and of the Council of Europe more generally, to protecting human rights in the field of biomedicine." (DH-BIO 2019, para. 28)

4.2.1 CoE on biotechnologies and their impacts

The CoE bolsters research in biomedicine, and its publications on the matter are indeed quite recent and focus mainly on HGE technologies, rather than PGD. "There is strong support for the better understanding of the causes of diseases and for future treatment (…) However, the application of genome editing technologies to human gametes or embryos raises many ethical, social and safety issues, particularly from any modification of the human genome which could be passed on to future generations." (Council of Europe, 2015, p. 2) It encourages scientific progress to advance human health, while acknowledging that inheritable consequences of these technologies raise concerns for their possible but unforeseeable irreversible harm, as repeated also in the SAP (para. 14).

Such attention for future generations bypasses their first stages of life, when HGE would be applied to them, and care only about life after birth when children become right-holders, in line with the UN CRC; again, the lack of comprehensiveness in the definition of childhood, not including life in the uterus thus considering a child as such only after birth, seems to provide a partial protection, and given the intricacy in dealing with the beginning of our worth as person with rights, the CoE discusses the consequences of biotechnologies in broader sense.

One of the main concerns of the CoE about HGE aftermath is due to the fact that "biomedical developments have the capacity to blur and challenge normative boundaries. They can translate rapidly from one field of application to another, where different regulations may apply. They can also create ambiguities in the application of regulatory measures, for example, over whether a particular use is medical or non-medical, or whether a given use is a therapy or a non-therapeutic enhancement." (Council of Europe, 2020, p. 10) Interestingly, the worry for increasing blurred lines mirrors the apprehension of UNESCO on the matter. So, precisely because "technological innovation often creates its own dynamic" (DH-BIO 2019, para. 14), prudence is essential when arguing whether new biotechnologies may be applied to human beings, and carefulness is needed also because "developments in biomedicine, especially new technologies, are often complex; they arrive in socially and culturally defined circumstances, and they embody not only possibilities but also uncertainties and ambiguities." (Council of Europe, 2020, p. 8)

Still, the latest technologies emerging in the field of genetics create opportunities in biomedicine through the promise of "significant benefits for individuals, for society and for future generations." (id, p. 5) Nevertheless, the CoE maintains that the concretization of these advantages "also raise new ethical challenges related to inter alia identity, autonomy, privacy, and non-discrimination." (DH-BIO 2019, para. 3) These four principles mirror the rights considered at stake in "interventions at the earliest stage of human development that affect the future child", as listed in a report entitled "The Rights of Children in Biomedicine" commissioned by the Committee on Bioethics of the CoE to Ph.D. graduates from the University of Uppsala (Sweden) as an independent analytical study on children's rights in biomedicine.

The intent of the report was "to identify potential areas of heightened concern for the rights of children that may be unfavorably affected by scientific advances and uncertainties in biomedicine", considering "the rights of children as class – formally collectively defined as persons from birth to age 18, unless they have attained majority status." (Zillén et al., 2017, p. 1) Despite excluding embryos and fetuses from the 'class of children', attention is however paid also to 'future' children. Indeed,

> this report was intended to emphasize that many biomedical interventions, both inside and outside the clinical context, pose risks to children, even intervening on behalf of *future children before their rights attach*. Many different types of advances in biomedicine and new technological developments have been offered to prospective parents with the hope of creating a healthy child or to diagnose and treat the condition of the unborn child at an early stage of development. (…) But while these technologies enable individuals to create children free from genetic

> disorders, they also introduce scientific and legal challenges in relation to the future child's right to health – taking into account the scientific uncertainty about all the risks involved. (id, pp. 75–76, italics added)

Even in this case, the suggested attitude is somehow conservative. In the report it is recalled that

> the current use of questionable and unproven treatments in pediatric care and the expanded use of new technologies outside the clinical context – such as in the field of assisted reproduction and genetic testing – raises profound questions as to how the rights of children can be protected, perhaps inevitably leading to renewed discussions of the need for a European human rights instrument specifically aimed at children in the field of biomedicine. The rights of children in the biomedical sphere are protected very generally and scattered across some core international and regional human rights treaties dealing with the rights of disadvantaged groups. (id, p. 80)

From these words, it can be convened that the actual preservation and care for rights in ART is just sufficient and in need of improvements. Moreover, although there is no explicit reference to the practice, suggested human rights such those to identity, autonomy, privacy and non-discrimination are key concepts in the field of designing children and enhancement. Indeed, the CoE assimilates these principle and affirms that "human rights challenges are posed by scientific and technological developments as well as by the evolution of established practices in the biomedical field" (DH-BIO 2019, para. 3), as for ART genetic tests.

The CoE is aware that these challenges and uncertainties related to progress in biomedicine are due to the fact that "the full extent of the risks and unintended consequences of a given innovation can only be fully appreciated with experience, and by that time, control and change can be difficult, if not impossible, as the technology becomes embedded in social infrastructures or human culture." (DH-BIO 2019, para. 12) The CoE stresses the relevance of time for the understanding of these ambiguous novelties, since

> risks and side effects often come to light only through practical experience. By the time the consequences become more apparent it may be too late to change the course of developments. Responsible approaches to biomedical innovation recognise a duty to anticipate and inform the public about developments that could have a profound impact on their lives and the societies they live in and involve them in guiding decisions towards an acceptable outcome, for instance how and under which circumstances to use a new technology. (Council of Europe, 2020, p. 8)

Experience in applying practices actually made evident which can be their side-effects, for example: “the establishment of prenatal diagnosis as a routine examination, in combination with simplified abortion methods, has led to significant reductions in the birth of people with Down’s syndrome in some society.” (id, p. 11) This perfectly illustrates what ‘child selection’ and the current wave of perfectionism entail. As a matter of fact, the CoE insists on the fact that biomedical developments – especially in the field of genetics – have strong power to the extent that they can reshape social norms. “This is why the directions taken by biomedical developments, and the way the risks and potential benefits are distributed, are of profound public interest.” (Council of Europe, 2020, p. 5) So, possibly, innovation in biomedicine could foster division in society rather than really improving it, and for this reason the CoE believes that “the promotion of public debate, where contrary opinions can challenge each other, combined with tools of evidence, is an important counterbalance to such developments” (id, p. 9) and an instrument for ‘peaceful’ cohabitation of different opinions within the same society.

4.2.2 CoE on governance and public involvement

According to the CoE, setting guidelines for the use of new biotechnologies is necessary but not sufficient, and a more extensive support should be provided. In fact, the CoE reflects on the task of bioethics in assisting governance on the matter, and it recalls that “bioethics is often construed as a ‘culture of limits’. However, its role should be to accompany progress in science and to reflect on and to protect and promote human rights. Bioethics serves to safeguard human rights principles and goes to the heart of how we want to shape both the lives of individuals and the broader society.” (DH-BIO 2019, para. 2) So, attention should be paid not only to newly developed practices, but also to their impact on humankind. Such comprehensive care for human beings is also reflected in the position of CoE with respect to future generations: public participation in delicate debates concerning new biotechnologies that are getting a foothold in ART, like in the case of child design, should look long-term. The CoE underlines the importance “to recognise that young people should be a key focal point for bioethical deliberations, considering that they will experience the impacts of emerging and converging technologies and that they will be shaping the future of society.” (DH-BIO 2019, para. 28)

Moreover, the CoE holds governance and public involvement to be equitably relevant and somehow ‘competent’ on these issues. On the one hand, it affirms that “governance frameworks are necessary to optimise the chances of stimulating innovation that contributes to human flourishing, whilst minimising applications that have negative consequences for individuals and society.” (id, para. 13) On the other hand, though, public debate plays a key role because the CoE sees it as “an important source of information and views when setting appropriate standards and a point of reference for the development of governance. Public debate can usefully broaden the basis for the appraisal of new developments, the consequences of which are uncertain.” (Council of Europe, 2020, p. 7) These uncertainties are indeed the reason why popular engagement is so much recommended by the CoE: since repercussions of possible side-effects of new methods fall back on society, if common opinions are in favor of these novelties, then fears influencing public approval would be limited or even clarified; therefore, setting laws will get easier for authorities. As a matter of fact, the CoE believes that

> governance that is guided only by political ideology, or that considers only limited technical questions such as the potential benefit and harms of treatments, or that responds only to existing preferences, may fail to address adequately these broader and longer-ranging questions. Given the potential effect on the lives of individuals, it is important that members of the public are informed about biomedical developments and can formulate, communicate and interrogate their views. This is important because it enables the public to take part in shaping policies and strategies for their society, and for building the competence of individuals to make informed decisions about their own health and welfare. It is equally important for policy makers to be aware of different opinions and diverse values among the public in order to respond to them. Public debate contributes to

> the responsible introduction of biomedical developments and technologies in the health sector. The long-term implications for individuals and for the future of society require democratically mandated decisions that are informed by shared values and demonstrate respect for human rights. (Council of Europe, 2020, p. 8)

Again, homogeneous opinions should not be inculcated, but rather diversity should be welcome to enrich our communities.

4.3 EU (EGE)

On the behalf of the EU, directives on matters regarding GE or other manipulations connected to ART are provided by the EGE, that stands for the European Group on Ethics in Science and New Technologies, which is an independent and multidisciplinary advisory body of the European Commission, which in turn is the executive arm of the EU. Its tasks regard discussions "where ethical, societal and fundamental rights issues intersect with the development of science and new technologies." ("EGE," n.d.) In recent years, it worked on the issue of HGE and the role of ethics in political commitment. In particular, in 2021 it published its "Opinion on ethics of Genome Editing", and the statement "Value for the Future: the role of ethics in European and global governance".

Similarly to the CoE, even according to the EGE, "there is an increasing need for shared ethical values and principles, in the face of the complexity of scientific and technological advancement, through critical reflection and dialectical argumentation." (EGE 2021b, p. 12) Among those suggested, there are values already promoted also at global level, like "the primacy of the human being over the sole interest of science or society, (…) equality, non-discrimination and solidarity; and caution and prudence in the face of uncertain or risky technologies that are likely to cause serious and irreversible damage to human beings, humanity, the environment and future generations." (ibid.) These concepts are the starting point, the basis for reflecting on scientific progress; indeed, the EGE believes that "given the powerful technologies available today to edit the human genome, there is a requirement to assess their impact on shared ethical principles and fundamental rights and freedoms" as those mentioned above. (EGE 2021a, p. 24) Yet, it acknowledges that uncertainties and expectations around biomedical techniques make it harder to set fixed criteria for regulation.

