# When parents look for a "better" child (reproductive choices and genetic planning)

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ABSTRACT: The focus of this paper is on the selection of apparently neutral characteristics, refused in several jurisdictions, namely in Europe. The reasons for such refusals are considered in this paper. However, arguments such as the difficulty in distinguishing apparently neutral features from others that are health-related, the recognition that some features are not so neutral after all, and the discredit of genetic determinism are counterarguments that may lead to a different assessment of non-health related reproductive decisions. The premise of this paper is that the prohibition of parental reproductive choices for selecting non-health related features should be reassessed due to the fragility of the arguments invoked against them.

KEYWORDS: Enhancement; genetic determinism; offspring selection; reproductive decisions; reproductive rights

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# 1. Introduction

f science continues to develop, it is possible that reproductive techniques and genetic technologies will provide parents the possibility to select almost all genetic characteristics of their children. The paper will use the concept of "genetic selection" to refer to all medical and scientific procedures that allow to determine offspring features. The concept includes preimplantation genetic diagnosis (PGD), but also genetic modification (gene editing), which is also a form of selection, since by modifying the genetic code of their embryo/foetus parents can select the traits of the future child.<sup>1</sup> That same aim can be achieved – eventually less successfully - using other procedures, such as

<sup>&</sup>lt;sup>1</sup> Recognizing that despite the difference between genetic selection (the authors are referring to preimplantation genetic diagnosis) and genetic modification both proceedings have the same aim, A.L. v. HAMMERSTEIN, A.L., M. EGGEL, N. BILLER-ANDORNO, *Is Selecting Better Than Modifying? An Investigation of Arguments Against Germline Gene Editing as Compared to Preimplantation Genetic Diagnosis,* in *BMC Med Ethics,* 20, 2019.



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the selection of gamete donors<sup>2</sup> or abortion,<sup>3</sup> which will also be considered under the concept of "genetic selection".

The range of choices might cover not only features with direct therapeutic implications, but also non health-related features, such as the QI, and even apparently neutral features, such as the eye colour. Currently most of these parental choices are not scientifically possible, but eventually they will become possible in the (near?) future, imposing the debate on these matters. Curiously, some forms of genetic selection that might seem too futuristic are in fact about to become reality. For instance, the scientific community already knows that when the CCR5 gene is deactivated (as it happened in the infamous experiment carried out by He Jiankui with the Chinese twins Lulu and Nana)<sup>4</sup> it can lead to increase learning ability.<sup>5</sup>

This paper will only deal with parents' choices to select features of their children that do not relate – at least, not directly – with health, hereafter defined as Non-Health Related Reproductive Decisions (NHRRD). Mainstream scholars<sup>6</sup> argue that parents should be allowed to select features related with the health of their progeny (for instance, abort a foetus with a severe malformation or select a certain gender for their child to avoid a disease associated to the opposite gender), but not to select other kind of features. Lawmakers around the world tend to follow this solution. The paper will focus its analysis on European countries, but references to other jurisdictions will also be made (part 2).

The paper will start by analysing the arguments commonly invoked against NHRRD, namely eugenics, the loss of genetic diversity, genetic discrimination, the commodification of the child in a way that he/she becomes an object of the parent's wishes, limitations on the child's free development (right to an open future), and the supremacy of elements coined by nature over man-made elements. As the paper will demonstrate, none of these arguments have real substance (part 3).

Encouraged by the failure of classic arguments, some authors (the position of John Robertson is paradigmatic in this regard)<sup>7</sup> have suggested that NHRRD are not undermined by these arguments,



<sup>&</sup>lt;sup>2</sup> For instance, see M.J. MCGINNISS, M.A. MCGINNISS, *Carrier Screening and Heterozygote Testing*, in R.E. PYERITZ, B.R. KORF, W.W. GRODY (eds.), *Emery and Rimoin's Principles and Practice of Medical Genetics and Genomics*, 7th edition, San Diego, 2018, 283-298, describing gamete donation as a form of selection against certain diseases.

<sup>&</sup>lt;sup>3</sup> Referring the similarity of aims between abortion and PGD see C. CAMERON, R. WILLIAMSON, Is *There an Ethical Difference Between Preimplantation Genetic Diagnosis and Abortion?*, in *J Med Ethics*, 29, 2, 2003, 90-92.

<sup>&</sup>lt;sup>4</sup> About this incident see V.L. RAPOSO, The First Chinese Edited Babies: A Leap of Faith in Science, in *JBRA Assisted Reproduction*, 23, 2019, 3 197-199.

<sup>&</sup>lt;sup>5</sup> There is a wide range of literature about this. See, for instance, D. Cyranoski, *Baby Gene Edits Could Affect a Range of Traits*, in *Nature*, 2018; M.T. JOY, E.B. ASSAYAG, D. SHABASHOV-STONE et al., *CCR5 Is a Therapeutic Target for Recovery after Stroke and Traumatic Brain Injury*, in *Cell*, 176, 5, 2019, 1143-1157; M. Zhou, S. Greenhill, S. Huang et al., *CCR5 is a Suppressor for Cortical Plasticity and Hippocampal Learning and Memory*, in *eLife*, 2016.

<sup>&</sup>lt;sup>6</sup> L.B. ANDREWS, N. ELSTER, *Regulating Reproductive Technologies*, in *Journal of Legal Medicine*, 21, 1, 2000, 35-65; L.M. SILVER, *Remaking Eden. How Genetic Engineering and Cloning Will Transform the American Family*, New York, 1998; S.M. SUTER, *A Brave New World of Designer Babies?*, in *Berkeley Technology Law Journal*, 22, 2007, 897-960; S.M SUTER, *The Tyranny of Choice: Reproductive Selection in the Future*, in *Journal of Law and the Biosciences*, 5, 2, 2018, 262-300.

<sup>&</sup>lt;sup>7</sup> J. ROBERTSON, *Children of Choice: Freedom and the New Reproductive Technologies*, Princeton, N.J., 1994; J. ROBERTSON, *Genetic Selection of Offspring Characteristics*, in *Boston University Law Review*, 76, 1996, 421-482; J. ROBERTSON, *Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses*, in *BMJ: Journal of Medical Ethics*, 29, 2003, 213-216.

arguing that parental decisions are supported by the figure of reproductive rights. The paper will argue that reproductive rights do not include NHRRD, but merely include in their scope parental reproductive decisions related to the health of progeny. Based on this assumption, the paper will conclude that to select features related to health is a choice grounded on reproductive rights, but all other types of reproductive parental choices cannot find proper legal and ethical ground in the norms granting reproductive rights (part 4).

However, this conclusion does not close the discussion. This would equate to sustain that conducts are generally prohibited unless they count with arguments in favour, when in fact it is the opposite: conducts are generally allowed unless there are sound arguments leading to prohibition. Even though NHRRD cannot find proper justification in reproductive rights, there are no sound arguments against NHRRD that justify their legal prohibition. Furthermore, the prohibition is very difficult to enforce because it faces two major difficulties. First, it assumes that there is a clear distinction between features related to health and all the remaining ones, which is not the case. Secondly, it assumes that characteristics not related to the health of the prospective child are irrelevant for his/her life, nothing more than parental whims or caprices, when in fact some of them can be as decisive as health-related features (part 5).

This paper argues that the traditional generalized ban on NHRRD should be reassessed and that some forms of NHRRD should be allowed, depending on the specific medical/scientific mechanisms used and the specific traits being selected (part 6).

# 2. Parental reproductive choices in light of the existing regulations

Parental reproductive choices and genetic planning are not allowed without limitations, which vary from jurisdiction to jurisdiction.

In what regards abortion, most jurisdictions in the world accept it when the aim is to prevent the birth of child with a severe disease or disability (though eventually conditioned by a temporal requisite).<sup>8</sup> In contrast, abortion based on non-health related characteristics of the child is generally banned.<sup>9</sup> In particular, abortion based on race/ethnicity<sup>10</sup> or gender<sup>11</sup> violates anti-discrimination laws. This trend might also be extended (under the same accusation of discrimination) to genetic abnormalities,<sup>12</sup> a classic justification for lawful abortion, that continues to be generally accepted in almost all

See also <u>https://maps.reproductiverights.org/worldabortionlaws</u> (last visited 02/07/2020).

<sup>&</sup>lt;sup>11</sup> S. ANITHA and A.K. GILL, *Making Politics Visible: Discourses on Gender and Race in the Problematisation of Sex-Selective Abortion*, in *Feminist Review*, 120, 1, 2018, 1-19; E. GREEN, *op. cit.*; E. LEE, *Constructing Abortion as a Social Problem: 'Sex Selection' and the British Abortion Debate*, in *Feminism & Psychology*, 27, 1, 2017, 15-33. <sup>12</sup> E. GREEN, *op. cit.* 



<sup>&</sup>lt;sup>8</sup> A. GUILLAUME, C. Rossier, L'avortement dans le Monde. État des Lieux des Législations, Mesures, Tendances et Consequences, in Population, 73, 2, 2018, 217-306.

