

## THE ETHICAL COLLATERAL DAMAGE OF QUASI-EUGENICS – PART ONE

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### **Abstract:**

The definition of “Eugenics” is “a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed.” This definition is not entirely suitable for the new advanced techniques in genetically engineering human beings, purposely amending the human race and its perspectives for the future (i.e., designer babies, Three Parent In Vitro Fertilization babies). The author feels it is necessary to implement better terminology, by investigating previously used terms describing these never before used quite-eugenic techniques. A large literature-review was done, and attention was given to the articles with controversial ideas and innovative terms. The author expresses his concerns and opinions over the ideas expressed on both sides of the aisle. Finally he suggests the term “quasi-eugenics”, which he considers as the most adequate, when compared to previously coined terms for such technologies and actions. PGD - pre-implantation genetic diagnosis, and PGS - pre-implantation genetic selection may be very well described by the new term quasi eugenics, because to a certain extent it maintains the old spirit of positive-eugenics, however being extremely costly and thus accessible for a few select people.

**Key-words:** PGS - pre-implantation genetic selection, Three Parent In Vitro Fertilization babies, eugenics, quasi-eugenics, principles of biomedical ethics

The regular knowledge and perception about “eugenics” is fundamentally changing in our days. The Merriam-Webster dictionary has for this term two definitions - a simple one: “*a science that tries to improve the human race by controlling which people become parents*”, and a full one: “*a science that deals with the improvement (as by control of human mating) of hereditary qualities of a race or breed*”.

In 2002 when my book “Euthanasia, Physician Assisted Suicide, Eugenics – pros and cons” was published, the chapter about “Eugenics” dealt mainly with its historical aspects and the modern sterilization programs running in the Western world. (1) At the time, it would have been very difficult to foresee the permanent appearance of new concepts (e.g., designer babies, three-parent babies), and how these technologies may resemble the practice of positive eugenics. The ethical issues derived from the practical applications of the new medical sciences - especially genetically engineered organisms and human genetic manipulation - are now well explained in Wikipedia, to say nothing that they are well-known and quite popular in the laymen’s world.

Few weeks ago in a long distance call with my 92-year old father-in-law, he asked me if I was aware about the new “*meshuganah*” in genetic manipulation, which was about to become legal in Britain. The word he used means in Hebrew “craziness” or even “madness”, and he was making reference to the new Three Parent In Vitro Fertilization (TPIVF) method – using genetic material from three donors. The procedure is intended to prevent mitochondrial diseases including diabetes mellitus and deafness and some heart and liver conditions in the offspring. It is still the subject of considerable controversy in the field of bioethics, and the procedure is not currently approved for general use in any country. However, in the United Kingdom, a draft of a law allowing TPIVF was debated and approved in February 2015. (2)

While the Human Genome Project was ongoing (1990 – 2003), new articles were popping-up every day. I was trying to keep myself updated, reading extensively about its purpose to determine the sequence of chemical base pairs which make up human DNA, and of identifying and mapping all of the genes of the human genome from both a physical and functional standpoint. Besides reviewing literature, I was attending conferences on Bioethics, trying to perceive and better understand the **changing trend in public and professional perception about genetically engineering in human beings.**

Meanwhile, some scattered ideas about “liberal eugenics”, a.k.a. "new eugenics", "neo-eugenics", "newgenics", or "techno-eugenics" were spreading around. My work of documentation resulted in a published editorial about general perception on eugenics, its legal insertion in some states' legislation and some new bioethical dilemmas. (3)

At its historical beginnings, eugenics was more than a theory, but was also a practice, and it became a movement that found adherents throughout American society. “Eugenics manifesto” was published in the journal *Nature* in 1939, under the title was “Social Biology and Population Improvement.” Even Presidents Theodore Roosevelt and Herbert Hoover were members of some eugenics organizations, and publicly endorsed eugenic laws, or signed eugenic legislation, without voicing opposition. (4)

Eugenicists wished to develop a taxonomy of human traits and to categorize individuals as "healthy" or "unhealthy," and "normal" or "abnormal," within their classification scheme. Working under the presumption that most, if not all, human traits are transmitted genetically, the eugenicists encouraged educated, resourceful, and self-sufficient citizens to mate and produce "wellborn" eugenic children. (4)

The term “dysgenic” was create, and still exists – it is defined in Merriam-Webster as: “*biologically defective or deficient; tending to promote survival of or reproduction by less well-adapted individuals (as the weak or diseased) especially at the expense of well-adapted individuals (as the strong or healthy)*”.