For this reason, they "recognise that genome editing technologies, particularly their application in humans, amongst other technologies, require a global governance approach." (id, p. 22) The complexity of the subject and different opinions and predispositions call for a global commitment both in geographical and cultural terms, and in fact "the EGE considers that deliberation regarding the acceptability and desirability of gene editing will require inclusive debate which extends to civil society where diverse perspectives and those with different expertise and values can be heard." (EGE, 2016, p. 2) As it can be noticed, the EGE focuses mainly on genome editing among other new biotechnologies, and it makes specific recommendations and proposal on this topic, since it deems "important to organize ethics oversight of international research collaboration and prevent ethics dumping." (EGE 2021a, p. 88) In particular, the EGE promotes "the initiative to found a Global Genome Editing Observatory for the purpose of hosting such debate" and "the creation of a European Platform to facilitate exchange of information and a broad and open public debate on the ethical and social implications of germline genome editing in human beings on the basis of sound and evidence-based information." (id, pp. 36 and 86)

These two proposals are of great importance because they would allow for official and comprehensive working groups on a type of artificial interventions having potential consequences on the whole humankind in the deepest sense, that is GE. The EGE suggests including several experts from different fields, involving "a range of publics, scientists, scholars in the social sciences and humanities, ethicists, legal and policy specialists, and other experts, organized civil society, with special attention to representatives of women's rights, rights of the child, gender equality, social equality, reproductive rights and justice, disability rights, and human rights in general." (id, p. 36) These different specialist knowledges would support a normative debate to delineate standards to follow. According to the EGE, deliberation on the kind of world we want to live in should be extensive and deep because it believes we are all responsible for shaping our present and the future of next generations; indeed, "collective responsibility goes hand in hand with societal dialogue, also – and particularly – across social, economic, cultural and ideological divides." (EGE 2021b, p. 4) Only the bypass of such divisions could allow for a concrete outcome from those debates.

4.3.1 EGE on biotechnologies

When discussing gene and genome editing, the EGE tackles two aspects of this subject: one the one hand, it enquires whether it is “safe enough” to use such biotechnology, and on the other hand, it ponders over the meanings of such application.

4.3.1.1 ‘Safe enough’ framing

The ‘safe enough’ framing deals with the idea that when a technology is so considered, then there are no risks in applying it; thus, the EGE affirms that this concept “is reminiscent of the ‘technological imperative’, the notion that ‘if it is technologically feasible then it ought to be done’” (EGE 2021a, p. 21), recalling what discussed also in chapter 3.2.2 by UNESCO. For the EGE, such simplistic view limits reflection about safety, which is actually a crucial criterion when examining the ethical acceptability of a technology. Aware of that, the EGE affirms that “determining what is ‘safe enough’ is not only about knowledge, but also about values, and scientific theories and practices are themselves value-laden.” (id, p. 23) Therefore, the concept is more complex than what it could be insinuated. As a matter of fact, the EGE defines two prerequisites for a technology to become ‘safe enough’: first of all, an intervention can be said to be so only when there is “knowledge about its effectiveness in terms of potential benefits, and about potential harms”; secondly, “risks must not exceed benefits.” (id, p. 31)

The debate about the safety of HGE started long ago, and already in 1975 the Asilomar Conference on ‘recombinant DNA’ signed “global consensus on prohibiting human germline gene modification.” (EGE, 2016, p. 1) This ban has been challenged in recent years due to increasing use of such technology in research and experiments (as the case of He Jiankui), but still “there is (almost) unanimous consensus that now genome editing for reproductive purposes is far from being safe enough for application.” (EGE 2021a, p. 34) Thus, it can be concluded that the EGE agrees in considering the resulting practice of designing children unsafe, and therefore – so far – unethical, even if not explicitly expressing it.

4.3.1.2 Meanings of use

In its 2021 opinion on the ethics of HE, the EGE takes on the issue around its possible aims. “The EGE holds that distinctions between therapy, prevention and enhancement can be of some use for assessing the ethical acceptability or even desirability of somatic and germline genome editing.” (id, p. 30) Yet, it recognizes that there is a blurring line between these scopes of application, and in fact, the EGE is conscious that “therapy, prevention and enhancement cannot be always clearly separated from each other.” (id, p. 28) Restoring health, avoiding diseases or improving wellbeing can overlap due to the lack of clear differentiation between medical and non-medical use. In the context of child selection, it could be said that the choice in favor of an embryo is made to avoid the possible development of an illness that could happen to other embryos, or because that embryo presents a characteristic that is valued more than other features of different embryos: in the first case, selection is based on medical terms, while in the second one it is pushed by the hope to have a child who is better than the others, not necessarily in terms of health. Similarly, in case of child design, the work done to create a ‘healthy’ individual is not for the purpose of health in itself, rather the aim is to exceed it and get an enhanced child.

Based on these premises, the EGE underlines the fact that “given the potential of genome editing techniques to be used for interventions that are not related to preventing or treating diseases but primarily serve enhancement purposes, their potential for fostering social inequality and undermining diversity should be considered.” (id, p. 87) Indeed, as noted in the first chapters, diversity is one of the features most at risk when dealing with the manipulation of genetic make-up. As a matter of fact, for the EGE, “genome editing affects diversity in important ways. (…) The new avenues offered by genome editing open the possibility to expand or narrow genetic diversity across the different domains of these technologies’ application.” (id, p. 18) This chance could be seen both as pro or con. The EGE views it like the latter, believing that “diversity has risen to the status of an accepted ‘good’, and a social goal to be protected and promoted, often against a background of its perceived precariousness due to human activity.” (ibid.)

It is exactly for the human activity that “diversity does not stand alone as a virtue, rather it is context-dependent” (id, p. 20) because the current trend toward perfectionism would make equality – intended as similarity – of traits as the ‘right’ way to follow, the best way to be competitive in our society. Yet, the EGE believes that diversity is important for helping “people to appreciate difference and care for and respect others, whereas having less diversity might make the lives of those with less common genetic traits still more marginal.” (id, p. 27) With its position, the EGE is clearly against the spread of new biotechnological practices that could hamper diversity, going against the motto of the EU that is indeed “United in diversity”.

4.3.2 EGE on HGE implications in society

The EGE somehow fears the overflow of GE leading to HGE because of its unforeseeable consequences that could be passed on to future generations. Moreover, it acknowledges that

> we have [already] moved into a phase of human development that is sometimes referred to as the era of ‘the Anthropocene’ or ‘voluntary evolution’ where human choices shape the course of evolution on Earth in important ways. Just as we started to find some relatively firm foundations for ethics in our common humanity, our evolutionary biology, psychology and common history, some suggest that we consider humanity as something that is not given and can be overcome and transcended by technological design and engineering. What we are, and what is good for us human beings, then depends on what we decide human beings could or should become. (EGE 2021b, 12)

If the idea that we can manipulate humanity becomes the leading one, then transhumanism will turn into reality, and for the EGE it is all in our hands. As a matter of fact, it “invokes human responsibility where anthropocentric effects have driven diversity loss” (EGE 2021a, 19), and this is a risk potentially occurring also with HGE. The desire to design the genetic make-up of a human being is prompted by the wish to make that individual ‘better than normal’; however, the EGE reminds us that “what is ‘normal’ is often not clearly defined and its definition changes over time and among societies.” (id, 29) In this thesis, as in our society, the dominant meaning of ‘normality’ is that conceived by the occidental world: what is normal for me is what I am used to, which is different to what people in Asia or Africa are familiar with. Actually, there are disparate perception about ‘normality’ even within the western world, for example the color of hair or eyes tends to get clearer the norther we move. This is to demonstrate that no consensus on this concept can ever be unanimously accepted all over the world.

Language and words can shape our understanding of and attitude toward what is normal. ‘Normal’ is something that is usually seen as ‘natural’, – or as the EGE says – “as in accordance with the laws of nature.” Yet, “genome editing questions common understanding of naturalness. (…) The natural stands in relation to its antithetic or complementary notions, the cultural, the technical, the artificial, the ‘human-made’.” (id, 16) Thus, human actions influence our perception of ‘natural’, and therefore of ‘normal’ too, and given that this power is in the hands of human beings, the EGE feels the need to reflect over the role we play. In this moment, thanks to scientific and technological progress, we are shifting our control: with the possibility to create ad hoc human genomes, we are *mastering* the laws of nature, as Sandel discussed, and such intrusion will change the way we look at others. The risk is that this capability will mold a new idea about ‘humanness’.

“As humans, we have an existential concern for what it is that makes us human, for what distinguishes humans from other forms of life, of intelligence, sentience, consciousness; and also for what responsibilities are incumbent upon humans – and humanity – with regard to others.” (ibid.) All these features are building blocks of ‘humanness’. Such concept is hardly defined though, because there is an ongoing debate over “what is typical for the human species, what is unique” to it (id, p. 25). The question around humanness has been boosted in the last decades by new technological interventions to create and select human beings. What is more of concern to the EGE is related to the impact of HGE to ‘humanness’:

> the question arises whether a change in the initial genetic condition of a human being fundamentally alters the nature of humanness or rather the relationship between humans by making them unequal with regard to their genetic starting conditions (…), whether a human embryo whose genome has been edited is still the same human being after the occurred alteration.” (id, p. 26)

As with the issue about the beginning of personhood, even in this case there will not be any agreement soon because of the different perceptions about HGE that vary among different cultures. Indeed, as social opinions change over time, beliefs in the desirability of artificial manipulations of genetic make-up will change, too. Aware of that, the EGE deeply reflects upon the role of ethics and values linked to governance and innovations, especially in fields like genetics and medicine. As it explains, the EGE believes that "values designate and shape the purpose behind our actions. (…) No narrative evolves, no decisions are taken, no advice is given, no technologies are developed without values shaping them, whether consciously or unconsciously, explicitly or implicitly." (EGE 2021b, 3) Thus, ethics becomes the background for our everyday life by guiding our acts through the principles we hold most dear. Therefore, "values and ethics are no limit or obstacle to innovation and change; [rather] they are the gist of innovation and change" (EGE 2021b, p. 4), in line with the CoE position.

