

Neither an 'Enhancement' nor 'Elimination': A Further Eugenic Route Towards PGD

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Abstract

The fine word 'enhancement' sounds even better when it is compared with its ferocious companion 'elimination'. In simple terms, the enhancement or elimination of human generations will lead to a eugenic disaster. The single terminology difference here is the violence in their applications. 'Enhancement' in new generations, according to the formal literature language of 'positive eugenics', can be applied by encouraging 'well-born' people to reproduce by rhetorical or biotechnological ways. On the other hand 'elimination', according to the formal language of 'negative eugenics', can be realized by sterilization or abortion applications in undesired people or even by genocide. For this reason, the role of pre-implantation genetic diagnosis (PGD) in obtaining the characteristics of an embryo is very important for practices towards eugenics. This study provides some evidence from street level for understanding the importance of, and for questioning eugenics types.

Introduction

Genetic engineering is growing stronger day by day in the context of more complex applications in health biotechnology and especially in reproduction technologies. On the one hand these applications give hopes to infertile or risk group people with respect to eliminating specific genetic diseases, while on the other hand threatening human variety and equality. PGD is already accessible for those couples who can afford to choose babies without certain diseases and with the desired sex. It creates inequality and tacitly stimulates efforts to achieve a 'better human strain'. If the family is accepted as the smallest unit of society, then nobody could point a finger of blame at me for my cheerless assumptions concerning the continued eugenic route towards PGD and the mothers and fathers of the future.

An article by a social scientist (Liao 2005, 116) on gene technology which I read some years ago also touched upon some traditional beliefs

on how to get babies of the desired sex. According to one of those beliefs, a male baby could result when the expectant mother eats foods high in sodium and potassium, for example, bananas, cherries, grapes, oranges, peaches, melons, broad beans, sprouts, celery, tomatoes, or sweet corn. The writer discussed the ethical dimension of that passion which differs according to the 'techniques' used: eating bananas in order to have a baby of the desired sex could be regarded as ethically acceptable while choosing the sex of children by PGD is not.

Social behaviour and technological applications, which are used for making people's hopes come true, are also the research subjects of sociology. These innovations lead sociology to rethink societal structures such as economy, beliefs, cultures; and ultimately the specific perceptions related to biology and genetics in order to understand their dynamics.

I will examine this issue further in this contribution. What does PGD promise people to do? What is technically possible but ethically or practically impossible in the context of reproduction technologies? How and in what ways does the country you live in affect these possibilities? Which should be ethically acceptable, the elimination of 'homosexuality' or of 'depression'? If we assume that 'the new eugenics' will indeed result in individual parent decisions, can all these eliminations and enhancements take us to another eugenic future? These questions are coming into prominence, because an idea may be the spark behind the establishment of a eugenic generation while being camouflaged behind personal perceptions. The assumption here is opposed to such kind of individualistic enhancements. On the contrary, a new elimination policy can – or possibly will – direct these enhancement efforts. Of course socio-economic, cultural, political, and in many respects religious, characteristics and family structures would determine the so-called 'individualistic decision' taken by the women and/or couples involved.

For this assumption, this study discusses PGD as a tool, not only for medical purposes but also its potential use for some socio-political goals. In other words, PGD can be defined as an enhancement tool geared to the preferences of mother candidates and/or an elimination tool for a new eugenic approach; or both of these since they have one and the same meaning!

PGD for what?

People who are suspicious about being carriers of genetic disorders or have genetic disease carriers among their relatives frequently opt for a genetic test. Genetic conditions, also called genetic disorders, are caused by changes (mutations) in genes that affect how the body works or looks. Although it is individually quite rare, – cystic fibrosis,¹ for example, affects approximately one in every 2500 babies born – there are thousands of different genetic disorders. Taken together, this means that an estimated two to three percent of all babies are born with a genetic or chromosomal condition – approximately 13,000 births every year in the UK (Buxton & Turney 2007, 115).