Harry Laughlin called dysgenic groups "socially inadequate" and included in the created category: the feeble-minded, the insane, the criminalistics (sic), the epileptic, the inebriated or the drug addicted, the diseased-regardless of etiology, the blind, the deaf, the deformed, and dependents (an extraordinarily expansive term that embraced orphans, "ne'er-do-wells," tramps, the homeless, and paupers). (4)

The “official” eugenic beliefs were:

- 1. that social, moral, physical, and mental qualities are transmitted in predictable patterns by the mechanisms of heredity;**
- 2. that the human race can be improved by selective mating; and**
- 3. that the ills of society (disease, crime, poverty, and other social abnormalities) can be eradicated by discouraging, or preventing if necessary, the reproduction of socially deviant individuals.** (4)

As a public health initiative, eugenicists used the image of diseased "germ plasm," their analogue for genetic material or DNA, combined with the alarming rhetoric of a spreading epidemic of crime, poverty, and feeble-mindedness to help garner support for their proposals. They enlisted the coercive power of public health law, a body of law that sets aside the usual restrictions that surround much of medical jurisprudence, as the solution for eliminating social problems. (4)

While reviewing more recent literature, I started picking-up some **conceptual tribulations about the factual evolution of genetic technologies**. The controversial opinions of the authors were obviously right-out of the titles of the articles [i.e., Neri, D. (1999) - On the concept of eugenics: preliminaries to a critical appraisal (5); and Li, C C. (2000) - Progressing from eugenics to human genetics (6)].

Neri, D. brings the quite inconvenient aspect of “*increasing capability of medical genetics to modify the genetic composition of the human species through direct interventions in the human genome for medical and non-medical purposes, i.e., the "risk" of a resurgence of eugenics.*” He raises several times the term "**phantom of eugenics**", but states that “*there is a great deal of*

*confusion on what counts as eugenics, partly because of broad conceptual disagreement over the notion itself.” (5)*

Li, C. C. states with clarity: *“Eugenics, unlike science, involves decision making on various issues, and decision making involves the risk of making errors. This communication first clarifies the nature and seriousness of making errors known as type II in the statistical literature, i.e. the error of punishing a person when he is not guilty of the crime attributed to him.”* He made the observation that: *“The explosive advances made in medical and population genetics in the last 40 years are replacing the conventional eugenics programs by new approaches. Modern genetic counseling has been introduced as the intermediate agent between the scientist and the family that needs advice”.* (6)

It became more and more obvious to me that some authors were aware of **the awkward feeling oozing around from all the novelty in genetic manipulation**, and it was time for **some new terminology to be introduced and properly used**.

Searching the Internet for some answers, I found a 1993 article, posted much later: *“Is gene therapy a form of eugenics?”* by John Harris in the publication “Bioethics”. (7) I feel that his quotation I am citing here clearly expresses the essence of the dilemma the scientist, the ethicists and the public were facing: *“If, as I believe, gene therapy is in principle ethically sound except for its possible connection with eugenics then there are two obvious ways of giving a simple and straightforward answer to a question such as this. The first is to say **“yes it is, and so what?”** The second is to say **“no it isn't so we shouldn't worry”**. If we accept the first of the above definitions we might well be inclined to give the first of our two answers. If on the other hand, we accept the sort of gloss that Ruth Chadwick gives on Galton's account, **“those who are genetically weak should simply be discouraged from reproducing”**, either by incentives or compulsory measures; we get a somewhat different flavor, and one which might **incline a decent person who favors gene therapy towards the second answer.**” (7)*