<sup>&</sup>lt;sup>9</sup> Note that the so-called abortion on request – abortion based on the sole request of the woman, without specifying the motivation, usually within a legally established time frame – might lead to that result, since the desire to avoid a certain feature of the child might be the woman's real motivation.

<sup>&</sup>lt;sup>10</sup> E. GREEN, Should Women Be Able to Abort a Fetus Just Because It's Female?, in The Atlantic, May 16, 2016, at <u>https://www.theatlantic.com/politics/archive/2016/05/sex-disability-race-selective-abortion-indiana/482856/</u> (last visited 06/06/2020).

jurisdictions of the EU<sup>13</sup> (except for Malta, that bans abortion in every circumstance).<sup>14</sup> However, since the parent's motivation is usually not disclosed, there is no chance to prevent it.

The same limit is present in reproductive techniques and associated procedures. PGD is a common mechanism for parents to exercise their reproductive choices, but in Europe those choices tend to be restricted to health-related characteristics.<sup>15</sup> The same is valid for gamete donation. The users of reproductive techniques can request the gametes of third parties (the donors) if the prospective parents are unable to procreate (infertility, reproduction by a single woman, gay couples) or if there is the risk of transmitting a serious medical condition to offspring.<sup>16</sup> However, prospective parents cannot resort to gamete selection to have a child with specific desired features. The selection of a donor having as criterion his/her facial traits, IQ or sports talent is banned in Europe. The only feature in which parents have a word to say regards phenotypic traits aimed to emulate the parents' phenotype and to create the fiction of a genetically based family. Even though parents cannot directly select children that look like them, some laws and/or medical guidelines demand the selection of donors that share their same phenotype, namely their ethnic group.<sup>17</sup> In Europe, this restriction is based on basilar principles coming from the Convention on Human Rights and Biomedicine.<sup>18</sup> Article 14 very clearly states: "The use of techniques of medically assisted procreation shall not be allowed for the purpose of choosing a future child's sex, except where serious hereditary sex-related disease is to be avoided". Gene editing is not yet a common practice for parents to exercise their reproductive choices, even though it might become so in the future. The general trend in European laws is to allow genetic interventions aimed to cure or prevent diseases as long as their effects are restricted to the person himself/herself. Genetic ameliorations not related to health are forbidden. The Convention on Human Rights and Biomedicine also follows this solution.<sup>19</sup> According to its Article 13: "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". In conclusion, in Europe (the same is valid for several other jurisdictions around the world, the US being an exception in some ways) parental reproductive choices and genetic planning are accepted (rectius,



<sup>&</sup>lt;sup>13</sup> ASSOCIAZIONE LUCA COSCIONI PER LA LIBERTÀ DI RICERCA SCIENTIFICA, *Interruzione volontaria di gravidanza nei Paesi dell'Unione Europea*, 2018, at <u>https://www.associazionelucacoscioni.it/wp-content/uploads/2016/09/IVG-nellUnione-Europea-1.pdf</u> (last visited 04/08/2020).

<sup>&</sup>lt;sup>14</sup> M. WEBB, A Year Later, and Abortion Is Not Yet Legal in Malta, in Dalli, Newsbook, June 26 2019, at https://www.newsbook.com.mt/artikli/2019/06/26/a-year-later-and-abortion-is-not-yet-legal-in-malta-dalli/?lang=en (last visited 20/05/2020).

<sup>&</sup>lt;sup>15</sup> M.J. BAYEFSKY, Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and its Implications for Reproductive Tourism, in Reproductive Biomedicine & Society Online, 3, 2016, 41-47; T. LEMKE, J. RÜPPEL, Social Dimensions of Preimplantation Genetic Diagnosis: A Literature Review, in New Genetics and Society, 38, 1, 2019, 83-84.

<sup>&</sup>lt;sup>16</sup> M. RICHARDS, G. PENNINGS, J.B. APPLEBY (eds), *Reproductive Donation: Practice, Policy, and Bioethics*, Cambridge, UK, 2012.

<sup>&</sup>lt;sup>17</sup> In detail about this issue see V.L. RAPOSO, Wrongful Genetic Connection: Neither Blood of My Blood, nor Flesh of My Flesh, in Med Health Care and Philos, 23, 2019, 318.

<sup>&</sup>lt;sup>18</sup> 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 (4 April 1997).

<sup>&</sup>lt;sup>19</sup> F. BAYLIS, L. IKEMOTO, *The Council of Europe and the Prohibition on Human Germline Genome Editing*, in *EMBO Rep*, 18, 2017, 2084-2085.



generally accepted, since even in this regard there are some exceptions) when they involve healthrelated features but banned in the remaining cases.

# 3. Classic arguments against NHRRD

The classic arguments to ban NHRRD can be summarized as such: eugenics, loss of genetic diversity, genetic discrimination, degradation of the child to become an object of a parent's wishes, limitations on the child's free development and replacement of the natural order of things by an artificial human order. This section will demonstrate there is not a sound argument to forbid NHRRD.<sup>20</sup>

# 3.1. Eugenics

Eugenics is probably the most invoked arguments against NHRRD, based on the assimilation between the latter and some atrocities that happened in the past.<sup>21</sup> The qualification of NHRRD as eugenics depends on the definition of this practice. In a broad sense NHRRD can be considered a form of eugenics because they do intent to select "better" features for prospective human beings.

However, what exact features are considered "better" is open to discussion. In the type of eugenics (assuming it is indeed eugenics, a kind of new eugenics,<sup>22</sup> also called liberal eugenics)<sup>23</sup> we have nowadays, features are picked by parents according to their subjective preferences, so, they might or might not be objectively an enhancement. Parents personal preferences do not necessarily lead to the amelioration of offspring, even though those particular parents consider it to be an amelioration.<sup>24</sup> For instance, some parents might prefer a child with blue eyes, but this eye colour is not necessarily praised as more valuable by the remaining community. Eventually, a genetic selection that parents consider



<sup>&</sup>lt;sup>20</sup> For a critic to these arguments, F. ALLHOFF, *Germ-Line Genetic Enhancement and Rawlsian Primary Goods,* in *Kennedy Institute of Ethics Journal*, 15, 1, 2005, 39-56; G. BOGNAR, *Enhancement and Equality*, in *Ethical Perspectives*, 19, 1, 2012, 11-32; C. GYNGELL, T. DOUGLAS, J. SAVULESCU, *The Ethics of Germline Gene Editing*, in *Journal of Applied Philosophy*, 34, 4, 2017, 498-513; D.B. RESNIK, D.B. VORHAUS, *Genetic Modification and Genetic Determinism*, in *Philosophy, Ethics, and Humanities in Medicine*, Article ID 9, 2006.

<sup>&</sup>lt;sup>21</sup> L. KASS, *Life, Liberty and the Defense of Dignity*, San Francisco, 2002; M.J. SANDEL, *The Case Against Perfection*, in *The Atlantic*, April 2004, at <u>https://www.theatlantic.com/magazine/archive/2004/04/the-case-against-perfection/302927/</u> (last visited 06/06/2020); S.M. SUTER, *A Brave New World*, cit.; S.M. SUTER, *The Tyranny of Choice*, cit.

<sup>&</sup>lt;sup>22</sup> J. DAAR, *The New Eugenics: Selective Breeding in an Era of Reproductive Technologies*, New Haven, Connecticut, 2017; M.J. SELGELID, *Moderate Eugenics and Human Enhancement*, in *Medicine, Health Care, and Philosophy*, 17, 1, 2014, 6-8.

<sup>&</sup>lt;sup>23</sup> In favour of liberal eugenics, for instance, E. FENTON, *Liberal Eugenics and Human Nature. Against Habermas*, in *Hastings Cent Rep*, 36, 6, 2006, 35-42; D. Fox, *The Illiberality of 'Liberal Eugenics'*, in *Ratio*, 20, 2007, at https://papers.ssrn.com/sol3/papers.cfm?abstract\_id=1072104 (last visited 03/04/2020).

These concepts – private eugenics or liberal eugenics – should not be confused with the new eugenics referred by Judith Daar in one of her latest books (J. DAAR, *The New Eugenics, cit.*) to refer the denial of reproductive technologies to some population strata, such as racial minorities, persons with disabilities, gay unions, and single people.

<sup>&</sup>lt;sup>24</sup> S.M. SUTER (*A Brave New World*, cit., 934 ff.) seems to consider that all non-health-related features are directed to enhancement, but this is not exactly so, or at least not all of them aim an objective enhancement, i.e., some features might be considered by parents as an amelioration but by other people as a neutral feature.

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an improvement for the child might even be in objective terms a harm,<sup>25</sup> as it happens when parents deliberately select a deft child.<sup>26</sup>

Even if we agree that both of them are eugenics practices, current private eugenics is totally different from past public eugenics in their ethical/philosophical base, their *modus operandi* and their goals.<sup>27</sup> The experiences we had in the past – whose apogee was the Nazism – were based on the assumption that some human beings had higher value than the others and thus that these others should be eliminated in the name of racial purity.<sup>28</sup> Based on this experience of dehumanization of human beings<sup>29</sup> the concept was demonised.