Genetic tests are now routinely used as a reproduction technique in order to obtain the genetic risk tendencies of couples who are planning to have or expecting babies. In many countries of the world pregnant women are screened through a series of tests in order to learn if there is a high risk of any sort of genetic disorders in their babies. There is frequently no other choice open to couples apart from an abortion, where a serious genetic risk is perceived in respect to an unborn child. PGD is another approach however, in particular for couples who will not consider a pregnancy termination (Buxton & Turney 2007, 147). The clear PGD explanation of Moore (2008, 25) will be useful here:

Doctors can bring a couple's sperm and eggs together in a laboratory to create an embryo. After a few days, the embryo will have grown so that it consists of around eight cells. Scientists can remove one of the cells and test its genes. If the test shows that the disease-linked gene is in the cell then the scientist discards the embryo. If the test shows that the gene is not in the cell, then the embryo is placed in the woman's womb and allowed to develop. This process is called *pre-implantation genetic diagnosis*.

This so-called risk-free application of genetics has opened up many ethical discussions ranging from choosing the sex of children to creating a new kind of eugenics. Because, if it [choosing] is technically possible, then couples who want to have a risk-free baby can also choose their babies' sex. In the light of equality, its opposite should also be possible; deaf,

obese or homosexual couples should have the right to parent deaf or obese or homosexual children with the reasoning of intra-familial conformity. In his book, Harris (2007) writes: 'No enhancement however dramatic, no disability however slight, or however severe, implies lesser (or greater) moral, political, or ethical status, worth, or value. This is a version of the principle of equality' (Harris 2007, 86).

Again Harris asks:

Is it wrong to prefer to produce a non-disabled child and attempt to achieve that preference ...:

- by wishing and hoping?
- by behavior modification?
- by postponement of conception?
- by interventions, therapeutic or enhancing (including gene therapy)?
- by selecting between pre-implantation embryos?
- by abortion? (Harris 2007, 89)

To ask these questions is important and moreover, to interpret the relations in the light of eugenics would take us to another dimension of discussion.

ART and PGD in some European countries

Manners and attitudes towards assisted reproduction technologies (ART) vary considerably across national borders. For example, about half of the European countries allow these technologies for cohabiting couples, while one-quarter limit them to married couples, and another quarter allow single women² to use the technology.

In their overview of reproductive services in Europe, analysts Darren Langridge and Eric Blyth classify country law into categories of 'laissez-faire, liberal, cautious regulatory, or prohibitive'. According to their study, Greece, Hungary and Poland are laissez-faire in their approach and place virtually no restrictions on use of ART. Great Britain, the Netherlands, and Spain represent examples of a liberal, permissive

approach on regulation. These nations have passed some legislation on the 'Donation and Use of Elements'. Germany and Austria have the most stringent regulations on use of conception technologies. Mindful of its Nuremberg Code and Nazi medical abuses, Germany's Embryo Protection Act of 1990 limits reproductive therapies to in vitro fertilization and sperm donation. The law does not allow egg or embryo insertion or surrogate motherhood (West 2007, 37–38).

PGD is currently offered at only eight centres in the UK – all are fertility clinics licensed by the Human Fertilization and Embryology Authority (HFEA).

Maternal health and PGD in Austria and Turkey

Austria

The maternal and child health programme was introduced in the early 1970s (specifically the 'mother-child passport'). Since then, together with improvements in living standards, there has been a continuous decline in infant mortality rates. Up to the mid-1990s, financial incentives (1,090 euros in several instalments) were offered to pregnant women to have the preventive check-ups included in the 'mother-child passport'. These funds were cut in 1996, as part of the consolidation pact, and means-tested bonus payments were introduced instead. The programme provides for five check-ups for pregnant women, including two laboratory tests, an examination by an internist, plus five examinations of the infant during the first year of life, including an orthopaedic, ear-nose-throat (ENT) and eye test. An extension of the maternal and child health service is under discussion. Check-ups proposed for inclusion in the mother-child passport have been under evaluation by the Supreme Health Board since 1993 (Hofmarcher 2001, 55).