To me, the critical article of John Harris seems to follow the famous principle of Blaise Pascal that *“Always we have to ask all the questions, despite the fact we may not get all the answers”*. I extensively analyzed his well opinioned statement, and found that it matches my way of thinking. As a consequence, I started looking for John Harris's more recent publications, and one from 1999 captured my attention: *“Doctors' orders, rationality and the good life: commentary on Savulescu - Journal of Medical Ethics, 1999;25: 127-129”* (8)

And where were the statements of this Savulescu published? Actually his debated opinion was published in the same journal, a few pages before Harris's article. The title of the paper, which stirred the commentary, was *“Should doctors intentionally do less than the best? - Journal of Medical Ethics, 1999; 25:121-126.”* (9).

I was somehow baffled by the insidious tone inside Savulescu's title, which reminded me of an obnoxious aunt of mine, who always used to criticize my school performance when I was 12 or 13 years old: *“Well, you may have gotten a 9 as a grade for your essay, but I am sure that you are aware that 10 is the best grade on this scale!”*

It also captured my attention, based on two reasons: one - it seemed that the content of both the article of Harris and that of Savulescu were known to each-other before being published in the same Journal, one after the other; second - Savulescu is, without any shred of doubt, a Romanian name.

I dealt with Romanian Bioethics for a long time, and I was not aware of any anymore ethicist with such a name, probably because the author was not living in Romania. Thus, I felt the need to see what these two authors were saying to each-other and to the rest of the world, including to me.

Savulescu directly names the papers of several authors including that of Harris, trying to convince the reader that they are somehow wrong in their approaches: *“The papers of Burley and Harris, and Draper and Chadwick, in this issue, raise a problem: what should doctors do when patients request an option which is not the best available? This commentary argues that **doctors have a duty to offer that option which will result in the individual affected by that choice enjoying the highest level of wellbeing.** Doctors can deviate from this duty and sub-maximize -- bring about an outcome that is less than the best -- only if there are good reasons to do so. The desire to have a child which is genetically related provides little, if any, reason to sub-maximize. **The implication for cloning, pre-implantation diagnosis and embryo transfer is that doctors should only produce a clone or transfer embryos expected to enjoy a level of wellbeing which is less than that enjoyed by other children the couple could have, if there is a good reason to employ that technology.**”* (9)

Wow, I said, Savulescu’s way of thinking makes me believe that he may have been really an acquaintance of my difficult to please aunt!

But, let’s see what did John Harris actually state in the previously mentioned article, in the paragraph entitled “The obligations of doctors”: *“From what Savulescu says it looks as though **sub-optimal states will never be objectively valuable unless some morally serious value can be shown to be at stake.** It follows that in assisted reproduction (and in industrialized countries almost all reproduction is medically assisted to some extent) **the poor should not be helped, neither should those who want extra children whose birth will decrease the total wellbeing of the family, nor should anyone be helped to have a genetic child when there are equally healthy babies waiting for adoption, nor should anyone be allowed to keep a second child while any infertile people who want children remain childless.**”* (8)

In the paragraph entitled “Rationality”, John Harris really mocks Savulescu’s inability to understand what they wrote about couple’s wishes toward their offspring: *“This, clearly obsessive, high-mindedness leads Savulescu to misunderstand the position Burley and I take. We imagine someone who prefers a mixed-race marriage even though, because they live in a racially prejudiced society, they know their children will be less well off than the children either would have had if they had opted for a same-race marriage with a different partner. Savulescu, gratuitously interprets the couple’s motives: **“but they want to make a political statement about racial equality .... This is a good reason to have a black child”.** With respect to Savulescu, this is not what they want and, in our submission, they don’t need a good reason. They just want kids with someone they love best”.* (8)

In my opinion, according to his personal statements, Savulescu **is basically situating himself on a virtual Utopian Planet, populated only by rich people, who would do anything to secure the societal success of their offspring, and ready to pay any price for this purpose – including distancing themselves from their children. Also, on the same Utopian Planet, medical doctors and specialists in genetically engineered humans will accomplish whatever those wealthy people may desire, using unlimited resources.**

