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JEAN MONNET CENTRE OF EXCELLENCE

INTEGRITY OF PERSON, THE PROHIBITION OF EUGENICS AND A RIGHT TO HEALTHY CHILD?

The new knowledge about the human genome is bringing about a revolution in the diagnosis of diseases and disorders and possibly an ability to improve people genetically. In recent years, the patenting of human genes has raised a new challenge to human rights, since according to some, it may revitalize the eugenics movement, which flourished during

the first-third of the 20th century¹.

In this respect, the international community faces the challenge of preserving human dignity, rights and freedoms, against the misuse of biological and medical advances.

¹ Kevles, D. J., 2011, From Eugenics to Patents: Genetics, Law, and Human Rights, *Annals of Human Genetics*, 75: 326–333.

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A BRIEF HISTORY ON EUGENICS

The term 'eugenics' was conceived by Sir Francis Galton (Charles Darwin's cousin and the inventor of composite photography) in the 19th century². Eugenic practice includes the systematic elimination of so-called "undesirable" biological traits and the use of selective breeding to 'improve' the characteristics of an organism or species. One branch of eugenics held that the rich and powerful were genetically superior to the poor, and that whites were in general superior to other races. Such a philosophy has provided convenient justification for a system of structuring inequities³.

The history of modern eugenics, in Europe and the United States, starts in the 19th century with the original idea that society should promote reproduction of those who had favorable characteristics and discourage the reproduction of those who had not. Eugenics became an academic discipline at many colleges and universities, and received funding from many sources. The first wave of eugenics, from its appearance to the end of World War II, found special support in the US, spread to Denmark, Switzerland, Norway and Sweden and seemed to have a strong influence in Germany, where applied to most extreme form with the Nazi rise to power in 1933. "Race", was a minor subtext in Scandinavian and British eugenics, but it played a major part in the American and Canadian versions of the creed. North American eugenicists were particularly disturbed by the immigrants from Eastern and Southern Europe who had been flooding into their countries since the late 19th century. They took them to be not only racially different from but inferior to the Anglo-Saxon majority⁴. After the Second World War and the fall of the Third Reich, eugenics as an

² However, the idea of eugenics to produce better human beings has existed at least since Plato suggested selective mating to produce a guardian class. Stanford Encyclopedia of Philosophy. Center for the Study of Language and Information (CSLI), Stanford University.

³ <http://www.nature.com/scitable/forums/genetics-generation/america-s-hidden-history-the-eugenics-movement-123919444>

⁴ Kevles, D. J., 2011, From Eugenics to Patents: Genetics, Law, and Human Rights, *Annals of Human Genetics*, 75: 326–333.

acceptable theory marginalized. However, some countries, mainly Sweden and the Canadian province of Alberta, maintained large-scale eugenics programs, including forced sterilization of mentally disabled persons, and other practices, until 1970⁵.

In USA, the “racial” pseudo-science, which legitimized systematic discrimination against racial and cultural minorities, was an important part of the context in which mainstream eugenic policies of “racial hygiene” were implemented, which included the banning interracial marriages and implementing forced sterilization laws. Moreover, a series of simplistic comparative studies on the inheritance of criminal behavior and mental retardation of various ethnic and racial groups led in 1924 to the adoption of the Federal Law on Migration⁶, which aimed at restricting the entry of immigrants from Southern and Eastern Europe countries, and the prohibition of immigrants of Italian, Asian and Indian origin in order to maintain the ideal of American homogeneity. With the landmark decision *Loving v. Virginia*, the US Supreme Court invalidated all laws forbidding interracial marriages⁷.

In Germany, the ideas of the “master race” (Übermenschen) of the German people resulted in the enactment of a series of laws on the sanitation of the German people from racially and genetically “inferior” people. More than 400,000 people were subjected to forced sterilization and it is estimated that 275,000 people were murdered by the euthanasia program “Action T-4”. Moreover, the law “On protection of German blood and German honor”, known as the “Nuremberg Law”,

⁵ Jackson E., *Regulating Reproduction, Law, Technology and Autonomy*, Hart Publishing, Oxford, Portland, Oregon 2001, p. 45.

