Reproduction, the Key to Human Evolution: a Legal and Ethical Study

Elena Ignovska, Gastón Federico Blasi*

REPRODUCTION, THE KEY TO HUMAN EVOLUTION: A LEGAL AND ETHICAL STUDY

ABSTRACT: Technological and medical development imposes paradigmatic dilemmas: are parents morally obliged to conduct preimplantation genetic diagnosis [hereinafter, PGD] or not, and as a consequence, are they responsible on an individual level to make decisions on behalf of their future children that will ultimately affect the wellbeing of human's future generations, and finally, is the State compelled to guarantee full access to PGD. The scope of this paper will be focused exclusively on these ethical and legal controversies surrounding the obligation to create healthy offspring relating it with the concept of responsible reproduction, placing them in the global international arena.

KEYWORDS: eugenics; human dignity; human evolution; preimplantation genetic diagnosis; responsible reproduction

1. Preliminary considerations

The history of the human ethos is characterized by three elements: moralism –moralizing human behaviors-, meliorism –belief that the current condition could and should be improved by human effort-, and individualism as representing human's free will to make decisions and act accordingly.[1]

Human beings have always possessed an intrinsic ability to adapt to our habitat and environment. Historically, we have always aimed to become something more than what we are, to overcome our biological limitations. Consequently, we tend to improve our intellectual capacities, mainly, through education and discipline, and our body through physical exercises and diets. As a matter of fact, our evolution has depended on manipulating both the environment in which we are immersed and our lineage, modifying our *natural* state.[2]

---

[*] Elena Ignovska Assistant Professor at the University Ss. Cyril and Methodius, Faculty of Law, department of Civil Law in Skopje. E-mail: e.ignovska@pf.ukim.edu.mk; Gastón Federico Blasi Doctoral candidate at the Faculty of Law, Universidad de Buenos Aires (Directive CD nro. 1177/2011). E-mail: gablasi@jusbaires.gov.ar. Essay selected by the Steering Committee among submissions to the Call for papers on Human Dignity.

[1] A. R. JONSEN, *The Birth of Bioethics: The Origin of Evolution of a Demi-discipline*, in *Medical Humanities Review*, 11, 1997, pp. 9-21.

[2] Until 1978 human reproduction was excruciatingly limited to male and female sexual intercourse –we may refer to it as the natural way or even the animalistic approach. However, the development of medicine and

In our global society, flooded by information from the media, the human impulse for competition, comparison and improvement of our abilities increases even more, aiming to be good, better, reaching to the *best*. The enormous development of science and technology enables us, then, to self-improve, and therefore to stand on the very verge of the human enhancement's revolution in face of the trans-humanitarian ideas.[3]

We, as a species, have acquired significant developments in the field of genetic medicine the last sixty or so years. The purpose seems to be, perhaps, the conquest of the last frontier, *i.e.* complete domination of our nature. Human society, then, faces the difficult task of growing the power and knowledge needed to study and intervene our genetic heritage to repair it.[4]

Medical science has been designed for our own benefit.[5] Its aim, as a matter of fact, is to restore and improve the quality of life by treating pathologies that ultimately affect our health conditions. Through this instrument, coupled with progress in the areas of genetics and technology today, undoubtedly, it becomes feasible to favor, control and even predispose our evolution, fighting natural selection. Thus, we face a new step in the evolution of medical science, *v.gr.* a personalized medicine that can address each individual from his/hers particular genetic makeup.

We do not try to place the gene as a cultural icon through which we can resolve questions about the essence of our existence, dreaming, or at least hoping to reach a certain longing for biological perfection. We must not limit our being, our complexity to a molecular entity, since the environment in which we find ourselves also presents a major role in the formation of our phenotype. But we must recognize that each day we discover that the number of pathologies linked to our genetic structure is increasing, without reducing the concepts of health and disease to genetic issues.

No doubt preimplantation genetic diagnosis provides us with the exceptional possibility of tackling down the genetic avatars from the very beginning –that is, from the moment the ova is fertilized by the spermatozoa-, offering an alternative to prenatal invasive procedures followed by abortion. In-

---

technology has permitted us to enlarge our *natural state* and include diverse reproductive procedures outside coitus, such as: *in vitro* fertilization, intrauterine insemination, intra-cytoplasmic sperm injection, and even cloning for reproductive purposes.

[3] N. BOSTROM, *The Future of Human Evolution, Death and Anti-death: Two Hundred Years after Kant, Fifty Years after Turing*, California, 2004; *The Future of Humanity*, in J. K. B. OLSEN, E. SELINGER, S. RIIS (eds.), *New Waves in Philosophy of Technology,* England, 2009, pp. 186-215.

[4] We consider more appropriate to use the term *repair* rather than *enhance, purge* or even *refine,* due to the fact that the latters, it might be alleged, entail a negative connotation with a discriminatory sense.

[5] «Because even the same spirit depends so closely to the temperament and disposition of the body's organs, if it is possible to find some way that makes men in general wiser and more skilled than they so far have been, I think it is medicine where to look. [...] We could get rid of many diseases, both body and spirit and even, perhaps, of senile degeneration, if we knew their causes and the remedies that nature has endowed us.» R. DESCARTES, *El Discurso del Método*, Buenos Aires, 1982, p. 93.

ISSN 2284-4503

deed, this new medicine overlaps two technologies: assisted reproduction and genetic testing.[6] However, as medical science boosts its limits, the ethical dilemmas grow in complexity.[7]

This technique, hence, is not an exception because it triggers a myriad of ethical and legal controversies, mostly regarding to issues such as: the dignity of the embryos to be discarded, the voice of the unheard –or the child to be-, the *renaissance* of eugenics policies –designer babies?- and, of course, the lack of a universal normative framework that circumscribes it.[8]

Even more, such a technology rises concerns on questions such as equality and just distribution, stimulating the opposite –inequality in a hypercompetitive world.[9] Imagining a *perfect world* without disparities, with an extended lifespan, would still face problems to adjust resources, energy, and retirement programs, etcetera.[10]

This procedure, in general, seems to have a dual (eugenic) purpose: on one side, it can be used to look for traits that prospective parents disapprove for their children –negative eugenics- and, on the other, it could serve to select certain qualities or attributes that they desire to pass on to their progeny –positive eugenics.

In order to delimit the scope of moral debate, gene transfer technology for enhancement is excluded. We will only focus on predictive tests of genetic disorders and the possibility to avoid them –rejecting any line of thinking based on traits preferences-, not only as a human right but also as a human responsibility and obligation –of the future parents- towards safeguarding healthy future generations, without committing to any particular religious or philosophical approach.

2. Normative aspects

Most studies on this topic, as a matter of fact, tend to explore the ethical conundrums by following a certain ideology to justify privileging one moral choice above others.[11] We have realized, on the contrary, that a reverse analysis could be more beneficial to answering our initial queries, *i.e.* instead of

---

[6] For a concise definition of this technique, see S. BARUCH *et al*, *Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos,* 4 and 7 (01/2004), https://jscholarshiatlibrary.jhu.edu/bitstream/handle/1774.2/978/PGDDiscussionChallengesConcerns.pdf?sequence=1 (last visited 27/07/2016).

[7] See M. MALINOWSKI, *Choosing the Genetic Makeup of Children: Our Eugenics Past – Present, and Future?,* in *Connecticut Law Review*, 36 , 2003, p. 205.

[8] A prospective study conducted in 2010 by a taskforce of the European Society of Human Reproduction and Embryology concluded that the existent normative and funding disparities at regional level have stimulated a new trend named *reproductive tourism*, *i.e.* the flow of patients across European borders to avoid *unfriendly legislation.* See F. SHENFIELD et al, *Cross Border Reproductive Care in Six European Countries,* in *Human Reproduction*, 25, 1, 2010, pp. 1-8.

[9] N. RESCHER, *The Canons of Distributive Justice*, in J. STERBA (ed .), *Justice: Alternative Political Perspectives*, Belmont, 1980.

[10] *Ib.* at 23.