PGD is prohibited in several countries worldwide, including Austria, Germany, Switzerland and Italy (Buxton & Turney 2007, 150). Through its 1992 Act on Procreative Medicine, Austria has introduced these limits as well as restrictions on sperm donation (West 2007, 38). In Austria, genetic testing is governed by the Gene Technology Act which regulates the con-

tained use of genetically modified organisms, the use of genetic testing and gene therapy in human beings. The act also stipulates that an intervention into the human germ line is strictly prohibited. Section 65 stipulates that genetic testing may only be carried out where it is at the request of a doctor specializing in medical genetics and either for verification of a predisposition to a late onset disorder or for verification of carrier status or the diagnosis of an existing disease or late onset disorder (EC 2002, 15).

Turkey

Mother and child health and family planning services have been given priority status in the policies of the Turkish government in recent decades. These services gained importance due to the large proportion of women of reproductive age and also of children³ in the Turkish population, high infant, child and maternal mortality rates, the demand for family planning services, and limited prenatal and postnatal care (Hacettepe University Institute of Population Studies 2009, 10). According to the findings about care during pregnancy in the same report (2009, xviii), ninety-two percent of mothers received prenatal care during the pregnancy preceding their most recent birth in the five years preceding the survey, with 90 percent receiving care from a doctor. Overall, 87 percent of women made a prenatal care visit before the sixth month of pregnancy. Younger, low parity women, women living in urban areas and in the regions other than the East, and women with at least first primary level education are more likely to have received prenatal care compared to other women.

A deficiency exists, however, in obtaining the informed consent of the people in various terms. Genetic testing during pregnancy is made routinely; in other words, without obtaining the consent of the patients. This situation poses an ethical question, because if the doctor of a pregnant woman asks her whether she wishes to know the trisomy risk of her child, many expectant mothers will refuse to take the test. In Turkey, however, women undergo these tests without being given sufficient information about them. All they know is the tests are essential for a healthy pregnancy and needless to say, the women involved have full confidence in their gynaecologists.

Turkey has serious problems about having an influential law including simultaneous genetic testing and diagnosis. PGD is forbidden in the country but there is no sanction associated with the prohibition. The country is thus faced with illegal applications of genetic testing: it is known that, in some assisted reproduction centres, sex selection via PGD is an option for the parent candidates. Moreover, people from countries where PGD is banned can come to Turkey and choose the desired sex from among their embryos. People know the option is open for them to travel and get these biotechnological services in another country!

Positive and negative eugenics

Eugenics is derived from the Greek word *eugenes*, meaning 'well-born' or 'good in birth' (Gray 1999, 84; quoted from Mehta 2000, 223). In the late 1800s, eugenic thought began to gain ground and momentum and significant problems occurred. Francis Galton – a cousin of Charles Darwin – had the vision to develop the 'perfect' group of people through selective breeding, by encouraging upper-class 'superior' people to reproduce (Mehta 2000, 223).

This practice was named 'positive eugenics'. Those who agreed with him tended to favour 'positive' eugenics, which, instead of discouraging or preventing reproduction by the wrong people, employed methods, such as propaganda or financial subsidies, to promote reproduction by the right people.⁴ After all, the success of efforts to encourage some people to have more children required the subjects' active cooperation (Paul 2007, 4).

Eugenics did not just mean encouraging parents of the right 'quality' to have more children (positive eugenics). It also took in discouraging the less promising specimens of humanity from breeding (Buxton & Turney 2007, 154). The standard narrative features racists and reactionaries – often Nazis – and policies that are 'negative' (that is, aimed at preventing or discouraging some people from reproducing), mandated by legislation, and coercively enforced. In these obligatory historical synopses, eugenic policies were based on 'pseudo-science' (Paul 2007, 3). Parallel with this explanation, the Nazis believed that if any German citizens were diseased,

were born physically or mentally disabled, or were part-Jewish, it was necessary to sterilize them to prevent further breeding. The Sterilization Law passed in 1933 permitted the Nazis to practice this form of 'racial cleansing' (Caplan 1992, 44; quoted from Mehta 2000, 224). That cleansing was named 'negative eugenics', which was practiced to discourage 'undesirable' individuals from reproducing.