It seems to me that Savulescu ought to see the movie **“Gattaca”**, a 1997 American science fiction film written and directed by Andrew Niccol, in which is presented a vision of a future society driven by eugenics where potential children are conceived through genetic manipulation to ensure they possess the best hereditary traits of their parents. (see Wikipedia)

Making reference to the famous fourth principle of Biomedical Ethics, dealing with the fair share of scarce resources, I must admit that John Harris is “my man”. So, forget about any ethnic solidarity with some thinker still wearing a Romanian-name, but estranged from Romania! [see

Tom L. Beauchamp and James F. Childress. Principles of Biomedical Ethics, 6th Edition: Oxford University Press, 2008. p. 417]

But wait, the controversy did not finish there - it appears that the opinion expressed by John Harris was opposed by another author: ***“Disability, gene therapy and eugenics--a challenge to John Harris”***, by S. M. Reindal in 2000 (10) This author’s answer is an attack on terminology: *“His definition of disability rests on an individual model of disability, where disability is regarded as a product of biological determinism or **“personal tragedy”** in the individual. Within disability theory this view is often called **“the medical model”** and it has been criticized for not being able to deal with the term **“disability”**, but only with impairment. The individual model of disability presupposes a necessary causal link between a certain condition in the individual and disablement. The **shortcomings of such a view of disability** are stated and it is argued that in order to have an adequate **ethical discourse on gene therapy perspectives from disability research** need to be taken into consideration.”* (10)

The statement of Reindal is arguing against someone whose opinion I share, so therefore it is a statement against my beliefs. What does he say? Going beyond the utility vs. futility analysis of medical technology implementation, he focuses on the definition of disability. This is an attack from a total different position. His argument implies two things: First, that the already coined scientific terms are subjected to different interpretations in different fields of study, and second, that it may be improper, if not ethically incorrect, to use such words in an adjacent field.

Since both Medical ethics and Bioethics are not sciences per se, but domains of study, they have to borrow the terminology of the adjacent fields of study, and to deal with those properly and consistently. For me, Reindal’s considerations about disability, even if epistemological correct, are just a game of smoke and mirrors, giving the idea that some experimental research may become regular medical technique, because someone in a very wealthy country needs it. In other words, we give a free-pass to legalizing some experimental research, which is actually dubious from the ethical point of view.

In my personal opinion, being overtly permissive to any new genetic engineering technique - satisfying the needs of just a few select humans - is as bad as being overbearingly forbidding to anything new in science and technology.

Going on with the literature review I found the following statement of R. Iredale, also published in 2000 (11): *“Recently there has been a revival of interest in the theory and practice of eugenics by both academics and lay people. The ongoing revolution in biology and the increasing ability to acquire genetic information has led to **concerns about genetics being used again for sinister eugenic ends**. Although the goals behind traditional eugenics--the minimization of disease and the improvement of human health--remain unchanged, **the means** by which these goals should be achieved **have altered significantly**. However, in debates about the impact of human genetic research, eugenics is sometimes viewed as a purely historical phenomenon and its relevance to the current situation is minimized.”* (11)

The statement of R. Irdale was in consonance with my thoughts, and I felt empathic for his way of expressing concerns. It seemed to me we were sharing similar feelings, that ***“Scientists were eager to practice positive eugenics in a new different way, while hiding the eugenic part, and praising the need for new science advances”***.

To my surprise and enjoyment, while I was trying to form and reform my own opinion about what is happening in the world of human genetic engineering, somebody else, **J. V. Neel, was trying to coin new terms for genetic manipulation techniques** in an article published at the beginning of year 2000: *“Some ethical issues at the population level raised by 'soft' eugenics,*