[11] By «ideology we stand on a distinction that is not a distinction of matter but one of point of view. We do not take as ideological what is left out when everything true, rational or scientific has been preempted. We take everything that is socially thought, believed, acted upon, on the assumption that it is a living whole, the interrelatedness and interdependence of whose parts would be blocked out by the a priori introduction of our current dichotomies.» L. DUMONT, *From Mandeville to Marx: The Genesis and Triumph of Economic Ideology,* Chicago, 1977, p. 22.

addressing them directly through a specific ethical line of thinking, we could infer the moral standpoint anchored by a determined community from the limited legal framework –indeed, law to a certain extent codifies the *minimum ethics*- under which predictive medicine, such as PGD, can be performed.

In order to articulate an intelligible and pragmatic discourse, we will consult the landmark jurisprudence generated by both the European Court of Human Rights [hereinafter, ECtHR] as well as its parallel version in America [hereinafter, IACHR]. The scope, indeed, will be to identify and later outline the underlying basic foundations that have been considered at regional level so as to determine the principle values adopted.

2.1 European continent

On European soil, the practice of the ECtHR has shown to be not only the human rights keeper but even more, the human rights developer by judging and analyzing individual cases from the Member States of the Council of Europe through the prism of the European Convention of Human Rights [hereinafter, ECHR].

The Court has repeatedly stated that the rules originating from the ECHR *cannot be interpreted and applied in a vacuum*; on the contrary, they must be read in the light of the integration and harmonization of the international conventions, in particular bearing in mind that this is a human rights' treaty.[12]

Human rights in the realm of private and family life have always been considered on the one hand, significant, so to be characterized as fundamental, while on the other hand, also out of subjective nature, allowing national States based on their own morals and traditions to rule what family life and choices encompasses. Extending the limits of the margin of appreciation to allow such morally, traditionally and culturally driven national regulations is in the intersection of the individual human rights and the nationally protected values.[13] Appreciating differences between the Member States sometimes collides with the protected human rights. The *European consensus standard* sets the limits of the margin of appreciation even further if, comparatively, particular breach is present in the national

---

[12] Loizidov v. Turkey, European Court of Human Rights, no. 15318/89 (Sept. 18, 1996).

[13] The concept of *margin of appreciation* of the ECtHR is the flexible framework of the space for maneuver in which the national authorities are to apply their obligations under the ECHR. The concept aims to balance the sovereignty of the Member States with their undertaken obligations from the convention while maintaining the court's role as an arbitrator between the States and their citizens. The Court should remain, for the members of the Council of Europe, a guide, and not to allow overuse of the margin of appreciation in the field of conflicts between fundamental rights.

Three factors are guiding principles when the possible infringements of the convention are allowed: (1) the *European consensus* standard, as a comparison among the regulations of the other member States; (2) the nature of the right (absolute or relative character); and (3) the aim to be achieved by the contested measure enacted by the State. See *The Margin of Appreciation*, Council of Europe, http://www.coe.int/t/dghl/cooperation/lisbonnetwork/themis/echr/paper2_en.asp (last visited 27/07/2016).

legal systems of more Member States. The space for calling upon this standard could be especially manifested, and even manipulated in the field of family life and application of science.[14]

In the field of contested moralities, such as in the section between medically assisted reproduction and family life, the margin of appreciation is especially flexible.[15] The court ruled in many cases in this intersection (right to access to assisted planned reproduction to families –heterosexual, homosexual or single parents- by cryopreservation, donation of genetic material, surrogacy arrangements, etcetera).[16] Nevertheless, it ruled only in several regarding PGD.

The case of *Maurice v. France*[17] involves a mistaken PGD due to switching bottles in a laboratory – similar to the case of *Draon v. France*,[18] but different because the later involved PND. Due to their similarity, the court brought decision for both cases on the same date.

The concerned couple complained in front of the ECtHR under the protection guaranteed in article 1 of Protocol No. 1 (peaceful enjoyment of property), article 8 (respect for private and family life) and 41 (in respect of pecuniary and non-pecuniary damage). While the French authorities recognized only compensation in respect of the damage caused by negligence by switching bottles, excluding the damage caused by the disability itself (since it was not a direct consequence of the negligence), the ECtHR recognized also damage in respect of the special burdens that would be incurred on account of the child's disability throughout its life (including the cost of house alterations and equipment purchases). Accordingly, the court found that there was a violation solely of article 1 of Protocol No. 1 unanimously and invited parties to reach a negotiated settlement. The compensation to the Maurices' amounted to €2,065,000 –of which €1,690,000 for provision of the child's material needs throughout life and €375,000 for all other damages taken together.

---

[14] The *European consensus standard* has been criticized for not possessing enough grounds on which the human rights protected by the Convention could be infringed –L. Helfer, *Coherence and the European Convention on Human Rights*, in *Cornell International Law Journal*, 26, 1993, pp. 133-165. On the other hand, the standard has also been favored as a tool that allows evolution in the interpretation of the ECHR, thus, strikes a balance between development and stability –K. Dzehtsiarou, *European Consensus and the Evolutive Interpretation of the European Convention of Human Rights*, in *German Law Journal*, 12, 2011, p. 1707.

[15] W. Van Hoof, G. Pennings, *Extraterritorial Laws for Cross-Border Reproductive Care. The Issue of Legal Diversity*, in *European Journal of Health Law*, 19/2, 2012, pp. 187-200.

[16] See for instance: S.H. and Others v. Austria, European Court of Human Rights, no. 57813/00 (11/03/2011); Evans vs. the United Kingdom, European Court of Human Rights, no. 6339/05 (04/10/2007); J.R.M. v. the Netherlands, European Commission of Human Rights, no. 16944/90 (08/02/1993); Mennesson v. France, European Court of Human Rights, no. 65192/11 (26/09/2014); and, Labassee v. France, European Court of Human Rights, no. 65941/11 (26/06/2014).

[17] *Maurice v. France*, European Court of Human Rights, no. 11810/03 (10/06/2005).

[18] *Draon v. France*, European Court of Human Rights, no. 1513/03 (10/06/2005). The case concerns a birth of a child with a severe disability not detected during pregnancy due to negligence while performing PND. The case shows the application of the Convention to *wrongful birth cases* and the consequences following a failure to diagnose pre-birth anomalies. The Court decided that there has been a violation of article 1 of Protocol 1 and that article 8 of the Convention was applicable to the case but not violated, while the other articles were either not examined (14 and 6 § 1) or not violated (13). Notwithstanding the Court's ruling, the case also provoked debates in the French society and worldwide regarding ethical issues such as: what is *wrongful birth* and *wrongful life* and does the acceptance of such claims recognize a right not to be born? See more in P. Lewis, *The Necessary Implications of Wrongful Life Claims: Lessons from France*, in *European Journal of Health Law*, 12, 2005, pp. 132-52.

ISSN 2284-4503

In both cases the regional Court regarded compensation for damage done not only to the parents, but also to their children because they were born with disabilities due to doctors' negligence. The amount of the atonement shows a great proportion in favor of the child's physical, psychological and material needs throughout life in comparison to the other damages caused to the parents. This means that despite of the medical and psychological hardship to both parents and children born with disabilities, there is also a great financial hardship –to adjust the living space, provide for the other specific needs of the child due to the disability etc.

In 2013, the European Court ruled on a case brought for an alleged violation of the right to respect for private and family life of an Italian couple (healthy careers of cystic fibrosis or *mucoviscidosis*) who were rejected from screening embryos for *in vitro* fertilization for purposes of selecting one that will not have the disease.[19]

After having their first child affected by that disease, for the second, the couple took advantage of PND that was allowed in Italy. The fetus was diagnosed as a positive carrier after which followed abortion. For the next attempt to have a child, they applied for PGD because they wanted to spare themselves from additional traumas related to selective pregnancy termination. They were rejected due to reasons that under Italian law, there were strict conditions under which one can benefit from in vitro procedure, being restricted to sterility and sexually transmissible diseases such as HIV or hepatitis B and C. [20]

Having no access to PGD on same grounds as the others, the ECtHR also considered that the Italian authorities have discriminated against them, thus infringing article 14 in conjunction with article 8 of the European Convention on Human Rights. The Court brought the decision based on the relevant European law,[21] the disproportionality of the State's interference with the applicants' right to respect for their private and family life[22] and on grounds of an existent European standard. [23]

---

[19] *Costa and Pavan v. Italy, European Court of Human Rights*, no. 54270/10 (28/08/2012).