⁶ Immigration Act of 1924, or Johnson–Reed Act, including the National Origins Act, and Asian Exclusion Act-Pub.L. 68–139, 43 Stat. 153, enacted May 26, 1924.

⁷ *Loving v. Virginia*, 388 U.S. 1, 1967. The court case of *Skinner v. Oklahoma* eventually did find the sterilization of criminals unconstitutional in 1942. However sterilization of other victims, most notably the mentally ill, was widespread in the United States until the mid-1970s.

included a) prohibited marriages between Jews and German blood citizens b) forbade sexual relations between Jews and citizens of German or related blood c) prohibited a Jew from recruiting a female employee of German or related blood under 45 years as a domestic helper and d) prohibited a Jew from lifting the new German flag. More specifically, the Nazi Party (NSDAP) elaborated and voted immediately after the seizure of power, a series of laws, in particular: a) the law for the avoidance of offspring with hereditary diseases in 1933, b) the law on Dangerous habitual criminals in 1934, c) the Act of homogenization of the health system in 1934, d) the law on the protection of German blood and German honor in 1935 and e) the law on the protection of the hereditary health (Erbgesundheit) of the German people, known as the law on healthy marriage (Ehegesundheitsgesetz) in 1935. Based on these laws, the first persecution of Gypsies began, who, as the Jews, were considered racially “inferior. In addition to the above groups, the practice of sterilization also applied to the so-called “Rheinlandsbastarde”, ie. children born to German women and black soldiers who served in the French army of occupation⁸.

The human right to personal integrity is considered to be the positive expression of the prohibition of torture, inhuman and degrading treatment and punishment, as laid down in Article 3 of the European Convention on Human Rights (ECHR) or in Article 7 of the UN Covenant on Civil and Political Rights (CCPR). The right to personal (physical and mental) integrity is a fairly broad right, which includes the prohibition of physical and mental torture, inhuman and degrading treatment and

⁸ Kühl S., *The Nazi Connection: Eugenics, American Racism, and German National Socialism*, Oxford University Press, Oxford, New York 1994, p. 70-74.

. Spektorowski A., Ireni-Saban L., *Politics of Eugenics: Productionism, Population and National Welfare*, Routledge, London 2013, p. 50-132.

PERSONAL INTEGRITY AND THE PROHIBITION OF EUGENICS IN THE EU CHARTER OF FUNDAMENTAL RIGHTS

punishment as well as a broad range of less serious forms of interference with a person's body and mind which have traditionally been covered by the right to privacy⁹.

The importance of the free and informed consent to medical and scientific procedures is based on the principle of autonomy, namely the idea that individuals should be able to make decisions about how to live. This is a concept at the heart of modern biomedical ethics and the right to integrity of the person. The decision of the Court of the European Union confirmed that a fundamental right to human integrity is part of the Union law and encompasses, in the context of medicine and biology, the free and informed consent the donor and recipient. This right also prohibits reproductive cloning and eugenic practices and other methods that offend human dignity¹⁰.

In the framework of the Council of Europe, the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine, which has been adopted on 4 April 1997 and entered into force on 1 December 1999, lays down a series of principles and prohibitions concerning bioethics, medical research, consent, rights to private life and information, organ transplantation, public debate etc. It bans all forms of discrimination based on the grounds of a person's genetic make-up and allows the carrying out of predictive genetic tests only for medical purposes. The treaty allows genetic engineering only for preventive, diagnostic or therapeutic reasons and only where it does not aim to change the genetic make-up of a person's descendants. It prohibits the use of techniques of medically assisted procreation to help

⁹ EU Network of Independent Experts on Fundamental Rights, *Commentary of the Charter of Fundamental Rights*, June 2006, p. 39-40: http://ec.europa.eu/justice/fundamental-rights/files/networkcommentaryfinal_en.pdf.

¹⁰ Judgment of the Court of 9 October 2001, *Kingdom of the Netherlands v European Parliament and Council of the European Union*, Report of Cases 2001, p. I-7079.

choose the sex of a child, except where it would avoid a serious hereditary condition¹¹.