In contrast, the kind of eugenics we have today is not related with the intention of purifying or improving humankind, but merely with parental decisions on what they believe to be better for their children.<sup>30</sup> Even if NHRRD are considered eugenics, it must be recognised that this is a totally different kind of eugenics and that the (very powerful) arguments against traditional eugenics are ungrounded regarding NHRRD. There are four main difference between NHRRD and traditional eugenics i) While traditional eugenics was guided (*rectius*, imposed) by the State, NHRRD consist in purely private decisions; ii) The motivations of NHRRD are very different from the motivations of traditional public eugenics, as its aims is to satisfy parents' wishes and their vision of what is best for the child; iii) Within NHRRD the target is a particular child while in traditional eugenics the target was the humankind in general; iv) Moreover, the features desired for humankind probably do not coincide with the ones that parents envisage for their children, since parents take their reproductive and genetic decisions based on personal and very subjective assessments, which do not always lead to the objective amelioration of the child.

<sup>&</sup>lt;sup>25</sup> About these cases see V.L. RAPOSO, *The Usual Suspects: Can Parents Be Held Accountable for Their Reproductive And Genetic Decisions*?, in *Revista de Derecho y Genoma Humano: Genética, Biotecnología y Medicina Avanzada/Law and the Human Genome Review: Genetics, Biotechnology and Advanced Medicine,* 47, 2017, 109-137.

<sup>&</sup>lt;sup>26</sup> M. SPRIGGS, *Lesbian Couple Create a Child Who Is Deaf Like Them*, in *Journal of Medical Ethics*, 28, 2002, 283. Regardless of the controversy about the qualification of deafness as a disability (which will not be developed in this paper), this preference was grounded on their subjective personal conditions, not on an objective positive assessment of deafness.

<sup>&</sup>lt;sup>27</sup> The difference between traditional public eugenics and private eugenics in G. CAVALIERE, *Looking into the Shadow: The Eugenics Argument in Debates on Reproductive Technologies and Practices,* in *Monash Bioethics Review,* 36, 1-4, 2018a, 1–22; T. DOUGLAS, K. DEVOLDER, *Procreative Altruism: Beyond Individualism in Reproductive Selection,* in *The Journal of Medicine and Philosophy,* 38, 4, 2013, 400–419; V.L. RAPOSO, *Gene Editing, the Mystic Threat to Human Dignity,* in *Journal of Bioethical Inquiry,* 16, 2, 2019, 249-257.

<sup>&</sup>lt;sup>28</sup> Nazism, and traditional eugenics in general, is much more complex that this brief description, which merely highlights its basic features. Further details in S. GRAUMAN, *Germline Gene Therapy: Public Opinions with Regard to Eugenics*, in E. Hildt, S. Graumann, (eds.), *Genetics in Human Reproduction*, Aldershot, 1999, 175; M. MALINOKWSI, *Choosing the Genetic Makeup of Children: Our Eugenics Past-Present, and Future,* in *Connecticut Law Review*, 36, 1, 2003, 134 ff.; S.M. SUTER, *A Brave New World*, cit., 901 ff.

<sup>&</sup>lt;sup>29</sup> Traditional public eugenics certainly was (S. BACHRUCH, *In the Name of Public Health - Nazi Racial Hygiene*, in *New England Journal of Medicine* 351.5, 2004, 417– 420; V. FINKELSTEIN, O. STUART, *Developing New Services*, in G. Hales (ed.), *Beyond Disability: Towards an Enabling Society*, London, 1996, 170-187.

<sup>&</sup>lt;sup>30</sup> In favour of liberal eugenics, for instance, E. FENTON, *op. cit*; D. FOX, *The Illiberality of 'Liberal Eugenics'*, cit.

# **3.2.** Loss of genetic diversity

One of the criticisms of NHRRD has been that human beings will all become the same, like products leaving an assembly line.<sup>31</sup> The argument claims that the loss of genetic diversity<sup>32</sup> and of "social heterosis"<sup>33</sup> will undermine the very survival of the human species. The existence of a plurality of genes makes humankind stronger to face challenges posed by virus, bacteria, and even climatic and environmental changes,<sup>34</sup> because it equips the human species with genetic resources to adapt to these events.

However, chances are that parents will not select the exact same characteristics for their offspring. Some may prefer children with blond hair, and others may prefer dark hair; some may prefer boys, and others may prefer girls. It is a fact that some features are more likely to be picked than others, taking into consideration what society considers to be beautiful or desirable. In a society that glorifies beauty, intelligence and physical power it can be assumed that these traits will be the most selected, provided science allows it. Nonetheless, the concept of beauty remains subjective, and so the choices will hardly coincide.

# 3.3. Genetic discrimination

The peril of discrimination has also been frequently invoked (genetic discrimination) against NHRRD.<sup>35</sup> The accusation of discrimination is based in two different (though related) arguments: i) money as a barrier to access NHRRD; ii) and the consequent prejudice against the ones that have not benefit from NHRRD.

The first argument states that NHRRD are discriminatory because only the ones with sufficient financial power can have the chance to decide the features of their offspring and consequently only their children can be improved (assuming that indeed these decisions will improve them) by NHRRD.<sup>36</sup> It will be money, and not merit or luck, to determinate the ones that have better chances in life. Let us take the case of intelligence: today there are few geniuses and thus they are praised; but in a genetically selected/modified society anyone whose parents can pay for fancy genetic techniques can become a genius, for the simple reason that they come from a wealthy family.

However, in many ways money already dictates one's fate. Parents with money can offer a better education to their children, provide better health care, give them various opportunities (universities, travels) and buy things that can make them look more attractive and eventually more socially accepted (fancy clothes, cosmetic interventions). So, the possession of wealth (or the lack of it) can indeed condition the possibilities open to someone. It can be said that all possibilities that depend on money

<sup>&</sup>lt;sup>36</sup> M.A. ROTHSTEIN, *Legal Conceptions of Equality in the Genomic Age,* in *Law & Inequality,* 25, 2007, 429-463.



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<sup>&</sup>lt;sup>31</sup> P. UNALKAT, Alubias, Genes y Temas, in C. Romeo Casabona (ed.), La Necesidad de la Precaución, in Biotecnología y Derecho: Perspectivas en Derecho Comparado, Bilbao-Granada, 1998, 399-404.

<sup>&</sup>lt;sup>32</sup> P.H. HUANG, *Herd Behavior in Designer Genes*, in *Wake Forest Law Review*, 34, 3, 1999, 645-653.

<sup>&</sup>lt;sup>33</sup> P. NONACS, K.M. KAPHEIM, Social Heterosis and the Maintenance of Genetic Diversity, in Journal of Evolutionary Biology, 20, 6, 2007, 2253-2265.

<sup>&</sup>lt;sup>34</sup> D.B. RESNIK, *Of Maize and Men: Reproductive Control and the Threat to Genetic Diversity*, in *Journal of Medicine and Philosophy*, 25, 4, 2000, 451-451.

<sup>&</sup>lt;sup>35</sup> R. RAO, *Equal liberty: Assisted Reproductive Technology and Reproductive Equality,* in *George Washington Law Review,* 78, 2008, 1467; S.M. SUTER, *A Brave New World,* cit., 940 ff., 954 ff.

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are to be repudiated and only possibilities conditioned by luck (that is, genetic lottery) should be accepted, but it remains to be seen why luck is better (more legitimate, fairer) than wealth.

From a different perspective, it has been stated that the referred inequalities should also be prevented,<sup>37</sup> so, they cannot serve as justification to other inequalities.<sup>38</sup> But if the aim is to combat inequality, why should we focus only on the ones based on money and the possibilities it can provide? What about the ones based on genetic dotation? The genotype and the phenotype of individuals is not all the same: some are healthy than others, some are more intelligent than others, some are more fit than others. Benefits based on money are not morally better than benefits based on luck. From this perspective, NHRRD could actually create some biologic equality among us.

The second argument is grounded on the previous one: since not everyone can beneficiate from NHRRD, the ones that are deprived of that possibility will be ostracised and thus this practice shall be forbidden. Taking again the example of intelligence, the children whose parents did not select a higher IQ will be considered less than the ones that were made "more intelligent". However, no matter how genetically homogeneous a society is, people with different features will always exist and they might be discriminated against.<sup>39</sup> The only way to avoid this outcome would be to create a society where everyone is exactly the same, but that scenario would certainly be criticized based on the argument of loss of genetic diversity.

#### 3.4. Objectification of children

The risk of a child being objectified has also been argued (child instrumentalization).<sup>40</sup> In the United States, it is common to find in newspapers advertisements looking for gamete donors (male or female) with certain desired characteristics, as "products" for sale.