[20] For more in depth analysis on the Italian law before and after the case see in S. Penasa, *The Italian Law on Assisted Reproductive Technologies n.40 of 2004 facing the European Court of Human Rights: the Case of Costa and Pavan v. Italy*, in *Revista de Derecho y Genoma Humano*, 37, 2012, pp. 155-178.

[21] Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine art. 12, *opened for signature* April 4, 1997, ETS no.164. Explanatory Report Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine par. 83, April 4 1997, ETS n. 164. European Parliament and the Council, Directive 2004/23/EC on Setting Standards of Quality and Safety for the Donation, Procurement, Testing, Processing, Preservation, Storage and Distribution of Human Tissues and Cells, L/102, 48-58 (31/03/2004). Steering Committee on Bioethics and the Council of Europe, Background Document on Preimplantation and Prenatal Genetic Testing. Clinical Situation, DH-BIO/INF (2015). Institute for Prospective Technological Studies, Joint Research Center of the European Commission, Preimplantation Genetic Diagnosis in Europe, EUR 22764 EN (2007). European Parliament, Report on the Proposal for a Council Recommendation on a European Action in the Field of Rare Diseases, no. 2009/C 151/02 (08/06/2009).

[22] Supra note 17, par. 71.

[23] At the time of judging, PGD was authorized in Germany, Belgium, Denmark, Spain, Finland, France, Georgia, Greece, Norway, Portugal, the Czech Republic, the United Kingdom, the Russian Federation, Serbia, Slovenia, FYR Macedonia, and Sweden. PGD was not a regulated in Bulgaria, Malta, Estonia, Ireland, Latvia, Luxemburg, Poland, Romania, Slovakia, Cyprus, Turkey and Ukraine (even though, the last three countries allowed it in practice). Only two out of thirty two studied States (Austria and Switzerland) banned PGD in such

Finally, in the *Case of Costa and Pavan v. Italy*, the Court condemned the Italian prohibitions to access PGD due to prevention of eugenic practices as being inconsistent with the fact that the Italian law allows PND and abortions if fetal abnormalities are diagnosed. Further on, the Court not only recognized that the scientific and medical development of reproductive technologies with an aim to exercise one's reproductive right falls under the protection of article 8, but it also made a distinction between the *right to reproduce* and the *right to a healthy child* (the right appealed by the couple to have access to *in vitro* and PGD for a purpose of procreating a child without the specific genetic disease).

2.2 American continent

Along the continent, moral contemplation of PGD may be relevant because it is practically unregulated. For instance, Latin American countries have not enacted any law regarding this subject matter yet. Though it is true that from the *Río Bravo del Norte* to the Strait of Magellan there are educational concerns, social inequalities and basic health issues that are top priorities in each governments' agendas, the improvement and expansion of technology in the field of reproductive medicine demands the full attention of both the legislative and judicial branches in order to face the demands and necessities of, in this case, prospective parents.[24]

In the United States, neither federal nor state governments have limited PGD itself, mainly because it is not considered a matter of human subject research; thus, the choice of this technique depends on the contract that a couple, in their reproductive freedom, made with private entities. In fact, it is accepted in cases of monogenic diseases and chromosomal abnormalities as well as sex selection due to conditions linked to sex. However, there are no policies against sex selection for non-medical reasons, social desires and, of course, designer babies. It is often alluded as a *free-wheeling Wild West system* because no formal law requires fertility clinics to provide information regarding the genetic tests used in PGD.[25]

Canada, on the contrary, through the *Assisted Human Reproduction Act* (SC 2004, c. 2) has specifically circumscribed the use of this technology for medical ends. In its article 5 states that «[n]o person shall knowingly… (b) create an in vitro embryo for any purpose other than creating a human being or improving or providing instruction in assisted reproduction procedures;… (e) for the purpose of creating a human being, perform any procedure or provide, prescribe or administer anything that would ensure or increase the probability that an embryo will be of a particular sex, or that would identify

---

circumstances. See supra note 24, par. 29 and 70. Later on, Switzerland amended the law and the Constitution introducing PGD following referendum. See more in K. OSWALD, *Switzerland Votes for PGD*, in *Bionews*, 809, 06/07/2015, http://www.bionews.org.uk/page_542222.asp (last visited 10/10/2016).

[24] It is worth mentioning that in Argentina, recently, the federal Supreme Court has ruled that preimplantation genetic diagnosis is not included in the mandatory procedures set out by the *medically assisted reproduction techniques act* n. 26.862 –cf. L. E. H. y otros c/ OSEP s/ Amparo*,* CSJN 3732/2014/RHl (01/09/2015), http://sjconsulta.csjn.gov.ar/sjconsulta/documentos/verDocumentoById.html?idDocumento=7243421 (last visited 27/07/2016).

[25] B. WILLIAMS, *Screening for Children: Choice and Chance in the Wild West of Reproductive Medicine,* in *George Washington Law Review*, 79, 06/2011, p. 1325. Also, S. BARUCH *et al*, *Genetic Testing of Embryos: Practices and Perspectives of US In Vitro Fertilization Clinics,* in *Fertility & Sterility*, 89, 05/2008, p. 1056.

the sex of an in vitro embryo, except to prevent, diagnose or treat a sex-linked disorder or disease; (f) alter the genome of a cell of a human being or in vitro embryo such that the alteration is capable of being transmitted to descendants». [26]

In addition, the main judicial organs of the Organization of American States, we referred to the IACHR and the Inter-American Commission of Human Rights [hereafter, IAcHR], have not ruled on a case related particularly to PGD yet.

To this extent we could affirm then that the scenario is particularly undefined. In spite of this, we find that intrinsic issues to this topic have been indeed addressed in two cases, *i.e.* the recognized extension of the *right to life* and the necessary aspects that have to be regulated in the implementation of the *in vitro fertilization* technique as part of the *right to found a family*.

In 1981, the IAcHR held that the abortion of *Baby Boy*, a viable unborn child that did not come to the normal term of pregnancy, was permissible under the *American Declaration of the Rights and Duties of Man* and, incidentally, the *American Convention on Human Rights*. Additionally, the Commission concluded that the United States' creation of a fundamental *right to abortion* through *Roe v. Wade* and *Doe v. Bolton* was not incompatible with both international instruments.[27]

The petition filed before the quasi-judicial regional human rights body was based on the alleged violations of *Baby Boy's right to life* by the United States government, since its Supreme Federal Court handed down the above-mentioned decisions.[28]

---

[26] http://laws-lois.justice.gc.ca/eng/acts/a-13.4/page-1.html (last visited 27/07/2016).

[27] Inter-American Commission on Human Rights, Annual Report 1980-1981, Resolution no. 23/81, case no. 2141 (06/03/1981), http://www.cidh.org/annualrep/80.81eng/usa2141.htm (last visited 27/07/2016).

[28] The *right to life*, in the United States, is guaranteed and protected by the Fourteenth Amendment of the Federal Constitution. The legal status of the unborn person, however, is somewhat peculiar, because until the Supreme Court put its rubric in *Doe v. Bolton* (410 U.S. 179, Jan. 22, 1973) and *Roe v. Wade* (410 U.S. 113, 22/01/1973) cases, there was no legal standard that set the precise moment when a human life began. The Court, as we know, favored the *right to privacy* of the mother over the *right to life* of the unborn child, arguing that the first means to be free from unwarranted state intrusion in matters relating strictly to self-referential morality, *v.gr.* the decision of any woman to beget or not a child –cf. *Eisenstadt v. Baird,* 405 U.S. 438 (22/03/1972).

Such ruling found support in the rationale that the term *person,* as mentioned in the Constitution, could not be extended to the *nasciturus*. It was argued that the legal status of the latter was different from that of a person already born, and therefore, could not entail protection from the guarantees of *due process* and *equal protection under the law* according to the provisions of the Fourteenth Amendment.

Furthermore, the justices, due to the absence of scientific consensus on the exact moment in which human life begins to exist, enlisted the possibility of autonomous survival in the *theory of viability*. This led to the conclusion that the conceived child, during the first weeks of pregnancy, is not a passive subject of rights and, therefore, the question arose between the autonomy of choice within the area of privacy of women and the state's interest to safeguard the potentiality of life that represents a human embryo.