Findings and discussion

About PGD

As Francis Fukuyama (2003, 109) wrote, this more compassionate version of eugenics which is appearing over the horizon, has neither an oppressive state nor is it imposed forcefully on the population; conversely, this time a smoother eugenics will be based on merely personal choices of parents. In other words, eugenics may possibly arrive this time around with public preferences, and/or personal perceptions towards pre-implantation genetic diagnosis, rather than state racism. If these personal choices are important in understanding technology use and eugenics, then it will be meaningful to look at some personal attitudes towards pre-implantation genetic diagnosis.

Table 1. The behaviour of undergoing pre-implantation genetic diagnosis (PGD) testing

PGD Chi-Square: 11.640, P < .01	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Yes	5	20	–	–	5	10
No	7	28	18	72	25	50
No comment	13	52	7	28	20	40
Total	25	100	25	100	50	100

Ocak (2010) carried out this study in 2009–2010, in Ankara, Turkey and Graz, Austria. The study mainly based on 50 interviews through a questionnaire form, which include open and closed-ended questions. These interviews showed how memories of the Nazi era or/and prohibition in Austria concerning PGD detained people from expressing their ideas explicitly, but could not prevent them from regarding this technique as an alternative. The 'no comment' answers of Austrian people must also be evaluated from this point of view. When Turkish responses about PGD are compared with those in Austria, the willingness and courage of Turkish people stand out clearly. The legal gap and the lack of comprehensive knowledge about PGD or the desire to make use of such an elimination or enhancement tool may lie behind the thinking and the responses of the Turkish interviewees. On the other hand their 'no comment' answers may also quite possibly have different meanings and motives, such as religious reservations, lower purchasing power or indecision on this issue. The 'no' answer group in Ankara, however, uses much more interesting expressions, including the answer of a male participant: 'I cannot be sure of the sperm origin (...) they could take it from another man.'

The intervention of others

Everyone is aware that they are affected by many actors from their immediate surroundings in deciding about various issues, not least when making important decisions. Whether or not a person should undergo genetic testing during pregnancy is one and perhaps the most difficult of these 'inescapable decisions'.⁵ People who are faced with this difficult choice would clearly be among those who seek advice from others, e.g. the partner, families, friends, doctors and religious authorities.

Here again people from different countries would most likely be influenced by different agents. An example of this kind of difference is seen in Ocak (2010). The influence of friends and partners' families was assumed to be the most important factor, but came out bottom (28 %) in both Turkey and Austria. When compared to Graz (12 %), the family's influence was relatively high in Ankara (44 %) so that a difference is clearly perceptible here.

The 'family' is of major importance in Turkey, especially in the lives of traditional communities. Due to the paternalistic structure of society, the family of the male is more dominant. Many modern families also maintain firm family roots. The decisions made by young families are of great interest to their families of origin. While a young woman has the least level of influence in daily family life, the oldest woman in the family enjoys the highest authority when her husband is not present or dead.

It was thus not a chance response of a participant of Eysel's study (2007, 7) when he was asked 'would you want your wife to undergo an abortion if the prenatal tests show a serious disorder in your baby's genes'? He replied that he had recently married and his family were eager for a grandchild. If the hoped for baby were to be male and with a genetic disorder, his family would probably not wish his wife to have an abortion. Even if she decided for the abortion, they could prevent her from this course of action, because this baby, who would maintain their line, would be the first male grandchild of a large family. This case is important in order to illustrate the crucial role of the husband's family in the wife's decisions about her pregnancy.