*euphenics, and isogenics*” (12) I was flabbergasted, even a little envious, but nevertheless I had to give the author total credit for creating these new terms. Let’s see what J. V. Neel was saying: *“It is argued that at the population level there are **three central genetic developments raising ethical issues**. The first is **the emergence of 'soft' eugenics**, due primarily to the increasing ability to detect carriers of genetic diseases, to monitor their pregnancies, and to provide the option to abort a fetus predisposed to major genetic disease. The second development is the recognition of the extent to which **many serious diseases of adult life are due to a disturbance of ancient genetic homeostatic mechanisms due to changing life style**, raising the question of whether a society that increasingly pays the medical bills should attempt to impose healthier standards of living on its members. Such an attempt at **'euphenics'** may be thought of as the **antithesis to eugenics**. The third development relates to recognition of **the need to regulate the size of the earth's population to numbers that can be indefinitely sustained; this regulation in a fashion (isogenic) that will preserve existing genetic diversity.**”* (12)

“Wow, this is a tough one!” I said, and I started asking myself if I may agree or not with the ideas behind the new terminology. On the first development, the author admits that the option to abort a fetus predisposed to a major genetic disease is eugenics, but a “soft” form. Then he introduces a complete non-scientifically coined term **“genetic homeostatic mechanisms”**, suggesting that such mechanisms existed for a very long time, but that they had been disturbed by modern life-style changes. As a consequence the author will suggest that society must impose “healthy” life-styles to some of its members – action called “euphenics”. The third development of J. V. Neel is just Malthusianism per se, or its new vision expressed by “The Club of Rome”, a global think tank that describes itself as "a group of world citizens, sharing a common concern for the future of humanity.”

I never endorsed the thinking of Malthus, and obviously, I have to dissent about imposing “healthy life-styles” to some of the members of society, basing my thoughts on the principle of Autonomy, although such measures were implemented before. A limit on soft drink size was enforced on March 12, 2013, in New York City, and the initiative was strongly supported by Mayor Michael Bloomberg and continues to be supported by his successor, Mayor Bill de Blasio, so there we have “euphenics” at work already.

Going back to genes and eugenics, here is a title from 2001: **“Can it be a "sin" to understand disease? On "genes" and "eugenics" and an "unconnected connection”**, by Neumann-Held, E M. (13) The author was - at his turn - aiming to clarify the inter-disciplinary use of terms and concepts, and the use of those terms while speaking to the public: *“Without claiming a logical relationship between genetic sciences and eugenics movements, a connection between both can become established. The distinction between scientifically validated statements on one hand and guiding hypotheses and assumptions on the other hand is blurred - as is observed particularly when scientists report their results to the public. It is required that a debate on biotechnology should include reflections on the validity of claims made by scientists.”* (13)

Yeah, I have to agree with this, because **an informed consent for a certain genetic procedure should include a complete disclosure using laymen terms and unveiling all the risks for the patient, for the offspring and at last, but not the least for the human society.**

But wait; do not enjoy the consensus yet, because the great controversial issue is still to come, in an article of 2002: **“Eugenics or empowered choice? Community issues arising from prenatal testing”**. (14) What Parker, Forbes, and Findlay have to say: *“The prevention of inherited disabilities is viewed in two contrasting ways -- **either as enhancing reproductive choice and improving population health, or as discriminating against disabled community members.** We*

*argue that modern clinical genetics, including **pre-implantation genetic diagnosis (PGD)**, reflects a persistent and defensible desire by the community to prevent disability, rather than as increasing discrimination or threatening to produce a 'new eugenic' society. **Screening should be presented as a distinct issue for decision-making about the prevention or acceptance of disability, rather than as a routinely accepted component of antenatal care.** The community must improve its understanding of the experiences of those who manage disability, and continue to debate the issues of discrimination, selective genetic prevention and enhancement, reproductive freedom, and eugenics.” (14)*

Huh, what am I going to say to this one? I will go again with the previously mentioned fourth principle of Biomedical Ethics (see again Tom L. Beauchamp and James F. Childress. Principles of Biomedical Ethics, 6th Edition: Oxford University Press, 2008. p. 417) – applied for this particular case – **with the money used for pre-implantation genetic diagnosis (PGD) in one case, I could feed 100 or more starving babies and save their lives, so I would go with just dispensing milk to these babies, avoiding their malnutrition and death.**