This precedent, confirmed on numerous occasions (Harris v. Mc Rae, 448 U.S. 297, 30/06/1980; Thornburgh v. American College of Obstetricians and Gynecologists, 476 U.S. 747, 11/06/1985; Webster v. Reproductive Health Services, 492 U.S. 490, 03/07/1989), has been losing strength since the '90s. In the case *Planned Parenthood v. Casey* (505 U.S. 833, 29/06/1992), the Federal Supreme Court gave states more power to interfere with women's autonomy, rejecting *Roe´s* inflexible trimester scheme and its interpretation that considered all pre-viability regulations of abortion unwarranted. Thus, it has been recognized the constitutionality of all those state laws enacted with the sole purpose of promoting appropriate measures enabling pregnant women to take informed decisions, recognizing also that the «state has legitimate interests from the outset of the

After verifying the admissibility requirements, the IAcHR, based on the *travaux preparatoires* of the *Declaration*, concluded that the definition given to the said prerogative «was incompatible with the laws governing the death penalty and abortion in the majority of the American States. In effect, the acceptance of this absolute concept –the right to life from the moment of conception- would imply the obligation to derogate the articles of the Penal Codes in force since 1948 in many countries because such articles excluded the penal sanction for the crime of abortion if performed in one or more of the following cases [inter alia]… iv) to prevent the transmission to the fetus of a hereditary on contagious disease».[29]

On April 1995, a Costa Rica citizen filed an action of unconstitutionality –cf. article 75 of law n. 7135- against the executive decree n. 24029-S issued by the Ministry of Health to regulate assisted reproductive techniques, including *in vitro fertilization*.[30] The Constitutional Chamber of the Supreme Court reasoned that the said technique violated *the right to life and dignity of the human being,* be-

---

pregnancy in protecting the health of the woman and the life of the fetus that may become a child.» Furthermore, in *Gonzales v. Cahart et al* (550 U.S. 124, 18/04/2007), the supreme justices held the constitutionality of the *partial-birth abortion ban Act of 2003*, a federal statute that in terms prohibits a certain form of late-term abortion, referred to by the medical literature as intact dilation and extraction, *in which a fetus is killed just inches before completion of the birth process,* showing the interest of protecting the integrity and dignity of human life within a woman's uterus.

[29] *Supra* note 26, par. 18) e).

A wide variety of American states have decriminalized abortive practices when the life in gestation suffers malformations or hereditary or contagious diseases. For instance, in Peru, the criminal code allows to perform an abortion within the first trimester when pregnancy leads to serious physical or mental defects, provided that there is medical diagnosis –cf. article 120(2). The Colombian penal code, after the Constitutional Court's resolution in the case n. C-355 of May 10th 2006, abortion can be performed if the fetus presents any sort of malformations. In Uruguay is the same: the termination of a pregnancy is allowed if a pathological process that causes malformations incompatible with life outside the womb is verified –cf. law n. 18987 and the executive decree n. 375/12. Mexican law also permits abortion when the unborn child is diagnosed with a genetic or congenital alteration that triggers serious physical or mental disorders –see article 361 of the Tamaulipas' penal code, article 154 Veracruz's criminal laws, article 229 of Jalisco criminal body, articles 279 and 280 of Tlaxcala's the criminal code, article 393 of Yucatan's penal law, among many others.

[30] The petitioner requested that the executive decree n. 24029-S be declared unconstitutional because «in vitro fertilization and embryo transfer is a lucrative service through which an individual seeks to implant into the uterus of a woman fertilized eggs –designed in a laboratory- by artificial methods, to achieve pregnancy… this extracorporeal technique of human reproduction implies the loss of embryos… the generalized practice of this technique violates human life, and owing to the private and isolated characteristics in which it takes place, any regulation would be difficult for the state to implement and control… Life starts from the moment of fertilization, therefore, any removal or destruction of conceived children results in a clear violation of the right to human life… In vitro fertilization is a business that does not provide a cure for a disease or emergency treatment to save a life…the elimination of the product of conception, in other words, children, discarding them, produces the same violation as eliminating them deliberately owing to the lack of technique in the procedure, attempting to win the game of percentages with the six children introduced into the mother». Del Valle, Hermes Navarro s/ Acción de inconstitucionalidad, dossier no. 95-001734-0007-CO, Constitutional Chamber of the Supreme Court of Justice of Costa Rica, judgment no. 2000-02306 (15/03/2000), par. 1, http://jurisprudencia.poderjudicial.go.cr/pj/scij/busqueda/jurisprudencia/jur_repartidor.asp?param1=TSS&nValor1=1&nValor2=128218&strTipM=T (last visited 27/07/2016).

cause many human embryos created by it die in the process, banning the practice due to unconstitutionality.[31]

The IAcHR, on behalf of nine Costa Rican infertile couples, brought the case before the IACHR in 2011, arguing that the criticized domestic decision violated theirs *rights to private* and *family life*, *equal protection* and *non-discrimination* –articles 11(2), 17(2) and 24 of the American Convention on Human Rights.[32]

After an extensive analysis, the Court stated inadmissible to grant personhood to the human embryo until its adhesion to the endometrium[33], emphasizing that the protection of the «right to life is not absolute, but rather gradual and incremental according to its developments».[34] Moreover, it established that the *right to private life* is excruciatingly linked to *reproductive autonomy* that included the right to have access to the medical technology (or health services) to ensure family planning.[35] Ergo, it concluded that the decision issued by the Costa Rican Supreme Court undermined the right to *reproductive autonomy* of the petitioners.[36]

Based on the factual and legal arguments brought forward in this case, the court esteemed appropriate to condemn Costa Rica to pay in concept of reparation the sums of US$5,000.00 (pecuniary damage) and US$20,000.00 (non-pecuniary damage) for each petitioner.[37]

3. Ethical quandaries

In our heterogeneous secular world, the moral concerns raised by preimplantation embryo genetic screening could be addressed from different philosophical perspectives, e.g. Kantian theory[38], utilitarianism[39], communitarianism[40]. However, none provides an integral assessment to definitively resolve them.

---

[31] The judges concluded that «once conceived, a person is a person, and this is a living being, and therefor (s)he is entitled to be protected by law… For human beings, life is not only an empirically verifiable fact, it is a right that belongs just to be alive. Every human being holds a right not to be deprived of his life or suffer illegitimate attacks by the state or private individuals, but not only that: the public authorities and civil society must help him/her defend himself/herself from the dangers to his/hers life (whether natural or social),… as the right [to live] is declared for all without exception –any exception or limitation destroys the very content of the right- it must be protected for both the individual who has been born as well as the unborn one.» See supra note 34, par. IV, V and VI.

[32] For a detailed insight of the specific situation of each couple, see case of Artavia Murillo *et al* (in vitro fertilization) v. Costa Rica, Inter-American Court of Human Rights, series C no. 257, judgment of 28/11/2012, par. 85-125.

[33] *Supra* note 29, par. 184 and 223.

[34] *Ib.* par. 264.

[35] *Ib.* par. 146/8.

[36] *Ib.* par. 147.

[37] *Ib.* par. 349-363.

[38] Kant stipulated: «[a]ct in such a way that you use humanity, whether in your own person or in the person of any other, never merely as a means to an end, but always at the same time as an end.» *Fundamentación para una Metafísica de las Costumbres*, Madrid, 2002, p. A 64-68.

[39] The utilitarian moral theory holds that the best moral action is the one that maximizes utility. Among the proponents, see J. BENTHAM, *An Introduction to the Principles of Morals and Legislation,* Oxford, 1907; J. STUART MILL, *Utilitarianism,* Chicago, 1906.

Furthermore, due to the difficulty to identify an objective and harmonious hierarchy of moral values –a sort of heretic dogmatic system devoted to supreme truths-, we propose to board the core moral challenges already identified *supra* through the rationale laid down by the case law previously outlined.