Table 2. Importance of advice from other people

PARTNER Chi-Square: 3.448, P < 1, .328	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Very important	19	76	15	60	34	68
Important	2	8	7	28	9	18
Not too important	1	4	1	4	2	4
Not important	3	12	2	8	5	10
No comment	3	12	2	8	5	10
Total	25	100	25	100	50	100

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MY FAMILY Chi-Square: 4.701, P < 1	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Very important	8	32	3	12	11	22
Important	8	32	12	48	20	40
Not too important	2	8	5	20	7	14
Not important	4	16	3	12	7	14
No comment	3	12	2	8	5	10
Total	25	100	25	100	50	100
MY DOCTOR Chi-Square: 12.351, P < .01	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Very important	13	52	3	12	16	32
Important	7	28	10	40	17	34
Not too important	1	4	6	24	7	14
Not important	1	4	4	16	5	10
No comment	3	12	2	8	5	10
Total	25	100	25	100	50	100

This study again confirmed that Turkish respondents give more importance to their partner's family's advice in genetic testing than Austrians do. When comparing the results within the Austrian group (partner's family 12 % and my family 60 %), the gap between the effect of family preferences is clearly seen. Despite the slightly egoistic approach of Austrian respondents about interference on the part of their families in their genetic testing, Turkish respondents value the advice given by their family (64 %) and that of their partner's family (44 %) on a more equal basis.

The partner's influence is high in both cities. Whether or not the partner is male or female, the couple cannot come to a decision about

genetic diagnosis testing without consulting each other. The couple is then transformed into 'an individual' because the decision is a joint one of the pair and not that of a single individual.

The effect the doctor has is quite different in Ankara (80 %) as compared to Graz (52 %). Medicine still has a 'supreme' position as a profession in Turkey and couples or other patients trust in their guidance. The manner in which these professionals explain the test results gains importance here. Explaining risks to patients or to pregnant women is a very sensitive issue, since it can result in the birth of an unwanted and disabled baby or also lead to an unnecessary termination of pregnancy, or again most likely, depression. For this reason, the final decision belongs to the patient or couple. In Turkey, however, great reliance is placed on the opinion of a medical doctor or specialist.

'Would you like to choose ...'

According to Buxton and Turney, it will probably never be possible to select embryos using a 'shopping list' of desired characteristics, even if there were a demand for such children. In spite of this opposition, they mention an exception to gender as explaining that some couples have already used PGD to select either a boy or a girl (2007, 153).

In this context it was thus meaningful for the author to ask people, if they had a chance to do so, would they like to determine the sex, beauty and intelligence levels of their unborn baby using PGD (Ocak 2010).

6 of 25 (i.e. more than 1/5 or 20/100) respondents want to determine the sex of their children, while 1/5 have no comment. The same ratios are also valid for determining the beauty or intelligence levels of babies.

In a study on the social applications and developments of the human genome project carried out in the four Latin American countries of Argentina, Chile, Mexico and Peru included interviews and questionnaires with biomedical researchers, legislators and lawyers with knowledge on legal aspects related to genetics, journalism and engineering students and lay persons, the researchers were also interested in scientific advancement and would accept more genetic enhancement for reasons related to beauty and intelligence (Yunta et. al. 2005, 243).

Table 3. Attitudes towards positive eugenics statements

'I WOULD LIKE TO DETERMINE THE SEX OF MY CHILD' Chi-Square: 10.578, P < .1	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Surely agree	–	–	1	4	1	2
Agree	4	16	1	4	5	10
Disagree	8	32	1	4	9	18
Surely disagree	11	44	19	76	30	60
No comment	2	8	3	12	5	10
Total	25	100	25	100	50	100
'GENETIC TESTS WILL BE USED IN ORDER TO INCREASE BEAUTY AND INTELLIGENCE LEVELS' Chi-Square: 15.467, P < .01	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Surely agree	2	8	–	–	2	4
Agree	12	48	3	12	15	30
Disagree	5	20	5	20	10	20
Surely disagree	2	8	13	52	15	30
No comment	4	16	4	16	8	16
Total	25	100	25	100	50	100
'A HEALTHIER SOCIETY CAN BE GAINED BY GENETIC ENGINEERING' Chi-Square: 13.111, P < .01	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Surely agree	–	–	–	–	–	–
Agree	16	64	5	20	21	42
Disagree	3	12	11	44	14	28
Surely disagree	1	4	5	20	6	12
No comment	5	20	4	16	9	18
Total	25	100	25	100	50	100

None of the respondents was sure, but 42 % of them agreed with the assumption that a healthier society could be achieved by genetic engineering. The meaning of these ratios from the viewpoint of eugenics is: people are sensitive about determining the characteristics of their unborn babies via biotechnology. However, only a few people want to use this technology in order to choose the desired characteristics. This small scale study is of course, not in itself sufficient to say definitively that the people in the surveyed cities want something or not, but it is nevertheless possible to say that many people believe in the power of genetic engineering as a means of achieving a healthier society (42 %). In other words, they believe that enhancement via genetic engineering is possible.