A "tailor-made child", chosen like a supermarket product, with a certain hair or eye colour, must be rejected. However, the argument of objectification lies in a profoundly naïf conception of parenthood, according to which parents raise their children as a blank canvas. This is obviously not the case. Parents use several mechanisms (apart from the genes) to create the kind of chid they wish.<sup>41</sup> The principles they teach to their children, the school they pick, the option between piano lessons or swimming lessons, all these conditions the kind of person the child will be.<sup>42</sup>

<sup>&</sup>lt;sup>37</sup> M.J. SELGELID, *op. cit.*, 10-11. About State duties to combat inequalities see F. GARCÍA GIBSON, *Conflicts Between Domestic Inequality and Global Poverty: Lexicality Versus Proportionality*, in *Ethics & Global Politics*, 9,1, 2016.

<sup>&</sup>lt;sup>38</sup> E. WESLEY, F. PETERSON, *Is Economic Inequality Really a Problem? A Review of the Arguments*, in *Soc. Sci.*, 147, 2017.

<sup>&</sup>lt;sup>39</sup> H. LOU, *Eugenics Then and Now: Constitutional Limits on the Use of Reproductive Screening Technologies*, in *Hastings Constitutional Law Quarterly*, 42, 2015, 409 (arguing the diminution of tolerance against those who are different).

<sup>&</sup>lt;sup>40</sup> For criticism about the child's instrumentalisation, see D.W. JORDAAN, *Preimplantation Genetic Screening and Selection: An Ethical Analysis*, in *Biotechnology Law Report*, 22, 6, 2003, 589; S.M. SUTER, *A Brave New World*, cit., 960 ff.

<sup>&</sup>lt;sup>41</sup> Parents do so in compliance with the parental duties imposed by family law (cf. K. BOELE-WOELKI, F. FERRAND, C. GONZÁLEZ-BEILFUSS, M. JÄNTERÄ-JAREBORG, N. LOWE, D. MARTINY, W. PINTENS, *Principles of European Family Law Regarding Parental Responsibilities*, Antwerpen, 2007).

<sup>&</sup>lt;sup>42</sup> The analogy between environmental and social determinism and genetic determinism in N. AGAR, *Liberal Eugenics*, in H. KUHSE, P. SINGER (eds.), *Bioethics: An anthology*, Oxford, U.K., 1999, 172-173; A. BUCHANAN, D.W.

The fact that parents try to shape children according to their own wishes<sup>43</sup> (although usually having also in consideration the children's best interest) demonstrates that people do not have children for the child's sake, bur for their own sake. The goal that motivates reproduction is a very selfish one: to create a human being that parents can model in light of one ideal.<sup>44</sup> Parents are willing to fully accept their children and love them, but still they try to select a child with features they highly praise.<sup>45</sup>

It can be argued that the two types of conditioning - the environmental and the genetic - are very different and that they cannot be compared in their modus operandi, and above all in their consequences. Quoting Prusak, « [w]hereas environmental manipulations work on phenotype, prenatal genetic manipulations would work, of course, on genotype».<sup>46</sup> Based on this distinction, the author states that though children can overcome whatever expectations parents could have created when picking a specific upbringing, this is not possible regarding the expectations they created by means of NHRRD.<sup>47</sup> But if the discussion is based on parents' expectations (similar to Habermas' argument on intentions that will be exposed below), the fact is that such expectations exist in both cases. Some parents that send their child at a young age to music classes expect to raise a musician, and if they don't achieve that goal, they will be as disappointed as the ones that resorted to NHRRD. Moreover, Prusack's statement that environmental conditioning only affects the phenotype, and for that reason this type of conditioning does not raise problems, might lead to the impression that phenotypes are less decisive than genotypes, which is not accurate.<sup>48</sup> The phenotype can dictate characteristics easily perceived by the community to praise or repudiate, and therefore dictate our chances in that community. Moreover, environmental conditioning can shape features to be passed to the offspring (skin tone, eye colour)<sup>49</sup> and therefore condition an entire lineage.

# 3.5. Violation of the child's right to an open future

It has been said that the NHRRD imposes on the child a certain destiny, that the child cannot modify, and thus he/she is forced to live the life that parents picked for him/her. Due to limitations on his/her



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BROCK, N. DANIELS et al., From Chance to Choice: Genetics and Justice, Cambridge, 2000, 160-161; J. ROBERTSON, Children of Choice, cit., 167.

<sup>&</sup>lt;sup>43</sup> See D. BENATAR, D. WASSERMAN, *Debating Procreation: Is It Wrong to Reproduce?*, New York, 2015, 183.

<sup>&</sup>lt;sup>44</sup> V.L. RAPOSO, O Direito à Imortalidade (O Exercício de Direitos Reprodutivos Mediante Técnicas de Reprodução Assistida e o Estatuto Jurídico do Embrião In Vitro, Coimbra, 2014, 250, 351.

<sup>&</sup>lt;sup>45</sup> J. MALEK, Use or Refuse Reproductive Genetic Technologies: Which Would a 'Good Parent' Do?, in Bioethics, 27, 2, 2013, 63-64.

 <sup>&</sup>lt;sup>46</sup> B.G. PRUSAK, *Rethinking 'Liberal Eugenics': Reflections and Questions on Habermas on Bioethics*, in *Hastings Cent Rep*, 35, 6, 2005, 38. In the same sense, J. HABERMAS, *The Future of Human Nature*, Cambridge, 2003, 61.
<sup>47</sup> B.G: PRUSAK, *op. cit.*, 38. In the same sense, J. HABERMAS, *op. cit.*, 61.

<sup>&</sup>lt;sup>48</sup> The differences between the two in P. TAYLOR, R. LEWONTIN, *The Genotype/Phenotype Distinction*, in Edward N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy* (Summer 2017 Edition), <u>https://plato.stanford.edu/archives/sum2017/entries/genotype-phenotype/</u> (last visited 05/06/2020).

<sup>&</sup>lt;sup>49</sup> R.A. STURM, D.L. DUFFY, *Human Pigmentation Genes Under Environmental Selection*, in *Genome Biology*, 13, 9, 2012.

ecial is

free development, the child could never be the master of his/her own destiny. The conclusion would be that NHRRD violate the child's right to an open future<sup>50</sup>.

Habermas, for instance, argues that a person whose genes have been selected by third parties (assumingly, the parents) will never feel himself/herself genuinely free, as the true author of his/her life<sup>51</sup>. Or, using Sandel's words: "children are free to choose their characteristics for themselves. But none of us chooses his genetic inheritance. The alternative to a cloned or genetically enhanced child is not one whose future is unbound by particular talents but one at the mercy of the genetic lottery".<sup>52</sup> However, both arguments (this one and the previous) rely on a premise that science proved to be wrong: genetic determinism, that is, the idea that genes would rigidly determine all our traits, without any possibility for surprise or divergence.

As Resnik and Vorhaus<sup>53</sup> very accurately demonstrated, genetic determinism is totally misleading. The success of any selection varies according to environmental influences. For instance, if parents select a physical trait, such as hair, skin or eye colour, they have more control over the result because these features are exclusively determined by genes, even though they are epistatic, (i.e., they do not depend on a single gene) and therefore difficult to "control". Alternatively, if parents look for an embryo with a higher level of intelligence, they can never be sure the child will effectively be more intelligent because environment (education, experience) is as decisive, or even more influential, than genetics, turning intelligence into a complex trait. Furthermore, epigenesis (the development of an embryo, starting from the single cell stage) plays a decisive role in the way genes express themselves; therefore, two people with the same exact genetic dotation (twins, clones) can become very different due to environmental influences and the individual development of the organism. Even though they share the exact same genotype, their features, their preferences and their skills might be completely different.<sup>54</sup>

If this is so, genetic selection does not turn children into parental "projects" whose fate is already determined. Parents cannot expect more from a baby with a "musical gene" than from a toddler who attended a couple of music classes. In both cases parents have simply provided the child with some tools for musical talent, but the final result is absolutely unpredictable.<sup>55</sup> Simultaneously, the child is not condemned to be a Mozart. The child might turn out to be a football player or an avid reader, without any particular musical talent. A natural (or, in this case, not that natural) gift for a certain

<sup>&</sup>lt;sup>50</sup> J. FEINBERG, *The Child's Right to An Open Future*, in W. Aiken, H. LaFollette (eds.), *Whose Child?*, Totowa, NJ, 1980, 124-153. This argument is further developed by D. DAVIS, *Genetic Dilemmas and the Child's Right to an Open Future*, in *Rutgers Law Journal*, 28, 2, 1997, 549-592.

<sup>&</sup>lt;sup>51</sup> J. HABERMAS, op. cit., 25

<sup>&</sup>lt;sup>52</sup> M.J. SANDEL, op. cit.

<sup>&</sup>lt;sup>53</sup> D.B. RESNIK, VORHAUS, op. cit.