Respect for human dignity and integrity of person in their process of balancing the freedom of science and biomedicine is reflected in article 3 para. 2 of the EU Charter of Fundamental Rights, which provides that: *In the fields of medicine and biology, the following must be respected in particular: (a) the free and informed consent of the person concerned, according to the procedures laid down by law; (b) the prohibition of eugenic practices, in particular those aiming at the selection of persons; (c) the prohibition on making the human body and its parts as such a source of financial gain; (d) the prohibition of the reproductive cloning of human beings.*

The prohibition of eugenic practices has been included in Article 3(2) on the initiative of the European Group on Ethics in Science and New Technologies. On the request of Commission President Prodi, this group has submitted in June 2000 a report on the draft Charter to the Convention, which included the proposal for an additional article on the 'prohibition of eugenics. The most serious forms of eugenic practices, such as forced pregnancy and enforced sterilization committed as part of a widespread or systematic attack directed against any civilian population, also constitute crimes against humanity, as prohibited by Article 7(1)(g) of the Rome Statute of the International Criminal Court of 17 July 1998. The reference to the ICC-Statute in the explanations of the presidium should not, however, lead to the conclusion that only such serious eugenic practices are covered by the explicit prohibition of eugenic practices in Article 3(2) of the Charter¹².

¹¹ CETS No.164: 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.

¹² EU Network of Independent Experts on Fundamental Rights, *Commentary of the Charter of Fundamental Rights*, June 2006, p. 39-40: http://ec.europa.eu/justice/fundamental-rights/files/networkcommentaryfinal_en.pdf.

According to the Explanatory Notes to the Charter, the prohibition of eugenic practices “relate to possible situations in which selection programmes are organized and impemate involving campaigns for sterilization, forced pregnancy, compulsory ethnic marriage among others”. The listed prohibited practices have an obvious link with integrity, as they are related either to compulsory selection programmes nased on eugenic considerations, or to campaigns which might affect the freedom of choice to individuals concerned. Because of this, victims of such practices are already protected by the right to integrity in Article 3(1), and, to the extent that these practices involve medical procedures, eg. In the case of sterilations by the requirement of informed consent set out in Article 3(2) of the Charter. The prohibition adds to the protection of the general right to physical and mental integrity the express condemnation of these practices in the fields of biology and medicine.

Today, the interest in the issue of eugenics has increased, especially regarding the field of pre-implantation genetic diagnosis (PGD)¹³. For example, the resolution of the Parliamentary Assembly of the Council of Europe, of 2011, sets out to outlaw the practice of prenatal and pre-implantation genetic testing to determine the child's sex, with a view to terminating the life of the fetus. The resolution, however, states that the selective abortion based on sex should be prohibited unless it is justified to prevent serious sex-linked genetic diseases and, except when it is justified to prevent serious hereditary diseases¹⁴.

In fact, the twenty-first century has produced a new movement of eugenics, which is called “liberal eugenics” as it

¹³ Parliamentary Assembly Motion for Resolution Doc. 12996, Combating eugenics and discrimination against people with disabilities, 06 July 2012.

¹⁴ Council of Europe, Parliamentary Assembly, Resolution 1829 (2011). Prenatal sex selection.

NEW-EUGENICS AND CONTEMPORARY DILEMMAS IN THE EUROPEAN PUBLIC ORDER

advocates for genetic modification of humans on liberal political grounds. Genetic modification includes everything from screening for genes that cause serious disabilities, to genetically producing “smarter” children. Liberal eugenics, proponents argue, is founded on traditional liberal values of pluralism, respect for personal autonomy, and egalitarianism¹⁵.

The European Court of Human Rights has faced a number of cases relating to prenatal diagnosis and abortion. Since the principles established by the Court in its case law are binding on all member states of the Council of Europe, the Court’s judgements are decisive for the interpretation of the principles of respect of human life, dignity and integrity of person. For example, on 2012 the Second Section of the European Court of Human Rights delivered the long-awaited judgment in the case of *Costa and Pavan v. Italy*. The questions raised originated from the application of an Italian couple who, being healthy carriers of cystic fibrosis, desired to resort to medically-assisted procreation and genetic screening in order to avoid the risk of transmitting the disease to their descendants. Relying on Articles 8 and 14 of the European Convention on Human Rights, they complained that the Italian Law, banning couples of healthy carriers of genetic disease from *in vitro* fertilisation and embryos pre-implantation screening, violated their right to respect for private and family life and the prohibition of discrimination as enshrined in the Convention. The European Court of Human Rights ruled that, by forbidding the recourse of couples carrying a genetic defect to medically assisted procreation and preimplantation screening, whilst simultaneously permitting abortion in cases where the foetus was suffering from such an illness, Italy had, due to this alleged inconsistency, violated Article 8 of the Convention – which guarantees the right to the