Initially, we have established the nub of our analysis, *i.e. could any individual (future parents) be morally obliged to conduct preimplantation genetic testing and, consequently, be morally responsible to make decisions on behalf of their future children?*

In principle, and according to both regional Courts, any person could be held (morally) accountable for his/her conduct, only if, under specific circumstances, (s)he has acquired the necessary information that would led him/her to decide the course of action to follow.

It could be argued then that PGD would set the threshold to eradicate selective pregnancy termination policies. Furthermore, this technique presents a great opportunity to (try to) eliminate the weight of increasingly broad spectrum of genetic defects afflicting our species.[41]

PGD, unquestionably, provides the knowledge to make decisions in the process of parenthood, *i.e.* implant the unaffected embryo in the woman's uterus or, instead, destroy the abnormal one. This technology has a dual functionality. On the one hand, it guarantees the right to know and, on the other, to decide the path to take based on that information, recognizing hence the autonomy and reproductive freedom of prospective parents, as both Courts have established.

On the opposite site, detractors has stated that PGD is a form of commodification of reproduction that favors to cross the portal to a *neoeugenics* era where human beings are selected according to certain genetic criteria or preferred traits.[42]

Before examining some of the ethical qualms that arise with respect to the use of this technology, in particular the fear of facing the rise of a eugenics trend, we briefly explore below the meaning of autonomy in the context of reproduction as well as the enigmatic notion of human dignity.

3.1. Terminological aspects: autonomy and freedom

Autonomy, as a capacity, encompasses a number of different aspects such as independence, privacy, self-realization and freedom of choice. Obviously being autonomous means taking responsibility for decisions and actions. An autonomous person, then, is someone who realizes his/her existential pro-

---

[40] This philosophy stresses that individual identity is molded by community relationships. See A. MacIntyre, *After Virtue. A Study in Moral Theory,* Indiana, 1981.

[41] Vaccination campaigns have been implemented precisely to combat the fragility of our species, so as to reduce our vulnerability inherent to our human condition. In a recent, controversial case, the Federal High Court of Argentina, referring to the interests of the child and the safety of public health, compelled the parents of a minor to comply with the official vaccination plan under penalty of proceeding compulsively. See N. N. o U., V. s/ Protección y guarda de personas, CSJN N. 157, L. XLVI (12/06/2012), http://sjconsulta.csjn.gov.ar/sjconsulta/documentos/verDocumentoById.html?idDocumento=6921362. In the same sense, Henning Jacobson v. Commonwealth of Massachusetts, 197 U.S. 11 (20/02/1905).

[42] *Neoeugenics* defines the use of reproductive technologies in eugenic ways, sharing the same goal with classic eugenics, *i.e.* increasing good birth, but, in difference, they occur at individual rather than state level. See S. M. Suter, *A Brave New World of Designer Babies?*, in *Berkeley Technology Law Journal*, 22, 03/2007, pp. 897-969.

ject inter-subjectively. Autonomy also imposes a duty to respect other people as autonomous beings –this means, without interfering in decisions pertaining to self-referential morality.

In order to judge whether a person has acted autonomously, it is necessary to determine whether or not (s)he acted freely.

The concept of freedom refers to the preferences and values that an individual has in a given scenario, whereas the concept of autonomy refers to the ability of a person to be able to reflect critically on those and therefore take a stand.

To act freely thus is to enforce one's own decisions without ignoring the desires and thoughts of those individuals involved by acquiring useful knowledge to that extent.

As a matter of fact, no man is an island. Individual autonomy and freedom can be belted to ensure general welfare and peaceful coexistence, while respecting certain insurmountable duties, such as: do not harm the other without justification, respect individual autonomy of the others and share equitably risks and benefits with the others, otherwise it would be intolerable, since tyranny of the majority is not acceptable.

To sum up, a liberal procreative autonomy vision defines the conceit that a free and autonomous action entails a three level of knowledge: in the first place, discerns one's own preferences; secondly, distinguishes others expectations and dreams; and, finally, be aware of the consequences that derive from the implementation of the decision at a personal as well as at global level. This means that the notion of autonomy demands to think of the self in relation to the interests, attachments and relationships derived from living in a community –and, indeed, the future generations- in order to overcome the individualistic cultural approach that reigns in Western countries.

In this sense, every individual has beyond doubt a prerogative to freely decide whether to beget or rear a child without unwarranted intrusion to the integrity of an intimate decision-making process,– reproductive autonomy. This matter involves the most intimate and personal choice a person may make along his/hers lifetime that may alter his/hers' own very existence by freely choosing to reproduce or not to reproduce in a genetic sense.

However, procreative liberty is not unlimited. In fact, we can draw reasonable and ethical lines between the decisions and norms analyzed concerning human reproduction to affirm that it covers «only actions designed to enable a couple to have normal, healthy offspring, whom they intend to rear. Actions that aim to produce offspring that are more than normal (enhancement), less than normal (Bladerunner), or replicas of other human genomes (cloning) would not fall within procreative liberty because they deviate too far from the experiences that make reproduction a valued experience».

PGD, when used for its original purpose –that is, to avoid the propagation of incurable transmissible genetic diseases and disabilities-, can be regarded as a therapeutic process that assures future parents' freedom to decide if and when to reproduce.

3.2. Human dignity: an empty concept

It is worth remembering that human dignity has evolved as the banner of humanity as well as the warhorse of the human rights law movement since the end of World War II. Accordingly, each single human being demands protection and respect from the very beginning of his/her existence solely because of his/her inherent (natural) condition, which relates to the importance of human life, regardless of socio-economic status, psychophysical capacities, ethnic background and religious beliefs.43

Human dignity, in fact, is presupposed as the basic rule that transcends cultural diversity. It has become the essence, the pillar on which human rights rise. This universal recognition brings the presupposition that human life has an inherent and supreme value. In this sense, human beings become inviolable, and consequently the permanence of genuine human life becomes a categorical imperative.44

What does it mean then that something is inherently valuable? Basically, it can be said that the intrinsic value of a thing, and even of an individual, unlike the instrumental one, is independent of its potential utility. The problem, then, lies in identifying why human beings are worthy in themselves.

History shows us that denying human beings innate value has been highly dangerous. For this reason, the international community has agreed that «[a]ll human beings are born free and equal in dignity and rights».45 This has led to recognize personhood to every human being, thus attributing each (human) individual a moral status simply because of his/her membership to the species. In other words, personality turns out to be a natural characteristic of every member of the human species, which must be legally recognized.46

We acknowledge, however, that the ontological status of the human embryo is a query that has been assessed in a myriad of ways –from a biological, philosophical, religious and even legal perspective-, and there is no agreed definition as to when human life begins, therefore to talk of an inherent dignity since the very moment of conception becomes arbitrary.47

In this line of reasoning, the worthiness or moral value of a human being, from a pluralist standpoint, cannot be assigned exclusively on the basis of its biological properties. On the contrary, we must necessarily consider the social history of the totality of relevance in which each individual plays a part. In other terms, the meaningfulness of a human embryo will be determined by the goals inherent to the practice in question.

---

[43] R. DWORKIN, *Life's Dominion. An argument about Abortion, Euthanasia and Individual Freedom,* New York, 1994, p. 236.

[44] The German philosopher Jonas claimed that the very existence of mankind was threatened by the power of intervention and manipulation over life in general that had been achieved. In his view, it was inadmissible to consider the disappearance of the human species by technological progress, so he devised the first imperative of his ethics of responsibility: *the continued existence of the idea of humanity*. In addition, he conceived that the precariousness of the human condition must also be preserved. See H. JONAS, *Il principio responsabilità. Un'etica per la civiltà tecnológica,* Torino, 1993.

[45] Universal Declaration of Human Rights, article 1. This document was proclaimed by the United Nations General Assembly in Paris, resolution 217 A on 10 December 1948.

[46] The international human rights law movement is based on the inviolability and unavailability of human life, considering it as a fundamental (self-evident) good, from which the other (natural) prerogatives of the human being emerge. Human life, therefore, is seen as a moral absolute from which non-negotiable duties derive, in order to avoid a possible normative relativism. See J. FINNIS, *Natural law and natural rights,* Oxford, 1980.

[47] Regarding the moral position of the human embryo, see Steering Committee on Bioethics, *Report on the Protection of the Human Embryo In Vitro,* CDBI-CO-GT3 (19/06/2003).