Human rights, democracy and the rule of law are among the main values for the European Union, and these are also key concepts for the EGE because they cannot exist but linked to ethics. Nevertheless, the EGE is conscious that there is no international agreement about which are the most important values, and this translates into disagreement in what is seen as 'good' or 'desirable' within a society; yet, it feels that "there is an increasing need for shared ethical values and principles, in the face of the complexity of scientific and technological advancement, through balanced critical reflection and dialectic argumentation." (id, p. 12) Taking this into consideration, the EGE ponders on an ethics that could be sustainable and practicable in the next years and it concludes that – to be effective – such ethics should address "the foundations of the practices and institutions that are responsible for the phenomena that it considers to be problematic. An ambitious public ethics does not rest content with responding to new developments – such as new fields of scientific research or new technologies – but it participates in shaping the agenda." (id, p. 16) Ethics should gain more power to influence and guide societies in order to keep them connected to their ideological foundations, and to do so politics should welcome ethical reflection. According to the EGE,

> the recent challenges show that the idea of state neutrality regarding potential controversies on the good life and on scientific and technological innovation is untenable. It is so because a clear commitment to underlying values has to be made, while providing opportunities for living according to different concepts of a meaningful life – a democratic value decision in itself. (id, p. 9)

Hence, greater commitment by States to confront their choices on ethical grounds will be welcomed and even required in order to cope with moral questions raised by scientifical progress and new biotechnologies.

4.4 CoE & EU side by side

The focus on the emerging practice of HGE, rather than the consolidated PDG, is an aspect that brings together the two factions at European level. In particular, they both reflect on the different scopes of application there could be and on the dichotomy around medical or enhancing aims, in line with the discussion by UNESCO and WHO. According to the Steering Committee of the CoE, HGE will create new opportunities for progress and health, while new challenges will also arise, so it believes that only time and experience will demonstrate whether HGE is good or not for humankind. Differently and interestingly, the EGE is keener on the implications of HGE on terminologies because of the changes it causes in our perception as human species, and due to the loss of diversity it risks entailing.

Moreover, the EGE does not explicitly consider children as involved in the issue, whereas for the CoE children's rights are to be further implemented to face possible challenges related to genome modifications and it underlines this point by suggesting concrete changes to pursue. Yet, despite these diverging core aspects, they both feel that the most important things to reach while discussing HGE are shared ethical values, which are seen as essential to regulate norms and shape public opinion; without a common ethical base, no common guidelines could be developed.

CHAPTER V – AT NATIONAL LEVEL: THE ITALIAN CASE

The public debate about the possibility to create ad hoc children is not popular in Italy. I would bet that most Italians are not really aware about technological advances that research on artificial reproduction is generating. Many still associate human enhancement and child design to science fiction, whereas a well-known practice is that of negative selection in the event that prenatal analyses show potential malformations on the 'child-to-be', and there is wide controversy on whether such abortion should be legitimate. So differently from the global and the European level, where the focus is mainly on child design, at national level, Italy pays a lot of attention to possibilities of child selection too.

The debate is also fired up by the apparent increase in conscientious objection of clinical professionals: in 2019 a report estimated 68.4% of gynecologists as conscientious objectors (Caruso, 2020), whereas a relation of the Ministry of Health denounced that in 2020 they were 66.4% (Ministero della Salute, 2022, tbl. 28), which actually mirror a slightly reduction of the number of abortion (id, tbl. 4). Nevertheless, it is argued that such percentage is very high compared to other countries, which has inevitable repercussions on society. On the one hand, it means that in Italy it is difficult to find a place where undergo a safe abortion and thus conscientious objectors are highly criticized for not doing what supposedly is their task; in fact, the research committee that worked on the draft of the Annual Report on Human Rights denounced that the Italian situation is not in conformity with the Law, fueling discrimination against women who would opt for a voluntary termination of pregnancy (Centro Diritti Umani Università di Padova, 2022, p. 153). On the other hand, conscientious objection is "constitutionally founded (…) and a democratic institution necessary to keep alive the sense of problematicity concerning the limits of the protection of inviolable rights;" (CNB, 2012, pp. 18) thus conscientious objectors are seen by many as "the new champions of the protection of human rights." (id, p.33) The issue lies between the efforts to avoid the exploitation of a profession by imposing obligations that may be against personal deontology, and the fact that granting abortion (as provided by the Law N.194/1978) implies the duty to provide such service.

In my opinion, the hurdle in discussing delicate topics like this is partly due the political parties not able to peacefully confront, rather they try to impose their view as the only right one, and such resistance to open talks might come from the influence exercised by the Church in the Italian mindset. In fact, "the principles of Catholicism are constitutive elements of the historical heritage of the Italian people." (Governo Italiano, 1984, p. 1) Although Italy has stated the secularity of the State in article 7 of the Constitution[4] that is regulated by the Lateran Pacts of 1929[5], and later underlined in the Agreement between the Italian Republic and the Holy See of 1984[6], and even if younger generations tend to distance themselves from a religious standpoint, I feel a strong residual influence in the political and social choices made every day in the public domain. The legal provisions formulated in the last half century manifested some progress on public discussion about methods of artificial reproduction, but many feel they haven't achieved their full potentiality yet, due to the ever-present dispute on whether the rights of the mother should prevail over the protection of the right to life, or vice versa.

Quoting an Italian feminist and historian, Emma Baeri, "the relationship among the female body, law, and rights is problematic at its origins. Maybe this problematic relationship cannot be removed, and it is unsolvable in the current symbolic, juridical and political order, but it is a problem to be faced." (Caruso, 2020)

5.1 Legal background

When considering the legislation and international documents endorsed by Italy on matters concerning genetic manipulation and child selection, it is interesting to note that Italy has signed the Convention on Human Rights and Biomedicine (Oviedo Convention) in the first day open for signature, that was April 4, 1997; moreover, it signed also the Additional Protocol concerning Biomedical Research (October 19, 2005), adding a

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[4] Article 7: "The State and the Catholic Church are independent and sovereign, each within its own sphere. Their relations are regulated by the Lateran pacts. Amendments to such Pacts which are accepted by both parties shall not require the procedure of constitutional amendments." https://www.senato.it/documenti/repository/istituzione/costituzione_inglese.pdf

[5] The Lateran Pacts signed the end of the so-called 'Questione Romana". The Lateran treaty was stipulated by Mussolini and the Vatical and "had three parts: a political treaty (giving the Vatican its own micro-state), a financial convention (giving the Vatican reparations) and a concordat (giving privileges within Italy, for instance by letting the Church influence public education). In return for all of this Mussolini received Vatican recognition of the Kingdom of Italy." http://www.concordatwatch.eu/how-the-lateran-treaty-made-the-catholic-church-into-a-state--t841

[6] "The new compromise amounts to a framework agreement of fundamental principles that regulate thee independency respectively of the State and the Church, identifying specific constitutional cornerstones. (…) Additional Protocol: 1. In relation to article 1 – it is considered no more valid the principle, originally recalled by the Lateran Pacts, of catholic religion as the sole religion of the State." [personal translation] https://presidenza.governo.it/USRI/confessioni/accordo_indice.html#2

declaration affirming that “the Government of Italy will not allow that a research which does not produce direct benefits to the health of the research participants be carried out on persons not able to give their consent and on a pregnant or breastfeeding woman.” (Committee on Bioethics, 2021). On the contrary, Italy has not signed the Additional Protocol concerning Genetic Testing for Health Purpose dated 2008. Moreover, looking specifically in the Italian legal framework, there are two laws that are relevant for these themes: Law 194/1978 and Law 40/2004.

5.1.1 Law 194/1978

The first one dates back to 1978 and it is Law N.194, which “reflects the obstacles and battles of the 1970s and the signs of historical compromise mark both its provisions and its ambiguous title: ‘Norms on the Social Protection of Motherhood and the Voluntary Termination of Pregnancy’.” (Caruso, 2020). As a matter of fact, its promulgation arrived following the 1968 revolts, in a decade characterized by a new wave of feminism. Nowadays, it is often belittled as the law declaring the right to abort, even though no article explicitly affirms such right, rather the law provides just the *possibility* for voluntary termination of pregnancy in specific cases and timing: article 1 starts by specifying its aim to protect human life since its beginning[7], which is the real focus of the law, and article 4 explains that the voluntary termination of pregnancy can be asked within 90 days just in case of ‘prevision of anomalies or malformations’[8]. Nevertheless, prenatal analyses that are available to reveal such probabilities are usually undertaken after the 11th week of pregnancy, that is almost at the end of the timescale allowed for abortion; for this reason, the lapse of time is enlarged by article 6.b only in situations when such potential condition could become a danger for the health of the mother[9], even if there is

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[7] Legge L. 22/05/1978, n. 194 ‘Norme per la tutela sociale della maternità e sull'interruzione volontaria della gravidanza’ Articolo 1: “Lo Stato garantisce il diritto alla procreazione cosciente e responsabile, riconosce il valore sociale della maternità e tutela la vita umana dal suo inizio”

[8] Legge 194/1978, Articolo 4: “Per l'interruzione volontaria della gravidanza entro i primi novanta giorni, la donna che accusi circostanze per le quali la prosecuzione della gravidanza, il parto o la maternita' comporterebbero un serio pericolo per la sua salute fisica o psichica, in relazione (…) o a previsioni di anomalie o malformazioni del concepito, si rivolge ad un consultorio pubblico”.

[9] Legge 194/1978, Articolo 6: “ L'interruzione volontaria della gravidanza, dopo i primi novanta giorni, puo' essere praticata: a) quando la gravidanza o il parto comportino un grave pericolo per la vita della donna; b) quando siano accertati processi patologici, tra cui quelli relativi a rilevanti anomalie o malformazioni del nascituro, che determinino un grave pericolo per la salute fisica o psichica della donna.

the possibility of autonomous life of the fetus, as affirmed in article 7[10]. As seen before, the concept of health can be subjective, thus the interpretation is actually open.

It seems to me that this law tries to assign the same value of protection both to the possibility to abort of the mother and the right to life of the fetus, but two sides of the same coin cannot triumph simultaneously. A title in Forbes once defined Law 194 as "the real Italian miracle" (Guerra, 2018) because it decriminalized abortion, although not explicitly making it a right. Yet, the limitations imposed are not really of help in making it so effective, successful, and available for all. In fact, there are also geographical disparities, showing that difficulties increase in the Southern regions of Italy (Caruso, 2020), negatively contributing to equality and wellbeing in the whole country.