'Would you like to eliminate ...'

'Eliminating' is a more sensitive issue in eugenics than 'enhancing' because it includes the destruction of some so-called 'wrong entities'. While in modern times the enhancement process of living organisms occurs only through genetic diagnosis, the elimination process materializes through genetic diagnosis and surgery.

It is possible to make an addition to Rabino's selection methods (2003, 89). He described elimination as 'selecting between pre-implantation embryos' and 'abortion'. The 'by killing' option can be added as an alternative. However, today, 'abortion' and 'elimination of defected embryos' are modern practices and thus, popular. Everyone today knows that termination is frequently a chosen course for babies with serious health risks such as trisomy⁶ or unplanned babies, and sometimes even for babies of undesired sex. In addition to all these reasons of termination, the author asked her respondents if termination could be ethically acceptable when the unborn child is most likely to be homosexual or depressive (Ocak 2010). Through this question, the writer surveyed whether people regard these conditions as 'illnesses' and thus whether they believed that termination was ethically acceptable for these reasons. According to her findings, some respondents in Ankara (20 %) believed that if it were possible to fully understand the homosexuality risk of the baby, the termination of that pregnancy would be ethically acceptable. The rate of acceptance in Ankara in the case of

depression is 28 %. These rates are important when compared with Graz, since no one there accepted termination for these conditions.

Rabino (2003a, 367) evaluated 1,236 surveys which were mailed to him by US researchers of the American Society of Human Genetics. According to his survey results, opposition to termination occurs with (1) conditions that are less serious or that would not necessarily be characterized as diseases, or (2) when the onset is later in life. Two results are therefore considered not ethically acceptable: if the unborn child is likely to 'be homosexual' (83 percent) or suffer from depression (70 percent) (Rabino 2003, 375).

Table 3. Ethical acceptance of an abortion / elimination for reasons of 'homosexuality' or 'depression'

HOMOSEXUALITY Chi-Square: 14.667, P < .0	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Very important	4	16	–	–	4	8
Important	1	4	–	–	1	2
Not too important	5	20	1	4	6	12
Not important	12	48	24	96	36	72
No comment	3	12	–	–	3	6
Total	25	100	25	100	50	100
DEPRESSION Chi-Square: 12.884, P < .01	CITY				Total	
	Ankara		Graz			
	N	%	N	%	N	%
Very important	2	8	–	–	2	4
Important	5	20	–	–	5	10
Not too important	5	20	6	24	11	22
Not important	10	40	19	76	29	58
No comment	3	12	–	–	3	6
Total	25	100	25	100	50	100

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The rate among Turkish people reminded me of the remarks of Selma Aliye Kavaf, who is the Secretary of State for Family and Women. She has stated that she believes homosexuality to be a biological defect, an illness which needs to be treated (Tokmako_lu 2010). Of course this narrow-minded approach of a politician in 2010 is a disaster for the representation and management of public opinion and also for the international political standing of the country.

Ultimately it can be hoped that this statement will remain no more than a blunder on the part of a secretary of state and a small group of like-minded people. This is, however, an informal interpretation for Turkey and there are quite possibly many more Turks who share this conservative view.