For instance, an embryo produced by an assisted reproductive technique, such as in vitro fertilization or intracitoplasmatic insemination, conceived to fulfill the desire of parenthood –undergoing PGD to discard those embryos that carry a genetic abnormality- comes into being under that specific activity and its aim depends on the underlying purpose of such practice. Namely, the moral value of the being in question will be related to the implicit intention that motivates a certain technique. Therefore, two beings, in principle, similar from the biological point of view, could come to differ in terms of moral status, and dignity cannot adjust it.

Further, if we ponder that we come to life –in most cases- to accomplish our parents' desire of having children, thus it would be valid to reckon that we become into life as instruments for their desires. In other terms, we could be seen as necessary means for our parents' self-fulfillment. We, then, could be instrumentalized to their ends until we become aware of being able to establish a subject-subject relationship.

International biomedical instruments, subsequently, present dignity as the golden rule, or even the last barrier against the abolition of mankind from the (allegedly) misused of technology in the field of Medicine.48

These documents, undoubtedly, contain no analysis or explanation of such term, nor its ethical foundations and legal implications. Nonetheless, a deeper examination leads to conclude that human dignity alludes nothing else than respect for individual autonomy. As a matter of fact, they state that medical research or treatment, in particular in the field of genetics, should not prevail over respect for human dignity of individuals. In order to control this goal each treaty or declaration lays out what we can address as the main or general triad, that is, balance risks and benefits, procure free and informed consent and, of course, maintain confidentiality.

It is also valuable to remember that the permanence and continuity of all life on this planet, not only human, is completely random, since we are undeniably at the mercy of climatic, geological and astronomical scourges capable of unleashing a potential natural catastrophe –e.g. tectonic movements, impact of asteroids and meteors against the earth's surface, eruption of volcanoes- that could lead even to our own annihilation.

To a greater extent, we should understand that our presence in the universe is solely due to an accidental question of mutation and not an ex nihilo creation. The fact that we have evolved from the apes shows that our species is not pure, and it is evident that nothing distinctive characterizes it, since our existence and evolution have been due, in principle, to fortuitous genetic alterations.

All things considered, human dignity could be retained as a drifting vessel for medical ethics, because it has brought more uncertainties than solutions to the present discussion, therefore it should be abandoned.49

---

[48] References to *human dignity* are found in a wide variety of international documents, such as: the Universal Declaration on the Human Genome and Human Rights, the Convention for the protection of Human Rights and Dignity of the human being, the Universal Declaration on Bioethics and Human Rights, among others.

[49] «Why, then, do so many articles and reports appeal to human dignity, as if it means something over and above respect for persons or for their autonomy? A possible explanation is the many religious sources that refer to human dignity, especially but not exclusively in Roman Catholic writings. However, this religious source cannot explain how and why dignity has crept into the secular literature in medical ethics. Nor can the prominence of the concept in human rights documents, since only a small portion of the literature in medical

3.3. Health v. disease: the eugenics' gateway?

Planned and responsible parenthood as a key goal of the United Nations Population and Development Strategy inevitably includes both individuals in the decision-making process of conceiving a child. The aim of family planning is to enable both couples and individuals to decide freely and responsibly about the number, spacing and timing of making informed reproductive choices. Consequently, family planning is in concordance with the promotion of optimum health, respect for the dignity of all persons, as well as family well-being.50 The enablement of free and informed choices should offer a variety of methods depending on the age, parity, family-size preference and other factors to ensure access to the proper effective family-planning methods.51

Procreative freedom though is not absolute, it solely, gives parents the possibility to choose a child (among the children they could have) with the best chances for the best life, according to the available and relevant information.52 Accordingly, this prerogative gives a green light to choose embryos in vitro depending from the potential threats of diseases or anomalous or defectives genes.53 It goes even further by promoting selection for non-disease genes. Therefore, it has been subject to many criticisms opposing such (moral) reasoning because, among others, it could be regarded as a form of new eugenics –by giving the future parents determined/predisposed choices conditioned by notions of parental responsibility.54

Eugenics' theory proposes to obtain an improvement of a certain species through reproduction over the generations. Hereditary characters are distinguished between positive –or eugenics-, and negative –or not eugenics-, favoring the former and preventing the latter to propagate. Scientific discoveries made along the nineteenth century gave impetus to the eugenics movement. When it was found that many of the physical characteristics were hereditary, proponents of this science strove to promote human features they considered positive and suppress those seen as negative. This was achieved on the one hand, stimulating and encouraging, through prizes and economic rewards, men

---

ethics addresses the links between health and human rights». R. Macklin, *Dignity is a useless concept. It means no more than respect for persons or their autonomy,* in *British Medical Journal*, 327, 12/2003, p. 1420.

[50] United Nations Population Fund, Report of the International Conference on Population and Development, A/CONF. 171/13, 44 (1994), https://www.unfpa.org/sites/default/files/event-pdf/icpd_eng_2.pdf (last visited 10/10/2016).

[51] *Ib.* at 45.

[52] Ethics Committee of American Society for Reproductive Medicine, *Preconception Gender Selection for Nonmedical Reasons*, in *Fertility & Sterility*, 75, 2001, p. 861.

[53] J. Savulescu, *Procreative Beneficence: Why We Should Select the Best Children,* in *Bioethics*, 15, 2001, pp. 413-426.

Reproductive health implies not only the freedom to decide if and when to procreate, but also «the right to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of choice, as well as the right of access to appropriate health care services.» Committee on Economic, Social and Cultural Rights, General Comment no. 14 (2000), The Right to the Highest Attainable Standard of Health (Article 12 of the ICCPR), E/C.12/2000/4, par. 14, footnote 12 (11/08/2000).

[54] See for instance R. Bennett, *The Fallacy of the Principle of Procreative Beneficence*, in *Bioethics*, 23, 2009, pp. 265-273; R. Sparrow, *Procreative Beneficence, Obligation and Eugenics, Genomics*, in *Society and Policy*, 3, 2007, pp. 43-59.

ISSN 2284-4503

and women with positive traits to copulate –policies of positive eugenics- and, on the other, sought to prohibit the reproduction of those subjects with genetic characteristics considered poor through laws inciting racial segregation, prohibition of intermarriage, sterilization and even genocide –negative eugenics policies.55

Following this line of thinking, many reject PGD as a neoeugenic practice, plainly because it is intended to serve as a tool that allows choosing one specific embryo over the others due to particular genes that is expected to carry. However, a similar objective could be addressed to prenatal diagnosis and homogamy.56

Which is then the difference between preventing a disease and (arbitrary) genetic selection? What sort of (ethical and legal) guidelines should be drawn?

The World Health Organization [hereafter, WHO] provides an unequivocal ambiguous definition of health, that is: «a state of complete physical, mental and social well-being, capable of operation, and not merely the absence of disease or infirmity».57

It is not contested though that Alzheimer's, Turner's syndrome or any other late-onset (genetic) affliction are terrible conditions, while the color of the eyes of an individual, the gender and sex (for non-medical ends) of any person can be retained traits related mostly to appearance or social acceptability.

The harshness of an affliction, as a consequence, could be determined by measuring the following three factors: first and foremost, the impact it would have on the future child's health –extension of suffering and functionality limitations-; secondly, the estimative age in which that condition will begin; and finally, the likeliness that the genetic constitution will modify the phenotype.58

These standards, albeit their evident usefulness, could be manipulated to include as many mental/physical conditions as are retained severe for future generations and, hence, for humanity to the extreme of enshrining some discriminatory ideals of genetic cleansing.59 Or, plainly, the difference between health and illness could increase to the extent of considering what once was seen as a disease-free (thus, normal), as abnormal.

In reality, health and disease cannot be derived only from the operation and biological structure of the person. It is essential to understand that psychic and somatic aspects are closely interrelated and

---

[55] See C. Davenport, *Eugenics: The Science of Human Improvement by Better Breeding,* 1910; A. Bell, *How to Improve The Race*, in *Journal of Heredity*, 5, 1914, pp. 1-7; F. Galton, *Eugenics: its Definition, Scope, and Aims,* in *American Journal of Sociology*, 10, 1904, p. 1; *Studies in Eugenics,* in *American Journal of Sociology*, 11, 1905, pp. 11-25; P. Lombardo, *Miscegenation, Eugenics, and Racism: Footnotes to Loving v. Virginia,* in *University of California, Davis Law Review*, 21, 1988, pp. 421-452; *Pedigrees, Propaganda, and Paranoia: Family Studies in a Historical context,* in *Journal of Continuing Education in the Health Professions*, 21, 2001, pp. 247-255.