In these days, the new government headed by Giorgia Meloni is turning on the spotlights on the delicate yet intricated topics subjected to Law 194. Her opponents criticize her because they fear she will limit the applicability of the law by reducing the possible scenarios to terminate pregnancy. Such worry is based on her political position because she belongs to the extreme right wing, which is historically conservative especially in issues related to the family. To reassure her opponents, she repeatedly guarantees that she will not change the law, instead she will work to reinforce it. Actually, it would be nonsense for her to modify these articles because she should then bear the responsibility for that, whereas she knows that the law – as it is – is already developed to limit its use. Furthermore, senator Maurizio Gasparri suggested to recognize the judicial capacity of the fetus: were it the case, Law 194 would lose the meaning that abortion activist claim. Gasperri's idea has been depicted as extremely conservative, and opponents fear it would make doctors practicing abortion guilty of homicide, and parents too; nevertheless, this would be a way to protect the dignity of human beings since the very beginning of life, if properly expressed. However, given the fact that this political and social turmoil is happening now, I will not go into details because everything is still on words and nothing has been decided yet, but in the next months there will be interesting discussions about Law 194 in Italy.

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[10] Legge 194/1978, Articolo 7: "Quando sussiste la possibilità di vita autonoma del feto, l'interruzione della gravidanza può essere praticata solo nel caso di cui alla lettera a) dell'articolo 6 e il medico che esegue l'intervento deve adottare ogni misura idonea a salvaguardare la vita del feto"

5.1.2 Law 40/2004

The second pertinent law is Law N. 40 of 2004 '*Norme in materia di Procreazione Medicalmente Assistita'* (Norms on Medically Assisted Procreation). Its importance for my thesis is given by consequences on the practices applicable for the selection or design of children. Above all, articles 13 and 14 set forth the following aspects: the former forbids any kind of eugenic selection of embryos or gametes or manipulation predetermining genetic characteristics (except for therapeutic reasons), seeing the practice as a potential crime; the latter prohibits embryos suppression, the creation of more embryos than those necessary for a single implantation and embryo reduction in multiple pregnancies.[11]

The restrictions prescribed by the law have been frequently questioned and toned down, though. Indeed, the Constitutional Court Sentence 229/2015 declared unlawful compare to a crime the practice of embryo selection to avoid the implantation of embryos potentially affected by inheritable genetic malformations. (Tomasi, 2014) With such decision, the Court conciliated on the one hand the possibility for professionals to select embryos in favor of parents' demand, and on the other the right to life underlining the illegitimacy of embryos' suppression, based on the idea that an embryo is not just biological material but is worthy of dignity and protection. (Castellaneta, 2015)

5.2 CBN

Italy established a committee to provide specific support on these matters, given the thorny character of arguments concerning ethical questions, such those on artificial reproduction and related techniques, that is: the Comitato Nazionale per la Bioetica (the

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[11] Legge 40/2004:
Articolo 13.2: "La ricerca clinica e sperimentale su ciascun embrione umano è consentita a condizione che si perseguano finalità esclusivamente terapeutiche e diagnostiche ad essa collegate volte alla tutela della salute e allo sviluppo dell'embrione stesso, e qualora non siano disponibili metodologie alternative"
Articolo 13.3 (b), vieta: "ogni forma di selezione a scopo eugenetico degli embrioni e dei gameti ovvero interventi che, attraverso tecniche di selezione, di manipolazione o comunque tramite procedimenti artificiali, siano diretti ad alterare il patrimonio genetico dell'embrione o del gamete ovvero a predeterminarne caratteristiche genetiche, ad eccezione degli interventi aventi finalità diagnostiche e terapeutiche"
Articolo 14: "1. È vietata la crioconservazione e la soppressione di embrioni, fermo restando quanto previsto dalla legge n. 194; 2. non devono creare un numero di embrioni superiore a quello strettamente necessario ad un unico e contemporaneo impianto, comunque non superiore a tre; (…) 4. Ai fini della presente legge sulla procreazione medicalmente assistita è vietata la riduzione embrionaria di gravidanze plurime, salvo nei casi previsti dalla legge 22 maggio 1978, n. 194"

National Committee for Bioethics, hereafter ‘Committee’ or ‘CNB’). Its foundation dates back to 1990 thanks to Adriano Bompiani, who was its first President, professor of Obstetrics and Gynecology in Rome and Milan, and Minister of Social Affairs, considered the “father of Italian bioethics” (Quotidiano Sanità, 2013). Its composition praises experts in philosophy, medicine and law whose tasks involve consultation for the Government, Parliament and various Institutions, the provision of reliable and qualified information for society, and the relationship with international ethical committees with respect to emerging ethical problems arising from scientific and technological progress in life/health-related fields.

The CNB draws up two kinds of documents:

a) ‘*Pareri e Risposte’* (Opinions and Responses) which are more frequent and entail complex argumentation, with a first draft followed by other consultations and then the final writing;
b) ‘*Mozioni*’ (Motions) instead concern a more concise topic and are used for urgent needs.

In the 32-years of existence, there has been documents on many different issues, and those connected to child selection, embryos manipulation and prenatal diagnosis are concentrated in the late ‘90s and early 2000s. Among the most specific ones, the following Opinions are those that I used the most as reference to develop my argumentations.

- *Diagnosi Prenatali* (Prenatal Diagnoses, 18th July 1992) derived from the developments of technologies to analyze the DNA in order to detect predispositions to genetic diseases, they reduced the time at which these anomalies could be noticed until early stages of embryonic growth, with the prospect of possible diagnosis even in earlier phases. The title is purposefully in plural terms to underline the variety of techniques available that are presented in the first part of the document, whereas in the second part the Committee discussed their ethical implications, focusing also on the psychological effects that could be caused, and on the evaluation between risks and benefits coming from these innovative practices, which have favored a vision of the unborn child as a new kind of ‘patient’. Nevertheless, the unclear status of the embryo provided ground for diverging positions, while there has been unanimity in confirming the consensus of the mother as imperative to apply any prenatal diagnosis, stressing the fact that the latter and therapy could not always go hand in hand and that abortion should not be the automatic response to a prevision of possible anomalies on the unborn child.

- *Progetto Genoma Umano* (Human Genome Project, 18th March 1994) reported the Opinion of the Committee on the worldwide project launched with the intent to map all DNA sequences in order to improve the knowledge on the constitution of the human genome. This colossal ambition has been promoted by the international scientific community, but the Committee was aware of the dual implications: in fact, on the first part, it highlighted the technological and scientific features of the project, underlining the foreseeable therapeutic benefits that could derive, while on the second part ethical and social possible consequences have been discussed (as, for example the problem of allocation of resources). Moreover, the Committee stressed the risk of discrimination due to predisposition for genetic anomalies that requires a comprehensive assessment on the procedure, so as not to fall into ‘eugenics’.
- *Venire al Mondo* (Coming to Life, 15th December 1995) analyzed birth as an event, rather than a consequence of reproduction, thus granting it global value. The birth of a human being is considered as a passage that broadens a family and that is influenced by the social and cultural environment in which it happens. The Committee acknowledged the fact that pregnancy and delivery always involve potential risks, but this should not be translated in an excessive medicalization of these events. Still, medical professionals must operate towards the wellbeing of their patients, supported by the moral obligation to use the available resources in order to identify any possible risk concerning pregnancy or the unborn child; furthermore, conscious about the fact that often health professionals face situations that lead to life-or-death decisions, which involve a complex balance between ethical principles and the confronted reality, the Committee suggests the importance of ad hoc trainings for medical specialist so as to provide them with the necessary skills to support their patients when dealing with hard choices.

- *Identità e Statuto dell'Embrione Umano* (Identity and status of the human embryo, 22nd June 1996). The need for such Opinion was caused by the spread of new technological practices applicable in the fields of biology and artificial reproduction, which could have had negative impact on embryos. Indeed, the document aimed at discussing the lawfulness of some treatments. It starts with an explanation about the debate on the status of the embryo and his/her resulting protection, that is questioning whether or when an embryo could be considered a person and consequently when there must be safeguard for his/her existence. Divergent positions have emerged among the members of the Committee: some affirmed that the embryo is a person since the very beginning so from fertilization, while other believed the individual identity is gained only later. Given the different perspectives, many remarks have been attached at the end of the Opinion, but nevertheless, they unanimously agreed on considering the embryo as part of the human species rather than a mere 'thing'.
- *Gravidanza e parto sotto il profilo bioetico* (Pregnancy and childbirth from the bioethical standpoint, 17th April 1998) was drafted pursuant the bioethical reflections motivated by issues regarding more suitable assistance to pregnancy and childbirth, and also the Convention for the Protection of Human Rights and Biomedicine of the Council of Europe, and the Universal Declaration on the Human Genome and Human Rights of UNESCO. The initial premises deal with a new conception of prenatal life that gained preciousness, promoting support for the health and life of the unborn child. After that, seven chapters described the following features of discussion: multiple pregnancies; health and medical professionals' preparation and ethical competences concerning high-risk pregnancies, in favor of the wellbeing and quality life of the unborn child; the delivery; pregnancy under the psychological point of view of the mother; the psychological experience of birth for the mother; birth 'humanization'; judicial and social safeguard of maternity. In this Opinion, the Committee stressed the importance of proper support related to life and health of the individuals involved during pregnancy, but also the recognition that psychological and social assistance and encouragement are essential for their wellbeing. Moreover, the Committee denounced the faked equality among embryos, and the consequent divergence in

guaranteeing the right to life when predisposition to genetic anomalies is detected in the unborn child. For this reason, the CNB underlined the fact that the untouchable value given to life was then seen as an achievement to be kept against technological innovations pervading society.