¹⁵ http://cdn.harvardlawreview.org/wp-content/uploads/pdfs/regulating_eugenics.pdf

respect of private and family life¹⁶. The case have been scrutinized and criticized for recognizing a right of parents to bear a child who is not affected by the disease they are healthy carriers¹⁷, or in other words a true right to a genetically healthy child, which may open the door to eugenics¹⁸.

Most recently, in the case of *Anita Kruzmane v. Latvia*, a mother (Kruzmane) complained that she had not been able to abort her Down's syndrome daughter. She claimed that her doctor had breached an obligation to prescribe a screening test for Down's, that this omission had caused her to give birth to the daughter, and that she had thereby suffered a violation of her right to respect for private life, which she said included the right to decide to have an abortion. The European Court of Human Rights concluded that the domestic courts' approach to the applicant's claim discloses the appearance of arbitrariness. The cumulative effect of the failings identified was that the domestic courts did not properly examine the applicant's claim that she had not received medical care and information in accordance with domestic law in a manner sufficient to ensure the protection of her interests. There has accordingly been a violation of Article 8 of the Convention in its procedural aspect¹⁹.

In technologically advanced societies, people with genetic disabilities increasingly suffer from a new widespread prejudice: eugenic ideology which considers their very existence as a

¹⁶ *Costa and Pavan v. Italy*, Application No. 54270/10, 28 August 2012. Puppinc G., The Case of Costa and Pavan v. Italy and the Convergence between Human Rights and Biotechnologies. Commentary on the ECHR Ruling in Costa and Pavan v. Italy, No. 54270/10, 28th August 2012 (July 1, 2013). Quaderni di Diritto Mercato Tecnologia - N°3, Anno III . Available at SSRN: <http://ssrn.com/abstract=2348142>

¹⁷ *Costa and Pavan v. Italy*, par. 65.

¹⁸ Puppinc G., The Case of Costa and Pavan v. Italy and the Convergence between Human Rights and Biotechnologies. Commentary on the ECHR Ruling in Costa and Pavan v. Italy, No. 54270/10, 28th August 2012 (July 1, 2013). Quaderni di Diritto Mercato Tecnologia - N°3, Anno III . Available at SSRN: <http://ssrn.com/abstract=2348142>

¹⁹ *A.K. v. Latvia*, Application No. 33011/08.

CONCLUDING REMARKS

medical error. In some European countries, over 90% of fetuses diagnosed as Down syndrome are routinely eliminated before birth. Eugenics is a reality in countries where prenatal screening has become systematic, in turn leading to the stigmatization of persons with genetic disability and their families, in particular those with Down syndrome. European and international law has repeatedly condemned eugenic ideology since the Nuremberg trials in Articles 4 and 10 of the UN Declaration on the Rights of Disabled Persons. Other European and international norms, such as the Universal Declaration on the Human Genome and Human Rights, the Convention of the Rights of the Child as well as the Oviedo Convention, contain similar provisions²⁰. The EU Charter of Fundamental Rights exemplifies the link between integrity, informed consent and the prohibition of eugenic practices.

Rather than being forcefully imposed, these new eugenic mechanisms reflect the ideological values of the social formation in which the rationalized reproductive process occurs. As Owen predicted, eugenic ideology, if not practice, is rapidly being naturalized. Under the guise of optimizing reproduction—and “improving” human beings—today’s reproductive technologies are being implemented without a critical discussion of their latent eugenic content²¹.

Nikolaos Gaitenidis

Research Associate

nikgait@yahoo.com



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²⁰ Parliamentary Assembly Motion for Resolution Doc. 12996, Combating eugenics and discrimination against people with disabilities, 06 July 2012.

²¹ Regulating Eugenics Harvard Law Review Vol. 121, No. 6 (Apr., 2008), pp. 1578-1599, http://cdn.harvardlawreview.org/wp-content/uploads/pdfs/regulating_eugenics.pdf

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