Final discussion

Buxton and Turney (2007) referred to designer babies and do not see a future for this kind of selection. However, they accept sex selection as an 'exception' and they explain it as 'a non-medical trait for which some couples have already used PGD to select either a boy or a girl' (Buxton & Turney 2007, 153). From this point of view, couples can use technology in whatever way they see fit. From this the conclusion can be drawn, or the question raised that some couples may wish to design other characteristics for their babies in the future. According to many writers a 'free choice' will be open to these couples and their choices will be regarded as 'exceptional'. In my view this raises a further ethical problem. Buxton and Turney (2007, 152) underline that there is evidently a significant difference between a state-controlled effort and personal decisions in reproduction, i.e. 'elimination' in the first case and 'healthy child' in the latter. Can a state be permitted to wish for healthier children, generations or breeds for the society it governs? Or will not parents themselves be responsible for eugenic eliminations by wanting healthier children, and moreover the best possible offspring? Gupta (1991, 46) provides a helpful reminder: one of the features of the Nazi state was its totalitarian tendency to wipe out the boundaries between public and private life and to politicise every aspect of the individual's existence.

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In brief, the line between individual decision making and state sanctions, which many authors want people to believe in, has a transitional structure. For instance, one can see this study as an effort to understand with whom we are forming our opinions. The family, a doctor, religious authorities can all determine or affect (more or less) the choices made by couples wishing to have children. In fact each agent questioned represented some infrastructure or other (economy, politics, society, culture, religion, etc.) of the respective country. The family unit of society will not, of course, make the decision alone; it will be determined by all these factors.

In the second part of the study, the ideas about 'desired and undesired characteristics' are shown and discussed. These statements permitted perceptions about negative and positive eugenics to be evaluated. More than half of the respondents (68 %) of Ocak (2010), approved of the idea that genetic tests would be used as a tool for increasing beauty and intelligence levels and for achieving a healthier society. In other words, many people accept that a positive eugenic result can be materialized via genetic diagnosis testing. Two specific situations [homosexuality and depression] were chosen and the perceptions about them were researched. Finally, it was also found that people from Ankara, Turkey, were more willing to eliminate persons identified with these specific conditions.

Finally, biotechnology is an issue that by its nature extends permanently into the future. Many people who launch attacks on it do so without first thinking coherently, or learning enough about this complex subject. Pre-implantation genetic diagnosis is one of its most controversial issues and its results and reflections on society have not yet been sufficiently analyzed or assessed.

According to Baldi (2001, 159) it was a mistake for scientists to believe that the use or misuse of science does not depend on them, but only on politicians. Specialists, and even lay persons, will have to make a self-evaluation on this issue. But the lion's share in this process will inevitably fall to the national states. In this context, however, there are no expectations that the states will search their consciences in addressing the fundamental moral issues. And it is thus the social scientists who will have to take on the responsibility for the relentless process of scrutiny and questioning and to do so again and again, and again ...

Notes

- ¹ Cystic fibrosis (CF) is the most common serious genetic condition in the UK – around one in 22 people of Northern European descent is an unaffected carrier of the disease (Buxton & Turney 2007, 121). In Turkey, this rate is quite low and is estimated at 1/3000 (Kiper & Yalçın 2003, 1). It mainly affects the lungs, where thick mucus builds up causing repeated infections and breathing difficulties.
- ² An example of this [single woman] is Nadya Suleman. She is famous for giving birth to her octuplets and six older children with the help of IVF. In other words; she demonstrated an example of ‘extreme measures’ of assisted reproduction techniques.
- ³ As is widely known, the Turkish prime minister is regarded as a prime supporter of families having at least three children.
- ⁴ In the Third Reich (i.e., in the late 1930s) ‘breeding camps’ were established, where selected, unmarried ‘racially valuable’ Germans were sent for the purpose of impregnating the women. Those who became pregnant could await child-birth in special maternity homes for unmarried mothers, which the Nazis provided under the so-called Lebensborn scheme. In addition, towards the end of the war, Hitler was even thinking of introducing selective polygamy for the purpose of making up the loss of men in the war, ‘improving the race’ and rewarding the all-male elite of the Thousand Year Reich (Gupta 1991, 41).
- ⁵ This term is used in David Mechanic’s book with the same title (1994) and in Bernhard Wieser’s article ‘Inescapable Decisions. Implications of New Developments in Prenatal Testing’ (2006).
- ⁶ Many years ago, people with trisomy 21 were named ‘mongoloid’ for having slanting eyes and thus appearing similar to Asians. This pejorative term was later replaced by ‘Down syndrome’, which was regarded as a more medical term. However, people who criticise Dr. Down claim that a person who mentions this syndrome with the name of ‘Down’ makes an injustice; because according to them Dr. Down was a person with a thought of people with ‘trisomy 21’ were ‘really down’ and rare in the western population. Thus ‘trisomy 21’ [or ‘trisomy’] are technical terms which are used in general (Vertosick 2001, 111).