- *Orientamenti bioetici per i test genetici* (Bioethical guidelines for genetic testing, 19th November 1999) represented an ambitious Opinion, given the multiplicity of genetic tests; the assortment and the ongoing evolution of these practices made it a complex evaluation, thus the Committee did not produce any specific conclusion, rather it highlighted many aspects concerning genetic testing techniques. The document suggested a theoretical explanation of what genetic tests, screenings, or counselling entailed, and how they practically work, followed by a discussion on their repercussions. In fact, the awareness of predisposition toward genetic diseases seemed to foster a sort of 'genetic discrimination' in social and working environment, as even at personal level through a devaluation of self-esteem for example. A focus has been made on the application of genetic tests before birth and in pre-implantation embryos, fueling the ethical discussion around equality. Furthermore, the Committee underlined several times the fact that these techniques provide knowledge on 'predispositions' – thus of potential risk, rather than absolute certainty – and it also affirmed that it must be reminded that different cultures have different perceptions towards these practices and their implications.
- *Considerazioni bioetiche in merito all' "ootide*" (Bioethical remarks on the so-called "ootides", 15th July 2005) was drafted to argue about innovative practices of medically assisted reproduction, more specifically about the sequence of events taking place during fertilization and the possibility to 'freeze' embryos. The 'ootid' is preferred as synonym of zygote or one-cell embryo by the Committee, who started its Opinion with a factual description of the phases that come in succession in human fertilization. Such narration has been unanimously accepted, in contrast to the point of views on its ethical interpretation. This was due to two different opinions with respect to the real beginning of individual life, that is when the human being is granted identity. For the majority of the members of the CNB, the spermic penetration of the ovum is fundamental and represents the start of the

process, which would develop in a ‘continuum’ until the birth of a human being; while some others believe identity to be a characteristic that develops in subsequent stages of life.

- *Adozione per la nascita degli embrioni crioconservati e residuali derivanti da procreazione medicalmente assistita (P.M.A.)* (Adoption for the birth of criopreserved and residual embryos obtained by medically assisted procreation MAP, 18th November 2005) has been required after the adoption of Law 40/2004 because it overlooked the issue related to the future of frozen and abandoned embryos created through artificial reproduction techniques. The Committee had already debated about MAP elsewhere, but there was the need to examine again the doubts concerning such practice. The question on embryo protection arose another time: if the embryo is perceived as a fully-fledge human being, then the right to life and therefore to be born should outdo any other position against it, and in order to guarantee such right, the Committee suggested the possibility of the adoption of embryos under specific circumstances.
- *Aiuto alle donne in gravidanza e depressione post-partum* (Assistance to pregnant women and post-partum depression, 16th December 2005) became an official document after years of debates on the matter. Aware that women are completely involved in first person in the most practical experience of human reproduction, and that this creates physical and psychological burdens to bear, the Committee stressed the importance of support during pregnancy and post-partum as an overriding collective commitment. Indeed, the Committee affirmed that the social and bioethical value of childbirth makes it a cultural topic that should prevail in the public discourse. The Committee promoted a widespread recognition of the value of human life, focusing on its concrete application to every component of the family unit. Moreover, it underlined the fact that there should be no automatism between the possible predispositions to genetic anomalies and voluntary termination of pregnancy, but appropriate support and a positive social environment toward maternity should be promoted, which is also in line with the provisions of Law 194/1978 for the prevention of abortion.
- *L’editing genetico e la tecnica CRISPR-CAS9: considerazioni etiche* (Ethical Issues in gene-editing using Crispr/Cas9, 23rd February 2017). The final version

> of this Opinion was drafted after various attempts, which failed to gain the consensus at least of the majority of members due to diverging beliefs about the CRISPR-Cas9 technique. The document begins with a description of the practice and the related risks or potentialities, followed by bioethical reflections, which saw the Committee agreeing on tests in vitro and on animals under international law, while disagreeing on other issues. The Committee promotes human somatic cells research, but it defines human GGE as illicit. In fact, the contrasting views are due to doubts about the safety and efficiency of this practice, especially in case when genome modifications could be inherited by future generations.

All documents have been drafted in Italian, but from those dated 1999 onwards there is also the official English translation, therefore, the citations covering the period 1992-1998 corresponds to a personal translation of the Opinions from the original draft that I quote in brackets. An exception is made by the Opinion of 1996 'Identity and status of the human embryo' because the official English translation covers only the first part of the document, thus the quotations of the initial part are the formal ones, while those on the second part have been personally interpreted. Taking the above-mentioned Opinions as reference, I provide below an overview about the position of the Committee with respect to intersectional topics, such as the status of the embryo, genetic manipulations, potential social and psychological consequences of medically assisted procreation techniques, and the moral values entangled and the involvement and perceptions on human rights.

5.2.1 CNB on the status of 'embryos'

A critical point emerging from the above-mentioned documents is the deliberation on the status of embryos, whether their value as persons is intrinsic since the very beginning of their existence given by fertilization or it is something gradually acquired – or later granted as with rights. (CNB, 1992, p. 33) The Committee is unanimous in accepting the factual description of events but not their ethical interpretation, for this reason it considers the starting point of individual life as arduous to determine, and it suggests another possible event that could be considered the dawn of personhood: amphimixis, "the moment of formation of the zygote." (CNB, 2005a, p. 10) In fact, each embryo discloses DNA sequences that are notably human, and biological data are not debatable, so it follows that embryos are certainly part of human nature, but this does not define for sure their individuality as persons.

Genetic identity is viewed as necessary but not sufficient to determine individual identity, and to delineate the latter the CNB suggests the so-called '*criterio di reidentificazione',* namely re-identification criterion (CNB, 1996, p. 12). This principle says that an adult is a human individual, who was the same person also at birth – even though her characteristics and capabilities were not matured yet – and supposedly was the same even before birth, but how far can such regression go? This is quiet problematic. The CNB does not accept the modern understanding of 'person' that is applicable only when the individual in question can exercise some functions, rather it affirms that – ontologically speaking – being a person is a consequence of having a rational nature. Since rationality is a requisite of the human nature, then any individual having human nature is also a person, even if some specific human functions develop throughout time; therefore, the majority of members asserts the personal identity of embryos since fertilization, recognizing the value of person in every phase of existence. The embryo is "intrinsically destined to develop until the birth of a complete human being" (ibid.), thus the embryo is one of us.

When discussing the fate of embryos deriving from AHR or the use of human embryos in research, some members of the CNB affirmed that also "embryos that are 'unsuitable for implantation', even if characterised by serious anomalies, are human beings (..) and have, therefore, absolute dignity, which forces us to always respect and protect their lives." (CNB, 2007a, p. 9) These positions may be arguable, but they grasp the extreme essence of human being as an individual entity worthy of respect and dignity since the beginning of her existence as such.

5.2.2 CNB on genetic manipulations and practices related to AHR

When it comes to clinical intrusion in the field of reproduction, many practices are concerned, and the related knowledge may vary geographically, depending on public and private investments. At length, the Committee discussed biological aspects available today on human 'fertilization' gotten through assisted reproduction techniques, and – more than once – it recommended the sharing of information on procedures and know-how regarding methods for prenatal analyses and genetic manipulation (CNB, 1994, p.

35), which have to be scientifically founded and to admit procedural limits and feasible risks. (CNB, 1992, pp. 9, 30) For this aim, it must be recognized that research is crucial for knowledge, and laboratory activities allow to anticipate the time of diagnosis to early stage of embryonic development. Until recently, it would have seemed impossible for an expecting mother to get to know in advance features on the child she was carrying in her womb; whereas, nowadays, this is not only available, but it is even brought forward by the possibility to influence such characteristics and potentially design them. The Committee is aware of these recent technological evolutions and for this reason it keeps discussing these kinds of issues from time to time.

As we know, in the last decades, a lot of progress has been achieved in the branch of assisted human reproduction; some applications can be already used clinically, while others are still limited to pre-clinical research. Among the practice in use today there are prenatal diagnoses, which are useful to discover conditions of the ‘conception product’, as referred to by the Committee. (CNB, 1992, p. 11) They can be invasive or not, as explained in Chapter 1.2, but when employed in an invasive way, the CNB recommends balancing the likely damage and genetic risk with desirable benefits; moreover, “particularly complex prenatal diagnoses should be carried out in centres recognized as having the required experience.” (CNB, 1999b, p. 21) Prenatal medicine aspires to well-being protection of the ‘conception product’, and it is preferable to intervene as soon as possible in case of evident alterations of normal development. (CNB, 1998a, p. 12) Indeed, prenatal diagnosis works to avoid the clinical manifestation of an illness and it is seen as prevention when it favors the correction of an observed anomaly, which should not be translated with the termination of pregnancy. (CNB, 1992, p. 29) This corresponds to a limit of the procedure because the risk is instead to foster a tendency to make abortion automatic in those cases.

The CNB dealt with this tendency targeting specifically situations of multiple pregnancy, and it underlined two practices that permit to eliminate the unwanted child: Multifetal Pregnancy Reduction (MFPR) and Selective Abortion. As the CNB explained (CNB, 1998a, p. 35), MFPR means the removal of one or more fetuses without interfering with the life of the remaining ones, when it is believed that the number of children carried could be too high, in order to ameliorate the prognosis for pregnancy success; whereas, selective abortion calls for removal of one or more fetuses that seem to have congenital anomalies, thus preventing her birth while favoring the birth of remaining healthy ones. These two procedures are often questioned, but they are usually accepted when performed in the name of the mother's health. (CNB, 1998a, p. 40) Furthermore, the CNB hopes for a decline of MFPR in the long-run because nowadays there are more adequate evaluations with respect to risks and benefits of artificial fertilization (CNB, 1998a, p. 44) and the custom to create more embryos to be implanted so as to ensure the successful start of a pregnancy is now outlawed by the previously anticipated Law 40/2004. However, there are other ways of intervention in case of foreseen anomalies and preventing the onset of an unwanted pregnancy – intended as deferring from what dreamt of –, as for example through genic therapy, which seeks to eliminate pathological results by directly manipulating the DNA of a gene, even if this technique could be considered as 'negative eugenics' because it leads "to the elimination of the 'harmful' genes." (CNB, 1999b, p. 21)

Moreover, the Committee forecasted that medicine could have advanced in creating instruments for the correction of chemical defects in early stages of human development, through the transplant of genetically modified cells (CNB, 1992, p. 36), and it was right. Indeed, genetic engineering has created sophisticated innovating practices that enable the modification of DNA sequences in a precise and relatively easy and cheap way. As mentioned in Chapter 1.2, this is called 'gene editing' or 'genome editing', and it is exemplified by the CRISPR-Cas9 procedure. Given the thinning of borderline between the aim to cure and the potentiality to enhance, the CNB pays particular attention to the matter, especially when concerning inheritable changes in the genome of embryos potentially used for reproductive ends.