But, who is going to listen, when the big money is where it is, and the individualistic views prevail in the Western World?! I recently refurbished one of my old essays in which I was clearly expressing my restrictive views about the use of expensive reproductive technologies: *“Personally, I still see the desire to reproduce as an altruistic and morally acceptable act, even if the couple is not naturally fertile, and some exceptional measures are required to reproduce. But if the couple cannot prove good faith and altruistic approach to the intended offspring, one should better forget about “reproduction at any cost, using special means”.* (15)

I was feeling lonely while defending those poor starving babies, and I needed someone else to back-up my opinion. I remembered one of my revered professors at the Law School in Case-Western Reserve University, Cleveland, Ohio, while I was studying there as a scholar in Bioethics. I always admired his humanistic views, and therefore I looked for a reference published under his name, and eventually I found what I needed: *“Maxwell J. Mehlman, THE PRICE OF PERFECTION: INDIVIDUALISM AND SOCIETY IN THE ERA OF BIOMEDICAL ENHANCEMENT 218-26 (2009)”* (16a) quoted in another paper with a much stronger title, both published in 2009: *“Maxwell J. Mehlman, Will Directed Evolution Destroy Humanity, and If So, What Can We Do About It?”.* (16)

Suddenly some memories came as a torrent and flooded me, and I immediately remembered how awkward was to me the concept of “unlimited procreative liberty”, spread by Robertson. *“If the moral right to reproduce presumptively protects coital reproduction, then it should protect non-coital reproduction as well. Charges that non-coital reproduction is unethical or irresponsible arise because of its expenses, its highly technological character its decomposition of parenthood into genetic, gestational, and social components, and its potential effects on embryos, women, and offspring.”* (17)

I still do not know why “the concept of reproductive freedom” was introduced, for whose benefit, and how such idea may be accepted in the countries with the highest populations in the World – China, India and Brazil?!

It appears that my rhetorical question was heard, and it got an answer in 2002, within this article: *“Ethical dimensions of yousheng (healthy birth or eugenics): the perspective of a Chinese ethicist”.* (18) Kailin Tang has a strong position: *“An important task or calling of contemporary bioethics and ethics of population is to discuss these issues in order for people, even people in different countries and cultures, to reach some basic consensus and have practical ethical guidance. Based on the practice of yousheng in contemporary China, this paper offers a*

*Chinese perspective on ethical dimensions of eugenics. It will argue that individuals, as members of society, have a duty to provide society with healthy and normal children. Moreover, this paper examines the relationships between the aim and the means and conflicts between collective value and individual value, in yousheng.” (18)*

I have to admit that I have to refrain expressing my opinion on that issue, because I cannot put myself in their shoes, and it is always preferable to go with the opinions of the people who know the best the realities of their own place. Multiculturalism is a growing issue in many Western societies in the European Union and the USA, and it is difficult to impose any Westernized attitude over traditions and customs, provided these are not “genital mutilation”-like. Trying to unnecessarily persuading and forcibly implementing one’s views in someone else’s reality is nothing but ethical imperialism.

Again, it seems that someone may have heard my thoughts, and brought the multiculturalism in a very ardent suit of topics, in an article in 2005: **“Disability rights, prenatal diagnosis and eugenics: a cross-cultural view”** (19). Aviad Raz *“addresses the contributing factors and causes that ultimately lead to a lack of informed consent and a very high abortion rate for fetuses diagnosed with Down syndrome. Many women are unprepared to make prenatal decisions because of societal pressures to have “normal” children, a negative view of persons with disabilities by many in society, a fear of legal liability by those in the medical community, the lack of genuine informed consent before undergoing genetic testing and abortion, and the failure of non-directive pre-abortion counseling in the medical community. Moreover, medical professionals fail to communicate correct and unbiased information before and during the genetic screening, diagnostic testing, and abortion decision-making process.”* (19)

Mm, it is not quite what I was expecting from the title, but still brings the idea that having a child with Down syndrome may be a blessing in one society and a curse in another. Well, this is a fact, isn’t it!?

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