References

- Baldi, Pierre (2001), *The Shattered Self*, Great Britain: The MIT Press.
- Buxton, Jess and Turney, Jon (2007), *Genes & Cloning*, USA: The Rough Guides.

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- European Commission (2002), *Genetic Testing: Patients' rights, insurance and employment. A survey of regulations in the European Union*, Belgium: Quality of Life and Management of Living Resources.
- Evsel, Gülsevım and Erbas, Hayriye (2007), 'Socio-economical differences and an overview of genetic testing of reproductive biotechnology: A comparison of two different districts', *Proceedings of the Sixth Ankara Biotechnology Days: 'Biotechnology, Bio-Safety and Socio-Economic Approaches'*, Ankara: Ankara University, 155–174.
- Fukuyama, Francis (2003), *İnsanötesi Geleceğimiz: Biyoteknoloji Devriminin Sonuçları (Our Posthuman Future: Consequences of the Biotechnology Revolution)*, Ankara: METU Publications.
- Gupta, Charu (1991), 'Politics of gender: Women in Nazi Germany', *Economic & Political Weekly* 26 (17): 40–48.
- Hacettepe University Institute of Population Studies (2009), *Turkey Demographic and Health Survey 2008*, Ankara, Turkey: Hacettepe University Hospitals Printing House.
- Harris, John (2007), *Enhancing Evolution: The Ethical Case for Making Better People*, London: Princeton University Press.
- Hofmarcher, M. Maria and Rack, Herta (2001), *Health Care Systems in Transition*, European Observatory on Health Care Systems.
- Kiper, Nural and Yalçın, Ebru (2003). 'Kistik Fibrozis', *TTB Sted.* 12 (4): 131–133.
- Liao, Matthew (2005), 'The Ethics of using genetic engineering for sex selection', *J Med Ethics* 31: 116–118.
- Mehta, Parendi (2000), 'Human eugenics: Whose perception of perfection?', *The History Teacher* 33 (2): 222–240.
- Moore, Pete (2008), *The Debate about Genetic Engineering*, New York: The Rosen Publishing Group.
- Ocak, Gülsevım (2010), 'Eugenics and Ethical Objections towards PGD', unpublished Master Work.
- Paul, Diane (2007), 'On drawing lessons from the history of eugenics', in Knowles, Lori P. and Kaebnick, Gregory (Eds.), *Reprogenetics*, Baltimore: The Johns Hopkins University Press.
- Rabino, Isaac (2003), 'Gene therapy: Ethical issues', *Theoretical Medicine* 24: 31–58.
- Rabino, Isaac (2003a), 'Genetic testing and its implications: Human genetics researchers grapple with ethical issues', *Science, Technology, & Human Values* 28 (3): 365–402.
- Tokmakoglu, A. (2010), 'Devletin Bakanından Escinsellik Yorumu', http://blog.milliyet.com.tr/Devletin_Bakanından_Escinsellik_Yorumu/Blog/?BlogNo=232920

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Vertosick, Frank (2001), *Beynine Bir Kez Hava Degmeye Görsün (When the air hits your brain – Tales of Neurosurgery)*, Ankara: TUBITAK Popüler Bilim Kitapları.

West, Darrell M. (2007), *Biotechnology Policy across National Boundaries*, Palgrave-Macmillan.

Yunta, Eduardo Rodriguez; Herrera, Valdebenito Carolina; Misseroni Adelio; Milla Lautaro Fernandez; Outomuro Delia; Lemus Irene Schiattino; Lues Marcela Ferrer (2005), 'Attitudes towards genomic research in four Latin American countries', *Electronic Journal of Biotechnology* 8 (3).