On the matter, the CNB stated that "the Committee believes there is a moral obligation to cure present generations with all the means available to science and technology." (CNB, 2017, p. 12) Yet, aware of the risks, it accepts the practice for its therapeutic ability, but restricts its application to somatic cells only. In fact, "the Committee agrees on the illicitness of the transfer into the uterus of modified embryos due to the high risks for the unborn child at the present state of scientific research" (CNB, 2017, p. 13) because the level of knowledge as it stands today is not so deep, and science does not acknowledge all possible dangerous effects of these modifications in the long term. Still, it is worth mentioning that the hypothesis of implementing genome editing techniques opens the door to a discussion on the creation and use of embryos for the purpose of scientific research, which has several ethical implications, but this goes out of the scope of my thesis, so I will not discuss it in this essay.

Genetic modifications are perceived as the most powerful intervention promoted by contemporary genetics, so it may sound confusing from a moral point of view. Undeniably, the doubtful position towards such innovations reflects some teachings that come from history, when genetic programs were associated to eugenics practices that were harmful for human dignity. We should bear in mind that we deal with uncertainty, both in the case of GE and of PGD, even if in different degrees: the former is limited to laboratory activity so far; the latter is showing a lot of improvement thanks to scientific research, but it does not provide a 100% sure anticipation of anomalies yet.

Nowadays, prenatal analyses and diagnoses are getting more precise and detailed in their previsions, but diagnostic capabilities are not necessarily connected to therapeutic ones (CNB, 1994, p. 40) and tests provide "probabilistic answers", rather than an absolute guarantee. (CNB, 1999a, pp. 20, 69) (CNB, 2005b, p. 9) For this reason, it is important to keep evaluating risks and benefits of new procedures and try to promote the practice that most balance the two, in order to furnish artificial interventions that are more widely acceptable, thus diminishing the unease felt in front of intrusive technological innovations in the future. Nonetheless, the CNB reminds us that there should be no pressure on individuals to go through all available technical instructions, and emotional responses to them should be taken into account as well. (CNB, 1994, p. 41)

5.2.3 CNB on social and psychological implications

Uncertainty about the future makes human beings feel the necessity to improve their knowledge to foresee how life might change, and this tendency is increasing with regard to human reproduction. The chance to undergo prenatal testing formulating a prenatal diagnosis might be of help because it predicts the likely outcome of the pregnancy, but it also influences feelings and inclinations concerning human gestation. Actually, contemporary mentality tends to hold the idea that if there is a possible risk, then it is essential to acknowledge it in order to reduce anxiety. In fact, the growing success of pregnancies, which has been caused by scientific progress of the last century, has diminished the tolerance on uncertainties about pregnancy results and consequently it increased anxiety about the outcome of pregnancy. (CNB, 1992, p. 29) PGD let intended parents to evaluate the previsions on the quality of future life of their children, implicating a significant psychological burden because often such evaluations revolve around life-and-death decisions concerning their offspring. On the matter, the CNB recalled that data show one third of life-and-death decisions are taken in situation of diagnostic uncertainty, leading to the risk of simplistic reductionism, where protocols become standards. (CNB, 1995, p. 36)

Such adaptation signals the mental weight given by a known pathological predisposition, which could become deeper if parents would have the opportunity to select the traits of their children through genetic manipulation. Most of the stress is caused by social pressure and the fear for future discrimination, "often solely on the basis of a greater probability, not the absolute certainty, that one day he/she may fall ill." (CNB, 1999b, p. 12) The ideal of perfection intrudes upon family choices on reproduction and influences the perception of risk; as a matter of fact, the concept of 'best interest' – which should be a primarily consideration – is not absolute and it can be differently interpreted. Furthermore, the Committee is aware that the risk approach in early stages of life is of a particular kind because it is evaluated at present but it must be projected into the future (CNB, 1995, p. 20), thus intensifying parental insecurity and anxiety. Parents do not have an adequate and specific knowledge to understand the effective meaning of genetic tests and they trust the opinions of professionals; however, if no caution is paid in the use of notions, then the danger of negative consequences on the collective perception toward bearers of genetic malformation and disabled persons arises. (CNB, 1994, p. 38) The misuse of a word by those in power because of their expertise could have far reaching social implications, at the expense of a popular minority. As a consequence, the Committee warns against the risk of "spreading a genetic-technological mentality – a cultural drift – which attributes to genetic data an all-encompassing deterministic role and promotes a social attitude of rejection of the subjects that are considered as abnormal." (CNB, 2005b, pp. 9–10)

The possible social stigma that parents fear on themselves leads them toward an increasing willingness to act and shape their offspring lives. In fact, the common parental demand is to guarantee physical and functional integrity to their children (CNB, 1998a, p. 14), and they do their best with as much effort as possible to achieve this goal. When we apply these lines of reasoning to prenatal life, the idea that has always gotten a foothold throughout history sees abortion as ‘the’ solution in case of inconveniencies during pregnancy, as in the case of child selection. Yet, voluntary termination of pregnancy challenges psychological dynamics experienced by women in the earlier phases of gestation, and such interruption can have detrimental effects if it lacks an adequate constructive elaboration, because otherwise the child will somehow leave a footprint in the body of the mother, or as the CNB says, it will intra-psychically remain. It is demonstrated that 1/3 of women who underwent a MFPR use words like ‘murder’ or ‘killing’ talking about the practice, while the majority of them confess they still think about their aborted fetuses. (CNB, 1998a, p. 40)

The Committee recognizes the simplistic way of thinking - which is widespread especially on younger generations - that views abortion as the quickest and easiest solution; in contrast, the CNB considers unacceptable the voluntary termination of pregnancy to be expected in case of probable fetal malformations, because this would be against the dignity and respect of all persons living with disabilities. For the CNB, more psychological support during pregnancy is essential, notably in case of “finding of a negative genetic data concerning the fetus, in order to avoid a certain kind of automaticity between specific results of genetic testing and abortion outcomes.” (CNB, 2005b, p. 10) (similarly reported also in CNB 1992, 43)

The Committee admits that these views are influenced by education and socio-cultural environment in which the individual grows up; therefore, it underlines the need for a “fundamental revaluation of a shared commitment to supporting women in pregnancy, so as to make clear (…) the existence of a positive climate, a sympathetic approach and solidarity” toward maternity. (CNB, 2005b, p. 12) Distinct cultures can have diverging opinions about these issues, some may be more sensitive with respect to moral disputes, while other may be more conservative in the application of medical technologies and their consequences. Also, different mental understanding and natural differences between women and men play a role on arguments about artificial reproduction implications. Indeed, ignoring this diversity would be equivalent to let the reproductive function conducted by women to limit substantial equality among sexes (CNB, 1998a, pp. 73, 100), since in this way the social function of maternity would be disregarded. Instead, maternity is something unique, an experience that cannot be compared with anything else, and which requires special attention.

5.2.4 CNB on the role of women

The indispensableness of the female body and soul for the life of offspring is recognized, even if the Committee considers the fetus as a distinct entity with respect to the mother. (CNB, 1998a, p. 104) Despite that, pregnancy is the only moment in life where two separate individuals are in the same body (except for rare malformations of Siamese twins), one supporting the creation of the other, one within the other. This uniqueness contributes to make this period of a woman life so delicate, because she cannot be prepared for the emotional, psychological and physical turmoil she will go through, unless she has already experienced it. The time of pregnancy represents a critical phase of life for its evolutionary potentiality and the Committee defines it "as the prototype of every intimate relationship or of care" (CNB, 2005b, p. 6), since the bond with the mother is the first ever enjoyed by the child; likewise, apart from the psychological effects, the nine months of pregnancy are significant because "the growth in the maternal womb is very important for the personality of the future child." (CNB, 2005c, p. 6)

The conceived embryo – that will develop into a person thanks to the womb of the mother that creates a fertile environment – interests for the biological individuality, which is the inescapable factor for any bioethical or legal judgement concerning the life and health of human beings. The beginning of life of a human being serves as 'improvement in quality' because it means the transition from 'not be' to 'be'; after that, "the 'principle of continuity' of the development is applied immediately from spermatic penetration onwards, and clearly goes over the temporal limit of fertilization, (…) pervading the whole life of the individual", as illustrated by the Committee. (CNB, 2005a, p. 6)

Despite the individuality of the unborn baby, her presence within the body of the mother gives the latter decision-making authority over choices related to life and health of the former. The Committee affirms that this power cannot be neglected, but rather it should be exalted though informed consent. (CNB, 1995, p. 64). The Committee considered worthwhile "to specify that the pregnant woman's consent is essential and must be obtained also in the case of medical, surgical or diagnostic intervention on the foetus throughout the period of pregnancy." (CNB, 2000, p. 3)

Nevertheless, the wording used by the Committee is more ambiguous when asserting that the consensus of interested parties is the necessary prerequisite for every genetic screening program because of the contrast arising between confidentiality right of the individual and collective interest on genetic knowledge. (CNB, 1999a, p. 108) When genetic screenings are employed as prenatal tests for diagnosis, it can be dubious who the interested parties are. In fact, the consensus of the mother and maybe also of the father are asked, but it is impossible to ask that of the unborn baby, even though tests would be made on her too. Depending on the perception of the embryo – and later fetus – as individual person since fertilization or acquiring such status only in subsequent phases of life, our stance is biased toward noticing the lack of possible fulfilled involvement; in contrast, those who do not consider the unborn baby as a person would not care about that.

5.2.5 CNB on ethical issues

Apart from the question on consent, genetic tests bring other bioethical issues highlighted by the Committee. First of all, excessive medicalization should not be determined by potential risks observed in prenatal diagnoses, but rather limits should be outlined (CNB, 1995, p. 8); however, the Committee is conscious that there is a "tendency which sometimes assumes the contours of a genuine cultural solicitation, towards an exclusively medical approach to pregnancy and motherhood" (CNB, 2005c, p. 7), that impoverishes the experience and challenges the conception of protection of life. As a matter of fact, the positive 'value' of human life should triumph as an ethical achievement of a technological society constantly growing, which is able to allow for the realization of the right to life to a rising number of people, whose existence was unimaginable until recently. The right to life should be backed up by the duty of whoever is in charge of providing support (CNB, 1998a, p. 14), so the extreme medicalization of pregnancy could be hindered. In fact, the medical paradigm that comes with scientific progress is not only biophysical, rather it is about the choice between the idea of 'holiness of life' and the idea in favor of 'quality of life' (CNB, 1995, p. 39), which is mirrored by the contraposition between bioconservatives and transhumanists.