<sup>&</sup>lt;sup>54</sup> R. PLOMIN, N.G. SHAKESHAFT, A. MCMILLAN et al., *Nature, Nurture, and Expertise*, in *Intelligence*, 45, 2014, 46-59. <sup>55</sup> For more on the excessive pressure on parents over these children and the consequential failure of expectations, see L.A. VACCO, *Preimplantation Genetic Diagnosis: From Preventing Genetic Disease to Customizing Children. Can the Technology Be Regulated Based on the Parents' Intent?, in Saint Louis University Law Journal, 49, 2005, 1195-1196.* 

activity does not dictate one's future, nor even one's ability to perform that activity, unless it has been properly nurtured and developed.<sup>56</sup>

Furthermore, even disregarding the possibility to decide the genetic code of their offspring, parents have many ways to define the child's life, by living in a certain place (a big city or a small rural village), selecting a certain school, and especially by the kind of education and values they transmit in their upbringing.<sup>57</sup> NHRRD are merely a mechanism, and by far not the most decisive, to shape the child's future.

Habermas tries to destroy the argument of genetic determinism by resorting to the underlying intention: it does not matter if genes can actually condition our life, but only the intention underlying the selection of those genes.<sup>58</sup> Transposing this reasoning to our questions: it is irrelevant how effective NHRRD can actually be, what is relevant is the purpose parents had in mind in their NHRRD. However, this argument if confusing. It is not clear what Habermas means by "intention". The logical answer is the parent's purpose, but when explaining the argument the author states that: "[t]he person concerned knows that the manipulation has been carried out with the sole intention of acting on the phenotype…". Therefore, one must wonder to which intention is Habermas referring to: the parents' real intention or what the children believe was the parents' intention? Whatever the answer ends up being, there is still a shortcoming in this argument. For it to be correct, it would have to be demonstrated that when educating their children parents do not desire to actually shape the child (or children would have to believe that parents do not actually desire that), while in NHRRD they effectively want to do so (or children believe they effectively want to do so). This is an assumption still waiting to be confirmed. Moreover, it is ambiguous (to say the least) to ground an argument on intentions or on what other believe those intentions to be.

#### 3.6. The artificial over the natural

Let's assume, for the sake of the argument, that genetic determinism is correct. If that is the case, then, NHRRD would be as much a violation of the child's right to an open future as (coital) reproduction itself. The mere fact that parents (involuntary) pass their genes to offspring conditions the child life: if parents have a propensity to be fat probably the child will also have it,<sup>59</sup> what might prevent him/her from being a sport star or a model; if parents have Attention Deficit Hyperactivity Disorder children have 50% chances of inheriting it,<sup>60</sup> which will obviously have a huge impact on the child's life and on his/her future as an adult. So, in a way, parents always condition the kind of life and possibilities their children will have. The difference is that this conditioning is considered natural, and therefore good, while the conditioning carried out by NHRRD is considered artificial and therefore bad.

<sup>&</sup>lt;sup>60</sup> 'About 40% of ADHD children have at least one parent with clinical ADHD symptoms' (M. STARCK, J. GRÜNWALD, A.A. SCHLARB, *Occurrence of ADHD in Parents of ADHD Children in a Clinical Sample*, in *Neuropsychiatr Dis Treat.*, 12, 2016, 586).



<sup>&</sup>lt;sup>56</sup> For a detailed exposure of the failures of genetic determinism, see D.B. RESNIK, D.B. VORHAUS, *op. cit.* See also S.M. SUTER, *A Brave New World*, cit., 939-940.

<sup>&</sup>lt;sup>57</sup> N. Agar, *op. cit.*, 172-173; E. Fenton, *op. cit.*, 38.

<sup>&</sup>lt;sup>58</sup> J. HABERMAS, *op. cit.*, 124.

<sup>&</sup>lt;sup>59</sup> V.V. THAKER, Genetic and Epigenetic Causes of Obesity, in Adolescent Medicine: State of the Art Reviews, 28, 2, 2017, 379-405.

Mainstream scholars share a fascination over the natural order of things.<sup>61</sup> This allure faces two problems. First, the difficulty in distinguishing what is natural to what is artificial, because "genetic technologies threaten this distinction because they enable manipulation of one subject by another and thereby blur the line between what is grown (the natural) and what is made (the artificial)".<sup>62</sup>

Secondly, the lack of justification of why natural is better.<sup>63</sup> Many things that happen in nature, without any type of human intervention, cannot be considered good by any parameter: young babies that die in their sleep, earthquakes and other natural disasters that kill millions. The lack of accountability, legal or moral, does not make this natural event good, or even neutral.

On the other hand, most aspects of human life nowadays are artificial (in the sense they are manmade), but still very beneficial to humankind. The fact that we, humans, have developed medicine to treat severe diseases and safe lives, for instance. This is far from natural. Under the rule of nature people with tuberculosis, pneumonia or even flu would die. I wonder if those scholars would find their death valuable just because imposed by nature.

#### 4. Parental reproductive choices in light of reproductive rights

Mainstream scholars sustain that reproductive rights<sup>64</sup> cannot justify the power to decide whether a baby is going to be blond or brunette, male or female. <sup>65</sup> Any of these choices would constitute a reproductive rights abuse.<sup>66</sup>

I agree with the thesis that reproductive rights do not include in their scope the possibility to determine offspring characteristics not related with health.<sup>67</sup> When someone decides to have a child, there are some expectations that should be preserved. The decision to procreate involves burdens that parents implicitly accept, related to raising, educating and taking care of their child. There is no exact measure or quantity of burdens, but a commonly shared idea accepts there is a reasonable level of parental obligations that "come with the job". When dealing with a severely ill child, parents bear an enormous

<sup>65</sup> Cf. S.M. SUTER, A Brave New World, cit.; S.M. SUTER, The Tyranny of Choice, cit.



<sup>&</sup>lt;sup>61</sup> For instance, Habermas claims in favour of a "right to a genetic inheritance immune from artificial intervention" (J. HABERMAS, *op. cit.*, p. 27); Annas considers many of the practices included in NHRRD as crimes against humanity because they undermine human nature (G.J. ANNAS, *American Bioethics: Crossing Human Rights and Health Law Boundaries*, Oxford, U.K., 2005, 37).

<sup>&</sup>lt;sup>62</sup> E. FENTON, *op. cit.*, 38.

<sup>&</sup>lt;sup>63</sup> A similar critique, for the specific case of gene editing, in I. DE MIGUEL BERIAIN, L. MASTRANGELO, *Cosa c'è di Sbagliato nel Modificare la Linea Germinale?*, in *BioLaw Journal – Rivista di BioDiritto*, 1, 2020, 240-241.

<sup>&</sup>lt;sup>64</sup> Some authors use the concept "reproductive rights" (V. ROZÉE GOMEZ, S. UNISA, *Surrogacy from a Reproductive Rights Perspective: The Case of India, in Autrepart,* 70, 2, 2014, 185-203), while others prefer "reproductive liberties" (T. BALDWIN, *Reproductive Liberty and Elitist Contempt: Reply to John Harris,* in *Journal of Medical Ethics,* 31, 5, 2005, 288-290). This dichotomy will not be discussed in the paper.

In opposite sense, J. ROBERTSON, Genetic selection, cit., 424-432; J. HARRIS, *Rights and Reproductive Choice*, in J. HARRIS, S. HOLM (eds.), *The Future of Human Reproduction*. Oxford: 1998, 34; J. ROBERTSON, *Assisted Reproduction, Choosing Genes, and the Scope of Reproductive Freedom,* in *George Washington Law Review*, 76, 2008, 1490-1512.

<sup>&</sup>lt;sup>66</sup> This paper will not discuss the existence of reproductive rights (for this see J. HARRIS, *Rights and Reproductive Choice*, cit.).

<sup>&</sup>lt;sup>67</sup> V.L. RAPOSO, *The Usual Suspects,* cit.

responsibility, that foes beyond what is reasonably expected. Therefore, no parent should be forced to keep a child with a severe disability, unless clear and informed consent has been given. Future parents should demand to be informed about the health hazards of their future children by using different methods of preconception diagnosis. If they decide to go forward, they should be informed about reproductive techniques and associated genetic interventions to eradicate severe medical conditions. Parents should not be forced to procreate if they know their child would be severely disabled. Likewise, if they are aware of a genetic predisposition to a certain disease, they should be allowed to employ scientific procedures (reproductive treatments using gamete donation, PGD, genetic engineering) to avoid passing that predisposition on to their offspring. This parental right is concomitantly a duty towards offspring, as with many other rights belonging to parents in the relationship with their children. Therefore, not only are we talking about a right belonging to those who want to reproduce (reproductive right), but also to a duty imposed on these individuals to protect their future children (reproductive duty).<sup>68</sup> "We do not have a moral duty to bring people into existence with good lives; but we do have a moral duty to prevent the existence of people who would experience so much pain and suffering as to make their lives not worth living for them on the whole".<sup>69</sup>

Health is a relevant consideration and having a healthy child can be a decisive factor in the decision to reproduce. Some non-health related features can also play the same role.<sup>70</sup> In this regard John Roberson provided the following example: <sup>71</sup> for a family dedicated to music, musical talent can be a decisive condition to reproduce, even though this is a mere subjective preference. However, for that family it can be as decisive as having a healthy child, which is an objective and universal preference.<sup>72</sup> However, this preference is not protected by reproductive rights.