[56] J. Robertson, *Ethics and Future of Preimplantation Genetic Diagnosis*, in *Ethics, Law and Moral Philosophy of Reproductive Biomedicine,* 1, 03/2005, p. 98.

[57] Preamble of the World Health Organization's Constitution, adopted by the International Health Conference in New York on July 22, 1946 by the representatives of 61 states, entered into force on April 07, 1948, http://www.who.int/governance/eb/who_constitution_en.pdf (last visited 27/07/2016)

[58] L. Silver, *Remaking Eden: Cloning and Beyond in a Brave New World,* New York, 1997, p. 57.

[59] Though *deafness* is not a life-threatening affliction, the United States federal government considers it as a disability –cf. United States Americans with Disabilities Act (2008), Pub. L. no. 110-135, sec. 4, no. 3, par. A, 122 Stat. 3553-, due to the impairments and limits to life activities of an individual –at https://www.ada.gov/pubs/adastatute08mark.htm (last visited 27/07/2016).

must also be viewed in the light of social, cultural and even political factors. Therefore, it is not a matter restricted only to scientific analysis, but also includes judgments.[60]

On that account, paternity's influence over rearing of children remains undisputed. In this sense, we should not be surprised that genetic make-up and health of the progeny have become paramount aspects to any parent. In fact, we could accordingly ponder that there is almost no difference between genetically selecting embryos to a responsible parenthood, which implies forging and influencing children through discipline and education.[61]

Every parent, broadly speaking, fantasizes and yearns that his/her offspring will reach superlative levels in various areas of life. In many cases the desire to have a child becomes a forced experience, so not complying with it makes it a (mandatory) need which, in turn, becomes an obsession and affects the individual's own happiness.[62] Obviously, the information that the progeny suffers from a genetic condition directly affects both parents socially as well as psychologically.[63]

Unconditional acceptance of a parent for his/her offspring is not always the case. Indeed, expectations, hopes and dreams that a parent deposits in his/hers progeny could be so elevated that in the presence of severe chromosomal abnormalities, such as Tay Sachs disease, the only acceptable way would be to discard that embryo.[64]

---

[60] There are several philosophical theories that explain the terms *disease* and *health*. Perhaps, we could confine the debate to two positions: the biological model and the holistic model. In the first case, the disease is determined by structural changes and diminished physical and mental functioning. In the second, psychosomatic, social and cultural factors are taken into account, so health is related to the operation of the whole person. This concept opposes the *Galenic* medical tradition, since the latter considers that the normal functioning of the body depends on being among the parameters set as normal within a particular group. See C. Boorse, *Health as a Theoretical Concept*, in *Philosophy of Science*, 44, 1977, pp. 542-73; *On the Distinction between Disease and Illness,* in Caplan, Engelhardt, McCartney (eds.), *Concepts of Health and Disease. Interdisciplinary Perspectives,* London, 1981, pp. 545-560; L. Nordenfelt, *On the Nature of Health. An Action/Theoretic Approach,* Dordrecht, 1995.

[61] «Because reproductive decisions often turn on the expected child-rearing experiences that reproduction will bring, some choice over the genome of prospective offspring should fall within the scope of procreative liberty. Is so, prospective parents should be free to obtain and act on information about a prospective child's health and make-up in deciding whether or not to reproduce». J. Robertson, *Procreative Liberty in the Era of Genomics*, in *American Journal of Law and Medicine*, 29, 2003, pp. 439-480.

[62] See Y. Dernier, *Need or Desire?*, in *International Journal of Applied Philosophy*, 20, 2006, pp. 81-95.

[63] See K. Steel, *The Road that I See: Implications of New Reproductive Technologies*, in *Cambridge Quarterly of Healthcare Ethics*, 4, 1995, pp. 351-354. Also, Royal College of Obstetricians and Gynecologists, *Termination of Pregnancy for Fetal Abnormality in England, Scotland and Wales*, London (05/2010), https://www.rcog.org.uk/globalassets/documents/guidelines/terminationpregnancyreport18may2010.pdf (last visited 27/07/2016).

[64] See a recent study that shows the difference between transferring an embryo that is potentially Tay-Sach carrier and an embryo with potential to be a BRCA-1 carrier. It argues that transferring an embryo possibly affected by an immediately fatal condition is different than an embryo that carries a threat of a medical condition that manifests later on in life, that it would never be in the future child's interest to be born like that and that the transfer of known affected embryos should be prohibited. See I. Insogna, E. Ginsburg, *Transferring Embryos with Indeterminate PGD Results: the Ethical Implications*, in *Fertility Research and Practice*, 2, 2016, https://fertilityresearchandpractice.biomedcentral.com/articles/10.1186/s40738-016-0014-9 (last visited 07/10/2016).

In another study, authors have called upon the liberal eugenic challenge to opponents of disability screening in order to argue that the coercive interference by the state to restrict parental access to embryo selection

Critics might immediately object the use of PGD arguing that this would be the first step in a slippery slope towards some kind of new (liberal) eugenics' –or neoeugenics- trend to create designer babies.65

We are fully aware that the twentieth century witnessed tremendous racist and discriminatory policies across the globe, some examples worth remembering are the heinous experiments on live human beings made, for instance, by the Japanese during the Second World War in order to increase scientific knowledge to improve bacteriological weapons; or, the compulsory sterilization practices that took place in the United States as well as Scandinavian countries well into the 1970's decade.66

Certainly PGD, as previously stated, does not encourage medical rampant persecutions similar to those that took place during the classical period of eugenics, i.e. discriminatory programs coercively applied by the state. PGD is not used to limit reproductive freedom, seeking to propose a genetic determinism subject to racial, ethnic, religious or social prejudice, nor is based on simplistic notions of inheritance of traits and behaviors. On the contrary, its primary medical objective is to repair genetic deficiencies that afflict our species, but individually, without further constraints, based on solidarity and voluntarism.67

Most parents pursue this procedure to prevent their progeny from suffering according to their position of what constitutes their child's best interest and, of course, to safeguard human kind, demonstrating that embryo selection is not based on genetic or social prejudices, but on the presence of certain genetic qualities that are transmissibly harmful and incurable for the individual as well as for the humanity as a whole.

---

technologies could be proved by the harm done, *i.e.* reduced diversity. They do however make a distinction between selection against severe conditions –*i.e.* Down Syndrome or Tay-Sachs- and selection against mild conditions –*i.e.* dyslexia or Asparger's syndrome. See C. GYNGELL, T. DOUGLAS, *Selecting Against Disability: the Liberal Eugenic Challenge and the Argument from Cognitive Diversity*, in *Journal of Applied Philosophy*, doi: 10.1111/japat12199, 02/2016.

[65] J. DANIS, *Sexism and the Superfluous Female: Arguments for Regulating Preimplantation Sex Selection*, in *Harvard Women's Law Journal*, 18, 1995, p. 219.

[66] Regarding the medical experiments conducted by the Japanese doctors of the infamous 731 Biological Warfare Unit, see Y.-F. CHEN, *Japanese Death Factories and the American cover-up*, in *Cambridge Quarterly of Healthcare Ethics*, 6, 1997, pp. 240-242; S. HARRIS, *Factories of Death. Japanese Biological Warfare 1932-1945 and the American cover-up,* New York, 1995.

In respect to the first forced sterilizations of human beings in Europe as well as the United States, see G. BROBERG, N. ROLL-HANSEN*, Eugenics and the Welfare State: Sterilization Policy in Denmark, Sweden, Norway, and Finland,* Michigan, 2005; P. COLLA, *Per la Nazione e per la Razza,* Roma, 2000; L. DOTTI, *L'Utopia Eugenetica del Welfare State Svedese* (1934-1975). *Il Programma Socialdemocratico di Sterilizzazione, Aborto e Castrazione,* Soveria Mannelli, 2004.