The acknowledgement of the notion of 'quality of life' paves the way for a new ethical vision coming over embryo-fetal life: it is reevaluated as a new preciousness. (CNB, 1998a, p. 12) The scientific progress went hand in hand with a psychological process gaining sensitivity with respect to innovations that are closer to intimate spheres of human life, as it is procreation. Indeed, maternity is no more a biological destiny, rather it is the outcome of a choice of fulfilment made by two lovers in a relationship; moreover, this new insight on human reproduction, together with the expansion of family planning, lead to fertility reduction and in parallel to an 'emotional concentrate' over ideal parenthood. (CNB, 1995, p. 55) The Committee links this emotional load related to maternity, and more in general to reproduction, to the domestic will of social ascent and wellness; as a matter of fact, on the one hand "pregnancy constitutes one of the most challenging tests for a woman, given the biological commitment and psychic elaboration that is involved in the event" (CNB, 2005b, p. 5), instead on the other hand there is the moral obligation she faces with regard to the foreseeable wellbeing of her child. (CNB, 1998a, p. 16) Once again, as it is deducible from the statements of the Committee, the pressure of society influences the behavior of individuals.

Social expectations are high and expectant mothers must endure them together with their personal disorientation, producing a mix of emotions that are hard to define, which could obfuscate and alter decisions linked to the life and health of their unborn babies.

5.2.6 CNB on moral values and 'human' rights

There is a common idea that in principle everyone is equal at birth and has inalienable rights as those to life and freedom, while actually it is not always so because – if pathologies are observed – the right to life could be prevented from being applied in its first concrete expression, that is birth. (CNB, 1998a, p. 14) However, the Committee affirms that the right to life, or even better, "the right to be born must prevail on any ethical or legal consideration against it." (CNB, 2005c, p. 2) This duality towards human rights and fundamental freedoms in the earliest phases of life makes them vulnerable.

In its Opinion on the Convention on Human Rights and Biomedicine of 1997, the Committee recognized the Convention as the first instrument promoting general protection of human rights in the fields of medicine, medical research and their applications, seen as a necessary in current time. This is due to the advancements of modern medicine, which is becoming more and more technological and invasive. In fact, the committee notes that the aim of the Convention is the respect for the human being without any discrimination, noticing the importance to ensure human dignity, rights and fundamental freedom with regard to an excessive use of biology and medical innovations. (CNB, 1997, pp. 19, 12, 18) New medical, technological and scientific knowledge is beneficial on a vast scale, but it could also be detrimental if it would reduce the person to a mere biological individual, because then genetic differences would become the basis for inequality and discrimination. (CNB, 1994, p. 7) If scientific innovations gain so much power and prestige that our rationality, values, experiences, expertise, and social status do not count anymore, that whatever is connected to our relations and sociality, or personality loses value, then what matters is our bodily constitution; consequently, practices of genetic manipulation would be extremely tempting to improve the human being, with the risk of augmenting social disparities. These differences could become even more discriminating if they are intentionally induced not on oneself but on a third person, like an embryo.

As we have seen before, prenatal genetic manipulation could be pursued only through AHR, but we know that the techniques involved there may render many embryos non-implantable. There are different schools of thought about their future, and the Committee made the following two bioethical options emerged:

a) "Although not denying protection and respect for the human embryo, (…) the embryo's destination to research can be justified, with the informed consent of the biological parents (…) even if this results in a destructive outcome for the embryo. (…) [In fact, there are cases in which] the embryo's protection finds its limit. This is because such protection has meaning only if the highest possible bioethical value is at play, that is: life." (CNB, 2007a, p. 4)
b) "Any exploitative use of the embryos with destructive outcome is never ethically acceptable because it is contrary to their intrinsic dignity and to their right to life" (id. p. 5)

When it is accepted that human beings should be granted dignity and identity, it should happen since spermatic penetration, therefore "any 'manipulation' carried out even during the short diachronic process of fertilization, which is not directed at the 'good' of the human being on whom it is conducted, exposes the latter to unjustified risks." (CNB, 2005a, p. 7) The grounds to qualify the aim of an action as 'good' are open and debatable, though, and the Committee stressed a relevant bioethical problem about the destiny of these embryos. In fact, medically assisted reproduction purposely creates embryos that would be used and manipulated, thus "their paradoxical destiny could only inevitably be that of those who, having been intentionally called to life, should die without ever being born." (CNB, 2005c, p. 4) This issue stands at the basis to define embryo selection (*'riduzione embrionale'*) as ethically unacceptable (CNB, 1998a, p. 13), and for some members of the CNB to consider as illicit "diagnosis on pre-implantation embryos, indiscriminately finalized to the suppression of embryos; (…) experimentations on embryos (…)." (CNB, 1996, p. 17)

As said, human embryos are naturally destined to develop towards the birth of a fully-fledged human being, so it cannot be seen as a 'thing' at our disposal. Accordingly, "the Committee unanimously believes that human community has precise, strong and binding moral duties of care towards the embryo." (CNB, 1996, p. 15) Such duties can be divided into *prima facie* and *absolute*: prima facie duties are more alike to moral obligations for respect, thus for example embryo suppression could be ethically admissible under limited circumstances; absolute duties "has to be respected unconditionally" (ibid.). This division is supported by the ethical principle of *tutiorism*, according to which doubting that an embryo could be seen as person is enough to refrain from harming it in any circumstance. (CNB, 1996, p. 16) The concept of 'Tutiorism' comes from the Latin word '*tutior*' that means 'more harmless opinion' ("tuziorismo in Vocabolario - Treccani," n.d.), so a tutioristic ethic corresponds to the recognition of the human being "on the basis of its very 'existence' independently of the stage at which it came about at the moment of observation." (CNB 2005a, p. 7)

Nevertheless, the Committee is aware that ethical principles are not worldwide shared, and it questions itself on the varying opinions related to life. Globalization leads to multicultural societies, where people have different cultural roots that are mirrored by different perceptions on the hierarchy of values and principles. This plurality of views challenges the concepts of 'equality' and 'diversity', if the latter weakens the former. The principle of equality of all human beings is set forth by the Universal Declaration of Human Rights and it must be shared by all cultures for reciprocal identification and communication; whereas, the principle of diversity counts as integrating part, because it affirms the respect for the specificities of every culture. (CNB, 1998b, pp. 2–3) When there will be the widest respect for all, no discrimination could emerge.

5.3 Facts from the field: UPV – CAV MPV in Treviso

Although this is not strictly linked to questions around child design or selection, it is interesting to notice that in Italy there is a movement quite active in the promotion of the right to life of the unborn baby, which is called Movimento per la Vita (MPV, Movement for Life). Its work is not only of propaganda, but it provides concrete help where needed, through the so-called CAV, which stands for Centri di Aiuto alla Vita (Centers to Help Life), and the telephonic support of SOS Vita (SOS Life). MPV is an association of volunteers that aims at supporting women when they face an unwanted pregnancy or cannot bear alone economic and psychological difficulties during gestation and the first years of life of their offspring. Such institution is present in many cities in Italy and that in Treviso is one of the most important and well organized because it merges together MPV and CAV in the institution of Uniti per la Vita (UPV, United for Life), and it is the only one who has a convention with the local health authority (ULSS 2). Indeed, it is one of the organizations that should cooperate with the public health sector to help women making informed decisions over the termination of pregnancy, as determined by Law 194, article 2.d[12].

I had the honor to do there my internship and cooperate with Lidia Netto, who is the coordinator of the branch in Treviso, and who showed me what it really means to listen to and welcome everyone, regardless of their status and beliefs about the creature they carry. Many women would have felt forced to abort without their support. The reasons behind such choice are varied, and all of them are worthy of respect. I witnessed with my eyes the precious help that they offer every day; meetings are scheduled to discuss physical adversities or mental burdens caused by pregnancy, surrounded by materials and food supplied to get ready for the birth. It becomes a concrete point of reference for expecting mothers.

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[12] Articolo 2.d "contribuendo a far superare le cause che potrebbero indurre la donna all'interruzione della gravidanza. I consultori sulla base di appositi regolamenti o convenzioni possono avvalersi, per i fini previsti dalla legge, della collaborazione volontaria di idonee formazioni sociali di base e di associazioni del volontariato, che possono anche aiutare la maternità difficile dopo la nascita."

I decided to bring this example to demonstrate that women who would opt for a voluntary termination of pregnancy can get a real help. For privacy reason and respect, I did not interview mothers, but I can give testimony of beautiful babies born only thanks to the presence and support of UPV, even though they were told to abort because the fetuses have Down syndrome or other malformations. They found competent operators who support them in the choice, who show them that abortion is not the only solution, and who do support them, not just by words.

Without this center, many case of child selection would have been imposed as the only available and valid alternative, probably because abortion would prevent society from the burden to care for human beings not 'fit' for the standard. I am nobody to judge the choices of other women, but this experience made me realize that it is not easy to go against the grain and ask for help. The possibility to abort must be kept so as to guarantee the freedom of choice and of opinion to everyone; yet, I strongly believe that more advertisement should be done to sponsor CAV, especially now that the new government wants to work in their direction. Nobody should decide on behalf of the expecting mother, but she should be equipped with notions on all accessible opportunities to evaluate every aspect of her choice. What is usually seen as a close-minded – almost sanctimonious – environment is not what I found in Treviso: there, women in need of a person who listen to them and support them in their choices find somebody ready and trained to do that, without prejudice or discrimination.

CONCLUSIONS

Scientific progress has provided knowledge to develop new biotechnologies that influence human reproduction: the possibility to select the embryo to implant based on genetic characteristics following PDG or to design a priori the genetic make-up of future offspring through CRISPR/Cas9 allow for the creation of ad hoc children. Despite the differences between child selection and child design, both aim at improving humanity to cope with the wave of perfectionism that is permeating our – western – contemporary society. In the first case, embryos with poor quality genetic features are discarded in order to avoid the possible onset of diseases in children, while favoring the one showing more convenient characteristics that will permit the individual to be competitive in society. Similarly, in the second case, preferred genetic characteristics are inserted in the genome so as to create a perfect, dreamlike child; although this technique is limited for research, rather than leading to a real pregnancy, the completion of the human genome sequence increases the likelihood of its spread in AHR.