Parents have a right (as an aspect of the right to reproduce) to ensure that their child will not suffer from a certain disease<sup>73</sup> (even this dimension is contested by some authors)<sup>74</sup> and to use scientific mechanisms to achieve that objective,<sup>75</sup> grounded on their reproductive rights. However, reproductive rights do not provide parents the possibility to determine other types of characteristics for their

<sup>&</sup>lt;sup>75</sup> V.L. RAPOSO, *O Direito à Imortalidade*, cit., 158 ff.



<sup>&</sup>lt;sup>68</sup> The nature of such duty – legal or moral – will not be discussed here. For further developments see V.L. RAPOSO, *The Usual Suspects, cit.;* V.L. RAPOSO, Bons Pais, *Bons Genes?: Deveres Reprodutivos no Domínio da Saúde e Procreative Beneficence,* in *Lex Medicinae,* 4, II, 2019, 471-483.

<sup>&</sup>lt;sup>69</sup> W. GLANNON, *Genes, Embryos, and Future People*, in *Bioethics*, 12, 3, 1998), 188. See also J. HAMMOND, *Genetic Engineering to Avoid Genetic Neglect: From Chance to Responsibility*, in *Bioethics*, 24, 4, 2010, 160-169.

This dimension won't be addressed in this paper. More developments on this issue are found in J. HAMMOND, *op. cit.*, 160-169; V.L. RAPOSO, *The Usual Suspects*, cit., 109-237.

<sup>&</sup>lt;sup>70</sup> C. Gyngell, T. Douglas, J. Savulescu, *op. cit.* 

<sup>&</sup>lt;sup>71</sup> J. ROBERTSON, *Extending preimplantation genetic diagnosis*, cit., 215.

<sup>&</sup>lt;sup>72</sup> As an exception, there are cases of parents that deliberately selected a child with a disease or a disability. See, for instance the case of a couple that selected a child with Down syndrome (M. HEALY, *Fertility's New Frontier: Advanced Genetic Screening Could Help Lead to the Birth of a Healthy Baby*, in *L.A. Times*, July 21 2003, at <a href="https://www.latimes.com/archives/la-xpm-2003-jul-21-he-pgd21-story.html">https://www.latimes.com/archives/la-xpm-2003-jul-21-he-pgd21-story.html</a> (last visited 06/04/2021).

<sup>&</sup>lt;sup>73</sup> L.B. ANDREWS, N. ELSTER, op. cit., 62 ff.

<sup>&</sup>lt;sup>74</sup> J. MITTRA, Marginalising 'Eugenic Anxiety' Through a Rhetoric of 'Liberal Choice': A Critique of the House of Commons Select Committee Report on Reproductive Technologies, in New Genetics and Society, 26, 2, 2007, 159-179.

children.<sup>76</sup> As Lee Silver put it, «[t]here's a big difference between curing infertility, on the one hand, and trying to make sure that your child inherits your curly hair on the other».<sup>77</sup> ecial

# 5. Problems faced by this position

According to the previous considerations, parents can select health-related features for their children but lack grounds to select other features. This conclusion, however, faces two major shortcomings. First, it does not provide a distinctive criterion for distinguishing health-related features from others. Second, it fails to demonstrate why health-related features are necessarily more relevant (that is, more decisive for the child's future) than non-health-related features.

# 5.1. The distinction between health-related features and other features

Doubts about NHRRD have arisen because there is no clear concept of health,<sup>78</sup> a doubt exacerbated by the World Health Organization's (too) broad definition of health as «a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity».<sup>79</sup> If we select a child whose characteristics can provide him or her with a happier existence and promote his or her wellbeing, such as having a sense of humour or empathy, this selection seems to amount to health-related features based on the WHO's definition and thus it would be allowed.

However, this is not the most commonly used operative concept of "health", eventually because of its extremely broad scope. Commonly, "health" appears related to medicine and medical decisions. This seems to be the distinctive criterion that grounds existing legal solutions, for instance, to define lawful abortion based on the unborn's features<sup>80</sup> and lawful PGD:<sup>81</sup> if intended to avoid the birth of a child with a disease or malformation, as such understood by medicine, these practices are allowed, if not they are banned.

However, this results in an additional problem. From a theoretical perspective, the distinction between health-related features (medically relevant choices) and non-health-related features (medically irrelevant choices) appears to be clear and justified on objective medical grounds. The problem is that

<sup>&</sup>lt;sup>81</sup> A.M. DUGUET, B. BOYER-BEVIERE, Preimplantation Genetic Diagnosis: The Situation in France and in Other European Countries, in Eur J Health Law, 24, 2, 2017, 160-174.



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<sup>&</sup>lt;sup>76</sup> Moreover, NHRRD are not included in the scope of protection of other rights (the more suitable candidates would be the right to privacy, the right to self-determination and the right to create a family). For this analysis see V.L. Raposo, O Direito à Imortalidade, cit., 157-169.

<sup>&</sup>lt;sup>77</sup> L. SILVER, *op. cit.*, 75.

<sup>&</sup>lt;sup>78</sup> Regarding this question, see J. ROBERTS, Treating the Enhancement Debate: Irrelevant Distinctions in the Enhancement Medicine Debate, in Kriterion – Journal of Philosophy, 28, 1, 2014, 1-12.

<sup>&</sup>lt;sup>79</sup> WORLD HEALTH ORGANIZATION, Preamble to the Constitution of the World Health Organization, as adopted by the International Health New 1946, Conference, York, June 19-22, https://www.who.int/governance/eb/who constitution en.pdf (last visited 03/06/2020).

<sup>&</sup>lt;sup>80</sup> Abortion Legislation in Europe, last update 12/30/2020, at https://www.loc.gov/law/help/abortionlegislation/europe.php (last visited 10 April 2021).

in practical terms the difference is much more complex. What is a disease or a disability, as opposed to a condition not connected to health,<sup>82</sup> or how to distinguish treatment from enhancement?<sup>83</sup>

Not even an analogy with the scope of medicine helps in our definition because medicine has progressively expanded its scope to include plastic surgery, fertility procedures, sport medicine, and so on. If we select a child with certain facial characteristics or athletic ability, this selection is still within the scope of modern medicine and could be allowed under this criterion.

Furthermore, many believe that disease is a social construction,<sup>84</sup> that is, that classifying certain behaviour as a disease or not is socially determined. This formula opens the door to, for example, homosexuality or sex addiction being qualified as diseases because they are considered as such in certain communities. Under this (very contested) criterion, we can select a straight child or a child with controlled sexual behaviour<sup>85</sup> (assuming we could control features such as sexual orientation and sexual behaviour by means of genetics, a possibility that presently lacks a scientific basis) under the umbrella of health-related features.

#### As Sonia Suter puts it

on a societal scale, the more we use technology to select against lesser conditions and traits, the more perfectionist we may become as a culture, and the more demanding we may become with respect to what is acceptable, normal, or healthy.<sup>86</sup> In sum, the absence of a clear concept of "health" is a major drawback of mainstream theories that ban NHRRD.

#### 5.2. The relevance of the selected features

Parents select certain features because they value them, i.e., those traits are not neutral for parents, even if the remaining members of the community do not consider them as valuable. The importance of this information is a subjective matter.<sup>87</sup> The specific content/design of the selected characteristics can vary widely because they basically depend on the subjective assessments of each set of parents. For instance, it is fair to say that most parents want a child physically attractive. However, the concept of beauty is far from uniform. Some may find a blond-haired child with brown eyes to be beautiful, whereas others may consider black hair and blue eyes to be more alluring.

Moreover, the apparent neutrality of non-health related features can be challenged. Some alleged "neutral characteristics" are indeed relevant to a child's future opportunities. For instance, in many

<sup>&</sup>lt;sup>87</sup> J. DAAR, ART and the Search for Perfectionism: On Selecting Gender, Genes, and Gametes, in The Journal of Gender, Race and Justice, 9, 2005, 269; J. ROBERTSON, Genetic Selection, cit., 430.



<sup>&</sup>lt;sup>82</sup> Also questioning this distinction, N. AGAR, op. cit., 173-174.

<sup>&</sup>lt;sup>83</sup> S. CHAN, J. HARRIS, *In Support of Human Enhancement*, in *Studies in Ethics, Law, and Technology*, 1, 1, 2007; J. HARRIS, *Enhancing Evolution*, Princeton, NJ, 2007; E. IGNOVSKA, G.F. BLASI, *Reproduction, the Key to Human Evolution: a Legal and Ethical Study*, in *BioLaw Journal – Rivista di BioDiritto*, 2, 2017, 117-119.

<sup>&</sup>lt;sup>84</sup> Cf. P. CONRAD, K.K. BARKER, The Social Construction of Illness: Key Insights and Policy Implications, in Journal of Health and Social Behavior, 51, S, 2010, S67. For more on this issue see S.M. SQUIER, Narrating Genetic Disabilities: Social Constructs, Medical Treatment, and Public Policy, in Issues in Law and Medicine, 15,2, 1999, 141-158.