[67] The Argentine civil and commercial code, in article 39, prohibits any practice intended to alter the genetic makeup of the offspring, except those that tend to prevent genetic diseases or predisposition to them. This standard would be sponsoring what the German philosopher, Jürgen Habermas, has criticized as liberal eugenics from the practice of PGD. This technique would be useful to transfer the fittest embryo to the woman's uterus, *i.e.* one who has been *cleaned up* of eventual genetic abnormalities, reducing or eradicating the individual trauma of abortion for any couple in general and for women in particular, as well as the pain and suffering that means living with certain physical and / or mental or the knowledge that we will die for a condition that cannot be treated. In other words, this *new eugenics*, as the author calls it, does not involve coercion, but respect for autonomy, freedom and informed decision for the wellbeing of any individual. See *El Futuro de la Naturaleza Humana: ¿Hacia una Eugenesia Liberal?,* Barcelona, 2002.

Eugenic practices are not reprehensible when they respect the autonomy and freedom of the individual. In this sense, no moral principle seems to provide sufficient reason to condemn individual eugenic purposes. The possibility to free ourselves from the scourges of natural selection by using medicine does not differ from the parental decision to teach his/her progeny certain religious values, or to enroll his/her offspring to practice a particular sport, or even to study foreign languages. If there is no external coercion or force, but individual decision, then it would become difficult to argue that the use of genetic knowledge to clean up health of future generations would prove to be a discriminatory practice based on social, racial or genetic aspects.68

The advance of applied science, however, allows us to agree that there is an obligation that rests with each one of us to deal with health costs and expenses, mainly because of our lifestyles.69 In any liberal society, people are free to do and undo according to their own desires and conveniences, but the interest and collective welfare bind us to respond later for the damages derived from our actions. Many families around the world deal with the consequences of genetically transmitted diseases on their own just because they never questioned if they were carriers or not. If PGD is a compulsory test, covered by the health insurance, the number of children born under the clause of wrongful life would be limited to incidents caused by doctor's negligence and would not be a matter of wrongful destiny.70

This technique must be included and covered by basic health insurance, so as to limit the number of children born under the clause of wrongful life to incidents caused by doctor's negligence. Thus the right to be informed about the genetic evolution of the unborn child, in fact, would become a social duty.71

Our autonomy decreases when we unreasonably opt not to know. Freedom of choice and decision in the context of PGD includes both the option to discard the embryo or to favor the pregnancy. The question lies in understanding that reproductive freedom is autonomous and individual, and cannot be restricted in advance, but subjected to further liability.

---

[68] A. CAPLAN *et al.*, *What is Immoral about Eugenics?*, in *British Medical Journal*, 319, 11/1999, p. 2. Also, A. BUCHANAN *et al*, *From Chance to Choice: Genetics and Justice,* Cambridge, 2000, p. 100.

[69] There is a dilemma about whether society should pay for medical treatment to individuals who have, for example, contracted HIV because of their lifestyles, *i.e.* drug users who share needles, individuals who consciously have unprotected sex. See W. MILLER, S. ROLLNICK, *Motivational Interviewing: Preparing People to Change Addictive Behavior,* New York, 1991; M. SCHECHTER *et al*, *Behavioral Impact, Acceptability, and HIV Incidence among Homosexual Men with Access to Post Exposure Chemoprophylaxis for HIV*, in *Journal of Acquired Immune Deficiency Syndromes*, 35, 04/2004, pp. 519-25.

[70] The ECtHR's ruling in *Draon vs. France* provoked debates in the French society and worldwide regarding ethical issues such as: what is *wrongful birth* and *wrongful life* and does the acceptance of such claims recognizes a right not to be born. All the cases mentioned above are ethically controversial by suggesting that there is a *right not to be born* that is consistent with *the right to life*.

[71] The European Society of Human Reproduction and Embryology (ESHRE) holds a stand that physicians as collaborators of the parental project ought to refuse transfer of an embryo that may be affected by a condition that possesses a high risk of serious harm to the future child. They should only refuse to assist patients in their reproductive efforts if the quality of life of their future child is so low that it would have been better not to be born. See more in F. SHENFIELD *et al*, *Task Force on Ethics and Law 13: the Welfare of the Child in Medically Assisted Reproduction*, in *Human Reproduction*, 22, 2007, pp. 2585-88.

In this sense, it would be correct to hold parents responsible if they do not use the aforementioned technique, since knowing is always better than not knowing when assessing the benefits and risks involved in human reproduction.72

4. Closing arguments

At the scene of the new power that our species display through genetic medicine, a new unconditional moral precept emerges: never deny an existence of the right to life free of suffering and physical and/or mental decline, as it is the condition for each individual to act freely.

Our species have been changing their structure, becoming immunologically more resistant, adapting to the various spaces and conditions in which we are inserted. To sum up, we have been thwarting our vulnerability by boosting sanitary conditions, eating habits, as well as developing drugs and medicines that allow health conditions to be sanitized.

Through this path, we would consider or even acknowledge that our evolution cannot be haphazard matter. On the contrary, it should become a duty for which we should be responsible, since we have to contribute through scientific progress.

One way of counteracting possible anthropocentric threats to our very existence on this planet –such as, nuclear wars, molecular nanotechnology, germ line interventions- is taking control of evolution itself through applied science, seeking to thrive. In this sense, it is feasible to infer that the Jonas' heuristics of fear, based on the horror of an eventual infinite failure, in fact it has only favored the stagnation of our species. If we realized that human action can have positive and negative consequences, then we need to regulate and control the way in which we wish to continue our evolution.

PGD involves individual's decision to reproduce, allowing prospective parents to identify life-threatening conditions, disable diseases, and different genetic characteristics of their progeny. The debate, hence, should not be solely circumscribed on elucidating whether it should be morally con-

---

[72] Some years ago, the European Court of Human Rights found that Poland had violated article 3 (prohibition of inhuman and degrading treatment), because of refusal of access to PND to a Polish citizen. According to the court, this meant humiliation and mistreatment of pregnant women, since it prevented them from taking a decision on the interruption of the pregnancy (due to the fact that the unborn child was suffering from Turner syndrome). In addition, the European Court found the doctors and the state responsible for not establishing a legal and procedural framework to protect the right to respect for private and family life of women (article 8). Finally, the court indicated that the «Member States are obliged to organize their hospitals to ensure the effective exercise of freedom of conscience of medical professionals in a context that does not prevent people access legal health services, as the decision to abort a fetus before presenting a malformation.» R. R. v. Polonia, European Court of Human Rights, no. 27617/04 (26/05/2011).

This case, all in all, dealt with the consequences that follow after involuntarily giving birth to a child with severe abnormalities that constitute a form of inhuman and degrading treatment and are against one's freedom to plan a family. If we defocus from the abortion debate, we will arrive to a point that clearly depicts the hardships for caring and being cared as a child with severe disorders, again calling into question the *wrongful life* claim. It is also questionable if doctors should conduct and give pre-genetic results only if the patients ask for them or is it their duty to inform the patient of possible health threats that the fetus may carry. It is completely another issue if despite the negative test results, the mother refuses to abort and if the child's health, and consequently life should depend on the mother's consent to give birth or not, again raising questions about *the right to life* against the *right not to be born* in the first place.

demned or not. Instead, the state of the art demands urgent, uniform regulation that could transcend domestic traditions, as well as religious and moral perspectives.

The need to regulate may be a mere intention if we do not accept that the issue at stake exceeds national borders. The action, then, must be global, establishing at international level a common ground that will facilitate prospective parents' unlimited exercise of their freedom of choice by accessing to the test, except when its scope is solely centered on identifying (and exterminating) traits irrelevant to health's concerns.

Despite the fact that there is an the absence of a concise and clear normative framework, a series of principles and liberties have been identified by both regional judicial organs in order to pave the way towards performing genetic tests in a petri dish.

In this sense, a total ban would be senseless, because it would not eradicate reproductive tourism. On the contrary, it is quintessential to enforce comprehensive rules, prone to defend human biodiversity by preventing the transmission of certain genes that medically have been reputed as incapacitating and deleterious, as well as to respect individual's reproductive liberty and autonomy.