Negative selection following PGD and genome editing by CRISPR are usually outlawed or restricted in most countries, but it will not be always the case because social pressure has the power to shape norms both in favor and against. Bio-conservatives like Sandel and Levin highlight one of the main risks that could come with these practices, that is eugenics: to master the mystery of birth, as Sandel would say, leads to a loss of diversity and therefore to a social and moral impoverishment; indeed, planning who will be born will create two classes of human beings based on whether they have better genetic endowments or not. Moreover, such choice will blow up responsibilities on parents, while turning children into commodities. Differently, transhumanists do not see any trouble in "playing God" and choose who will come into existence, rather they feel a moral imperative to enhance human beings because this would follow the natural flow of species evolution; in fact, as Savulescu underlines, what is normal – especially in the sense of medical advisable – changes over time, depending on cultural ideas. To do this genetically will ease and accelerate the process.

The line between medical and non-medical use of these biotechnologies is hardly defined because of the overlapping scope of action between treatment and enhancement. Furthermore, these biotechnologies entail many uncertainties, especially in terms of clinical safety and consequences, that make authorities cautions toward them; yet, given their capacity to satisfy family intimate desires, they could become attractive in the near future. The possibility to lawfully plan future offspring can be an interesting subject for an Overton Window (see Annex I.a), which is “a model for understanding how ideas in society change over time and influence politics. The core concept is that politicians are limited in what policy ideas they can support — they generally only pursue policies that are widely accepted throughout society as legitimate policy options. (…) Often the window moves based on a (…) complex and dynamic phenomenon, one that is not easily controlled from on high: the slow evolution of societal values and norms.” (Mackinac Center, n.d.)

Ideas that are inside the Overton Window are ‘safe’ from a political point of view because they are accepted by population, while those outside it might be seen as too radical to be approved. Bio-conservativism and transhumanism could represent the two extremes of the Overton Window, namely the ban on the possibility to influence the existence of future generation versus a moral obligation to do so, whereas in between there are different degrees of openness with regard to the two options. So far, the various stances of governances at various level that have been analyzed seem to share a similar position: they tend to be closer to the bio-conservative view, in favor of a cautious approach against these practices (see Annex I.b). Such attitude is adopted by all the institutions considered in this thesis – especially by UNESCO, EU, and Italy – even if some openness appears at global level by WHO, which is the institution that most welcome scientific progress, followed by the CoE that recognizes the importance of progress while also acknowledging that implications will become visible only with experience.

As we restrict the field of governance, moving from the global level to the national one, we face an intensification of resistance toward biotechnologies able to shape humanity, and in my opinion, this hesitation could be due to the comparative increase of responsibilities that authorities would bear: bioethical consultation at national level suggests more intransigence because the State would be the first to be accountable for the authorization of child design or selection, whereas at the intermediate (European) level and at the (global) macro-level, governances do take some distance from child design and selection while not preventing the possibility to improve their use in the future, too. Time plays a key role because it will demonstrate the consequences of these practices and the social response to them. Moreover, time is needed to have public discussion about these issues. Although consensus is hardly achievable given the intricacy of the subject, the analyzed institutions agree on the importance to involve also civil society on the debate over practices that will affect them, together with several kinds of experts in related topics. In particular, it is essential to reflect on key concepts like the status of unborn babies – that is embryos and fetuses – and human rights that would be put at stake, were child design and selection widely permitted.

There is no unanimity in defining the moral status of the human being not born yet. Some say that it will gain value after birth, and this is what officially affirmed in all relevant document; still, this is in contrast with the feeling of expecting mothers, who talk about the creature they carry in their womb as their ‘child’ rather than a mere ‘fetus’. Different words are often used by doctors and clinicians in order to keep the distance from the individual not born yet, and to care for the existing woman first. Surely, no universal agreement can be reached on the matter, but this discussion is essential due to the emerging techniques involving the ‘child-to-be’, who has a human genome but is not officially recognized as worthy of human dignity and respect. This controversy highlights the weight words have in our moral understanding: words are the features that influence our personal view on the world.

Despite any possible interpretation of the product of conception, the pivot of the whole thesis is future humanity. We should ponder over the way in which we hope our society will evolve and whether it would be fair to exploit upcoming generations by designing them so as to become most suited, though based on current ideas of perfection and social competitiveness. Genetically enhancing the human species is very complex because we, as human beings, are granted some important rights. Indeed, to choose who will come into existence concerns fundamental principles like the best interest of the child, the right to an open future, the right to life, the right to health, freedom of choice, freedom of thought, no discrimination, and equality. These last two values will be those most in danger in an environment inhabited by two classes of human beings for two conflicting, yet connected reasons: firstly, enhanced individuals will probably not respect other persons seen as inferior; secondly, child design and selection would lead towards standardization of traits that will erase diversity. Consequently, in both cases the risk is actually to run into discrimination and inequalities in an impoverished society.

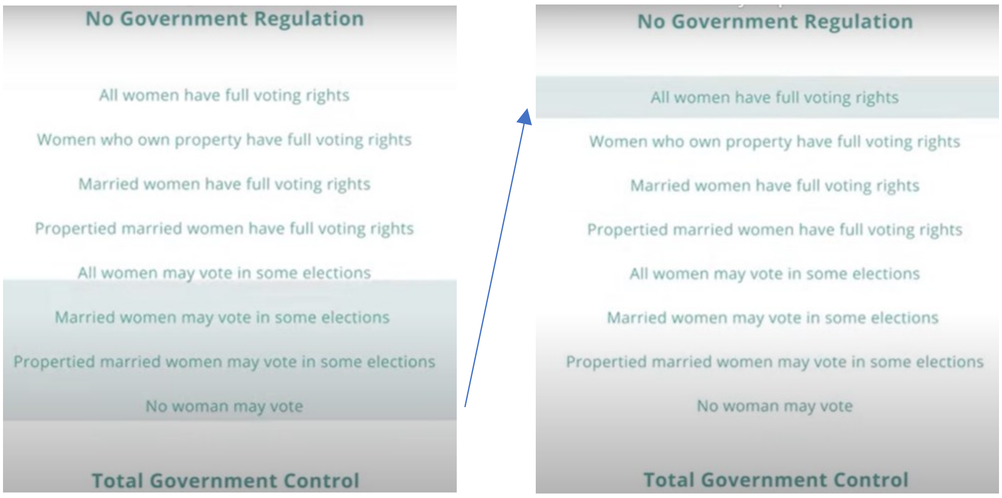
Ethical reflections will soon become even more important to guide governance toward the possible future reframe of norms on child selection and the regulation of emerging practice of child design. The recent discovery of these biotechnologies makes the development of this thesis difficult because of the lack of exhaustive argumentations, both theoretically and legally, especially from a female perspective; interestingly, even if women are indispensable means for the growth and birth of future individuals, the main authors on the subject are men. Nevertheless, this permits wide opportunities for governances at various levels to discuss and cooperate to try to harmonize laws, so as to guarantee respect and dignity for all parties involved, in line with the universal applicability of human rights, and to foster female voices on the matter.

We should keep in mind that it is not always the case that what is scientifically possible is also socially advisable, and given the power of public opinion, it is important to evaluate the feasibility of all possibilities. Genetic enhancement may turn out to be the right option to pursue, but this does not mean that we can objectively define perfection and defects, and that genome editing and negative selection are the best way to achieve it because they risk to reduce diversity, while it is actually diversity that really enriches the world.

Annex: the Overton Window

I.a) An example of the shift of the Overton Window (green square) throughout time:

Women's Suffrange



No Government Regulation

All women have full voting rights

Women who own property have full voting rights

Married women have full voting rights

Propertied married women have full voting rights

All women may vote in some elections

Married women may vote in some elections

Propertied married women may vote in some elections

No woman may vote

Total Government Control

No Government Regulation

All women have full voting rights

Women who own property have full voting rights

Married women have full voting rights

Propertied married women have full voting rights

All women may vote in some elections

Married women may vote in some elections

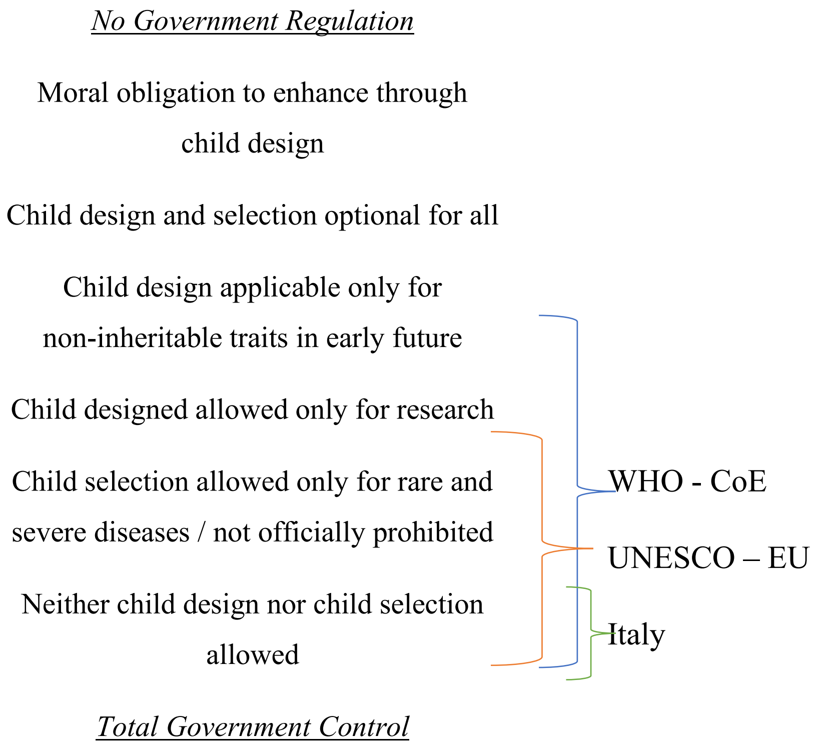
Propertied married women may vote in some elections

No woman may vote

Total Government Control

Source: https://www.mackinac.org/OvertonWindow

I.b) Overton Windows of governances at global, European and Italian level:



No Government Regulation

Moral obligation to enhance through child design

Child design and selection optional for all

Child design applicable only for non-inheritable traits in early future

Child designed allowed only for research

Child selection allowed only for rare and severe diseases / not officially prohibited

Neither child design nor child selection allowed

Total Government Control

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