<sup>&</sup>lt;sup>85</sup> Dahl, for instance, sustains that parents should be able to select the sexual orientation of their progeny. Cf. E. DAHL, *Ethical Issues in New Uses of Preimplantation Genetic Diagnosis*, in *Human Reproduction*, 18, 7, 2003, 1368-1369.

<sup>&</sup>lt;sup>86</sup> S.M. SUTER, A Brave New World, cit., 936.

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societies tall people may be more highly valued, so parents may select embryos that produce taller human beings.<sup>88</sup> Some research has shown that appearance influences success. For instance, eye colour can condition your achievements in life ("blue-eyed people being more intelligent and brown-eyed people having faster reaction times").<sup>89</sup> Furthermore, not only is it common knowledge that attractive people have more success, but some studies have attested they generally have higher incomes.<sup>90</sup> What about sexual orientation? This is far from being a neutral feature. Most parents prefer "straight" children, primarily because they are more easily accepted by society.<sup>91</sup> Accordingly, one can assume that if a "gay gene" were to be discovered, some parents would select against it. In the case of gender, it can hardly be deemed a trivial feature when some cultures stigmatise females. Thus, even if gender selection is allowed in certain jurisdictions<sup>92</sup> disregarding health issues,<sup>93</sup> it should only be permitted in countries where male babies are not systematically desired, and females undervalued.<sup>94</sup> When prospective parents deem a feature to be important, in such a way that it conditions their decision to procreate (even if for the average person it is redundant), why not allow the selection of

In favour, B. STEINBOCK, Sex Selection: Not Obviously Wrong, in Hastings Center Report, 32, 1, 2002, 23-28; J. HARRIS, No Sex Selection Please, We're British, in Journal of Medical Ethics, 31, 5, 2005, 286-288.

Against, T. BALDWIN, op. cit.; R. MACDOUGALL, Acting Parentally: An Argument Against Sex Selection, in Journal of Medical Ethics, 31, 10, 2005, 601-605.

Presenting arguments for and against this possibility see the ETHICS COMMITTEE OF THE AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE, Use of Reproductive Technology for Sex Selection for Nonmedical Reasons, in Fertility and Sterility, 103, 6, 2015, 1418-1422.

<sup>93</sup> The paper is not referring to sex selection aimed to prevent the transmission of a particular disease, a possibility admitted in most national laws and in Article 14 of the Convention for the Protection of Human Rights and Biomedicine (Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, <u>https://rm.coe.int/168007cf98</u>, last visited 20/04/2020).

<sup>94</sup> The same ban would apply to specific communities (Indian, Chinese) in Western countries. There was a study performed in Asian communities (from India, China, and South Korea) in the US that found that when these families had a girl as their first child the chance that the second child would be a boy was much higher than in other communities, suggesting that some kind of medical intervention was used to select a baby boy. Cf. D. Fox, *Interest Creep*, in *The George Washington Law Review*, 82, 2, 2014, 330.



<sup>&</sup>lt;sup>88</sup> Some considerations about the value of being tall are discussed in C. GYNGELL, T. DOUGLAS, Stocking the Genetic Supermarket: Reproductive Genetic Technologies and Collective Action Problems, in Bioethics, 29, 4, 2015, 243.

However, if more tall people are born this may lead to two different and opposing consequences: the idea that being tall is better than being short might be perpetuated or being tall might become so common that being short will have more value.

<sup>&</sup>lt;sup>89</sup> J. WATSON, Eye Colour and Reaction Time: An Opportunity for Critical Statistical Reasoning, in Australian Mathematics Teacher, 64, 3, 2008, 30-40.

See also P.J. ROWE, P. EVANS, *Ball Color, Eye Color, and a Reactive Motor Skill*, in *Perception Motor Skills*, 79, 1Pt2, 1994, 671-674.

<sup>&</sup>lt;sup>90</sup> "The average cost of being ugly is \$230,000 out of your paycheck over your working lifetime. Deduct another significant chunk from your salary if you are obese, but only if you are female. Fat women earn about \$14,000 less per year than their average-weight sisters, or about 12% if you are Caucasian and 7% if you are African American. On the other hand, remarkably thin women earn \$2,000 more each year than the average woman on the job" (N. ROSEN, *Blondes Really Do Earn More Money*, Sep. 1, 2011, http://www.businessinsider.com/the-ugly-tax-2011-8).

<sup>&</sup>lt;sup>91</sup> B. WILLIAMS, Screening for Children: Choice and Chance in the Wild West of Reproductive Medicine, in George Washington Law Review, 79, 4, 2011, 1321-1322.

<sup>&</sup>lt;sup>92</sup> In the absence of a legal ban, it is legally practiced in some US states, Ukraine, Thailand, Mexico.

that characteristic? Here we are faced with a dilemma. It can be said that despite the importance that feature has for a specific person, it is objectively irrelevant; therefore, there is no point in selecting it. But if so, there is no reason to forbid parents from choosing it. That is, if the desired feature does not influence the child's existence or its future possibilities in life, the State has no reason to intrude in this kind of parental decision. On the other hand, it might be the case that the feature is actually relevant for the child's development and future, and if so, parents should have something to say about it. Quoting John Harris, «if they are not important, why not let people choose? And if they are important, can it be right to leave such important matters to chance? ».<sup>95</sup>

# 6. The admissibility of some NHRRD

# 6.1. Reasons leading to the admissibility of NHRRD

Based on the arguments advanced in the previously section, it is difficult to sustain the complete legal ban of NHRRD.

The eventual admission of NHRRD is not based on the right to reproduce. As stated supra, the scope of protection of this right does not include the right to choose the type of child one may have, but simply the right to have a child free of serious illnesses or malformations. Accordingly, in view of reproductive rights, the only characteristics parents should be entitled to select are those that are health related. It is not possible to provide an exact definition of "health", but it should at least include the avoidance of serious and untreatable medical conditions.

There are three reasons for allowing NHRRD. First, it is not always possible to clearly distinguish the features related to health from all the others. Secondly, assessing the value of these features is quite complex. Some of them are as relevant to parents as the health condition of their offspring. Thirdly, there are no sound reason to forbid NHRRD. As demonstrated *supra*, the arguments usually invoked against NHRRD all fall short on their intent. In the legal world the rule is not that a conduct is forbidden unless there are reasons to allow it, but rather that the conduct is admissible unless there are reasons to forbid it.

# 6.2. Features to be selected

In theory, parents can select non-health related features objectively harmful to the future person, such as violent behaviours or a low level of intelligence. However, the selection of characteristics that would deprive the child of opportunities in his/her life and reduce his/her wellbeing should not be allowed. Most of the features referred in this paper will indeed improve children's quality of life. A reasonably good state of health is not the only characteristic able to provide people a good standard of living. This was recognized by the Nuffield Council on Bioethics on its report on genome editing from 2018, which systematically invokes the notion of welfare (for existing and future generations):

<sup>&</sup>lt;sup>95</sup> John Harris manifests his concordance in relation to the selection of those attributes because he does not qualify this practice as discriminatory. Cf. J. HARRIS, *Rights and Reproductive Choice*, cit.



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In our view, what is morally important about human beings is not dependent on the possession of a particular set of genomic variations: we find the concept of 'the human genome' to lack coherence in any case. We conclude that so long as heritable genome editing interventions are consistent with the welfare of the future person and with social justice and solidarity, they do not contravene any categorical moral prohibition.<sup>96</sup>

The concept of "welfare" clearly surpasses the mere notion of "health". It can even embrace features traditionally considered enhancement, such as intelligence.<sup>97</sup>

#### 6.3. Offspring selection and the destruction of human life

The procedure use in the NHRRD is of utmost importance because it can change the ethical and legal assessment of the decision.

Pre-conception scientific procedures are less problematic because they do not have to overcome constraints based on the protection of the unborn. When genetic selection takes place before conception (in other words, in gametes),<sup>98</sup> the unborn's protection cannot be invoked to forbid it, given that at this time a "person" does not yet exist. As for gametes, they are not human life, and therefore the protection afforded to human beings does not apply to them.<sup>99</sup> Thus, at this moment the range of parental choices is wider.

More problematic is when in vitro embryos are already created. At this stage embryos might have to be destroyed for not presenting the desired features. Due to the potential destruction of human life some jurisdictions have (almost) completely banned any kind of embryonic selection. For instance, the German Embryo Protection Law of 1991<sup>100</sup> forbids sex selection, except to avoid the transmission of a disease (par 3), and in its original version it also banned PGD. However, after a 2011 reform, Germany came to allow it, although with restrictions and only regarding severe medical conditions (par 3a).<sup>101</sup> In the past couple of years, several reforms have emerged in Europe to relax the rules on PGD and allow embryonic selection under certain conditions.<sup>102</sup> However, PGD is never allowed for non-health



<sup>&</sup>lt;sup>96</sup> THE NUFFIELD COUNCIL ON BIOETHICS, Genome Editing and Human Reproduction: Social and Ethical Issues, 2018, 158, http:// nuffieldbioethics. org/ project/ genome- editing- humanreproduction (last visited 23/04/2020).

<sup>&</sup>lt;sup>97</sup> C. GYNGELL, H. BOWMAN-SMART, J. SAVULESCU, Moral Reasons to Edit the Human Genome: Picking Up from the Nuffield Report, in Journal of Medical Ethics, 45, 2019, 518.

<sup>&</sup>lt;sup>98</sup> By selecting donors with certain characteristics parents can indirectly select the features of the child (see V.L. RAPOSO, *Wrongful Genetic Connection*, cit., and the case law therein referred). This is, nonetheless, a genetic lottery, as the child might not inherit those characteristics.

<sup>&</sup>lt;sup>99</sup> M.T. BROWN, *The Potential of the Human Embryo*, in *Journal of Medicine and Philosophy*, 32, 6, 2007, 599-603. <sup>100</sup> Act on the Protection of Embryos (Embryonenschutzgesetz - ESchG) of 13 December 1990, Bundesgesetzblatt 1990 Part I pp. 2746-2748, amended by Article 1 of the Act of 21 November 2011 (Bundesgesetzblatt 2011 Part I p. 2228, <u>https://www.drze.de/in-focus/stem-cell-research/modules/the-german-embryo-protection-act?set\_language=en</u> (last visited 06/04/2020).

<sup>&</sup>lt;sup>101</sup> B.B. VON WÜLFINGEN, Contested Change: How Germany Came to Allow PGD, in Reproductive BioMedicine and Society Online, 3, 2016, 60-67.

<sup>&</sup>lt;sup>102</sup> Bayefsky describes the reforms in Italy, Switzerland, France and the United Kingdom in M.J. BAYEFSKY, *op. cit.* 

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related features. For instance, both the Portuguese<sup>103</sup> and Spanish<sup>104</sup> laws on assisted reproductive techniques allow the use of PGD, but only to detect health conditions.<sup>105</sup> This is essentially the same rule stated in Article 12 of the Convention on Human Rights and Biomedicine.

The most problematic scenario concerns uterine embryos and foetuses, because they are a form of human life (unlike gametes) in a more developed stage of development (when compared with in vitro embryos), and thus they require stronger protection.<sup>106</sup> This reasoning is based on the theory of gradual protection of the unborn,<sup>107</sup> generally accepted by several courts in Europe. See in particular the two decisions on abortion from the German Constitutional Court (BVerfGE) at the end of last century: BverfGE, 39, 1 (1975) and BVerfGE 88, 203 (1993). Generally, abortion based on the unborn's features is legally restricted to its therapeutic aspects. Thus, the only available option for NHRRC is abortion by request. In the context of a legal system wherein abortion can be freely performed in the first weeks of gestation, even on a healthy foetus, there is no plausible ethical and legal justification, nor any effective mechanism, to forbid an abortion based on non-health related features. If the unborn does not have the parents' desired features,<sup>108</sup> no matter how futile those features are, abortion (by request) is still allowed,<sup>109</sup> because the idea underpinning abortion by request is that no justification is required<sup>110</sup> (and it is fair to assume that few parents would publicly disclose that the real reason to abort was a non-health related feature, such as gender). That said, there is a distinction between abortion and other forms of offspring selection.<sup>111</sup> Abortion involves the destruction of human life at a later stage of development, and so it faces more legal and ethical restrictions than when in vitro embryos are involved or, a fortiori, gametes alone, which are not even a form of human life.

Gene editing is another mechanism for NHHRD. It can be used at any stage of development: prior to or after birth, and even prior to conception (on gametes). From the perspective of human life protection, gene editing raises fewer issues because gene editing does not involve the destruction of human life (unlike it happens with abortion and with PGD),<sup>112</sup> but rather the modification of an existing

<sup>&</sup>lt;sup>112</sup> Pointing out the differences between gene editing and PGD, and favouring gene editing in his analysis, I. DE MIGUEL BERIAIN, *Is the 'Serious' Factor in Germline Modification Really Relevant? A Response to Kleiderman,* 





<sup>103</sup> 7, Articles 28 and 29 of Law 32/2006. from 26 July, n. http://www.pgdlisboa.pt/leis/lei mostra articulado.php?nid=903&tabela=leis (last visited 22/03/2020). <sup>104</sup> Article 12 of Law 14/2006, from 26 May, <u>https://www.boe.es/buscar/act.php?id=BOE-A-2006-9292</u> (last visited 02/06/2020).

<sup>&</sup>lt;sup>105</sup> For a discussion of the use of PGD to screen non-health related features, see B. WILLIAMS, *op. cit.*, 1311 ff. <sup>106</sup> M.T. BROWN, *op. cit.*, 603-605.

<sup>&</sup>lt;sup>107</sup> C.M. ROMEO CASABONA, El Derecho a la Vida: Aspectos Constitucionales de las Nuevas Biotecnologías, in Tribunal Constitucional (ed.), Actas de las VIII Jornadas de la Asociación de Letrados del Tribunal Constitucional, Madrid, 2003, 40 ff.

<sup>&</sup>lt;sup>108</sup> "The question is whether something which is not positively in a child's interest can be tolerated or permitted if it is not positively against the child's interests" (R. ASHCROFT, Bach to the Future: Response To: Extending Preimplantation Genetic Diagnosis: Medical and Non-Medical Uses, in Journal of Medical Ethics, 29, 4, 2003, 217-219.

<sup>&</sup>lt;sup>109</sup> However, some US states have banned abortion based on gender, race or the results of pre-natal diagnosis.

 <sup>&</sup>lt;sup>110</sup> Studies have shown the perils of "free" abortion: in a study quoted by Lori Andrews (L. ANDREWS, *Brave New Babies*, 2007, <u>http://www.pbs.org/independentlens/frozenangels/babies.html</u>, last visited 12/06/2020),
12% of parents declared that they would abort a foetus if they knew it had a propensity for being obese.
<sup>111</sup> This difference is pointed out in L.A. VACCO, *op. cit.*, 1219.

genetic code. These notes make this method very appealing (but only when it reaches the required levels of safety and efficiency). However, just like the previous procedures, in the European scenario gene editing is also restricted to health-related features.<sup>113</sup>

To summarize, apart from cases of severe or incurable illness or malformation (i.e., health-related causes), the selection of all remaining features must be completed before conception (for instance, by means of gamete selection) and not after, to avoid the destruction of embryos and foetuses just because they lack the desired features.<sup>114</sup> To destroy an in vitro embryo carrying a severe medical condition or, *a maiori, ad minus*, to abort a foetus in that situation, is not comparable to the destruction/abortion of embryos and foetuses that are healthy but simply lack a preferred gender or eye colour.<sup>115</sup> The exception is gene editing because this procedure does not involve the destruction of human life (i.e., embryos, foetuses and those who are already born), so, it could be used in later stages when its safety is demonstrated.

## 7. Final considerations

The paper has argued that despite the existing legal prohibition in several jurisdictions – namely in Europe, the geographical focus of the paper – there are no sound reasons to ban NHRRD. The arguments commonly invoked against the selection of non-health-related features have demonstrated their fallibility.

The paper is not sustaining that NHRRD do not raise any legal issues, nor is it advocating that the law should allow these choices without any restriction or condition. Instead, the paper simply states that the general understanding that NHRRD should be banned by law must be reassessed, because the arguments usually raised against them are insufficient.

This is not a new discussion. The determination of offspring traits has been an ancestral aspiration, but the most recent discoveries and scientific achievements regarding the human genome have prompted the rebirth of this aspiration. The new genetic and reproductive techniques have brought with them the promise of a seductive and fascinating future, even though (it must be recognized) it may be a potentially dangerous one.

In a sense, genetic selection become unavoidable because competition among the human species compels parents to look for the "best child" they can have. New scientific acquisitions have agitated our traditional convictions. We have tended to believe that genes are supposed to be established by nature. However, we are on the verge of replacing genetic lottery with deliberate parental choice. After all, is serendipity really more valuable than planning?

<sup>&</sup>lt;sup>114</sup> This is under the assumption that the unborn is not a person but is, nonetheless, a form of human life. <sup>115</sup> A similar argument is made by B.L. WILDER, *Assisted Reproduction Technology: Trends and Suggestions for the Developing Law,* in *Journal of the American Academy of Matrimonial Law,* 18, 2002, 204.



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Ravitsky and Knoppers, in Journal of Medical Ethics, 46, 2020, 151-152; G. CAVALIERE, Genome Editing and Assisted Reproduction: Curing Embryos, Society or Prospective Parents?, in Medicine, Health Care, and Philosophy, 21, 2, 2018b, 215-225.

<sup>&</sup>lt;sup>113</sup> *Vide* Article 13 of the Convention for the Protection of Human Rights and Dignity and Article 13 of Spanish Law n. 14/2006.

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Whether we like it or not, the future of humanity is in our hands now. Rather than fearing genetics,

we should embrace it. We can do better than chance.<sup>116</sup>