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Genetic Knowledge and Genetic Reproduction Technologies as New Modes of Governance – are We Witnessing a New Form of Eugenics?

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Abstract

This article aims to examine whether there is continuity between eugenics as employed in Nazi Germany and modern-day medical genetics. Drawing on Foucault's conceptualization of the relationship between power and knowledge, it draws the conclusion that despite the differences in the means employed and underlying motivations, both may serve as disciplinary tools and shape human behaviour. Finally, it addresses ethical issues that arise during genetic reproduction counselling. Namely, it reviews how genetic information during genetic reproduction counselling is presented to those being counselled and puts forward the idea on how to stay committed to the principle of non-directiveness.

KEY WORDS:

eugenics, genetic knowledge, disciplinary tools, reproduction counselling

Introduction

Today, the increased knowledge about genetics and reproductive technology has opened the door for manipulating an individual's genetic makeup (genotype) with the aim of repairing faulty genes. Genetic technologies undoubtedly have a great promise to treat, but may also serve as a tool for "normalizing"[1] and controlling individuals.

This paper will seek to examine whether there is a continuity between the eugenics ideology and what we today call genetics, or using Fraser's words: "whether there is continuity of parts of Nazi medical and legal ideology within today's institutional discourses and practices" (Fraser, 2005, 419). Its aim is to review how genetic information is dealt with today, especially during the genetic reproduction counselling. It will not suggest that increased knowledge about genetics and the way such knowledge is employed today will lead to another Holocaust. However, I believe there are certain similarities in ideologies which surrounded Nazi eugenics and the genetics ideologies that exist today, even though those ideologies are implemented through different strategies. The paper will argue that today, although there are no laws prohibiting procreation of people with genetic disorders, the genetic knowledge itself shapes the agency of designated persons. Thus, it could be argued that medical knowledge became part of a social policy. If genetic knowledge has a capacity to govern a subject's agency, an important question arises: namely, what are the moral issues that we should be worried about with respect to this governing power knowledge? Despite there being concerns with regard to the use of genetic test results in the employment and insurance contexts, the purpose of this essay is to flash out the issues arising from informal ways of regulating acts of counselees during the genetic reproduction counselling.

The paper has been organised in the following way. The first part gives an overview of the eugenic practices and laws during the Nazi era.

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[1] Throughout this paper the term normalization will refer to processes and means of compelling people to conform to social norms. For more general remarks on the topic of what is considered normal in our society and how social norms induce people to conform with them see L. Fiedler (1984) 'The Tyranny of the Normal', The Hastings Centre Report, vol. 14, no.2, 40-42.

The second part will examine new modes of governance arising from contemporary medical knowledge and their ability to regulate the acts of designated individuals. This analysis will draw on Foucault's insights about the power and knowledge. The third part will deal with reproduction counselling ethics and policy as a core genetic worry, and it will seek to address the ethical dilemmas arising from the use of genetic information in reproduction counselling.

Historical Perspective - Eugenics During the Nazi Era

The idea of eugenics was created in the United States, long before Hitler came to power in Germany. Francis Galton coined the term eugenics in the mid-19th century and claimed that breeding between only talented persons would result in better offspring (Black, 2003). Black describes eugenics as a racist pseudoscience, determined to wipe away all human beings deemed "unfit" (*ibid*), while it can be argued, one of Hitler's goals was to create a uniform, homogenous society. Hitler's vision of homogenous society meant that only those genetically and physically healthy citizens are deemed to be a part of society. Conversely, this meant that he targeted not only minorities, but the whole of society. It was held that the future of German people depended on the preservation of German blood. This preservation was done on two levels – through "positive" eugenic measures encouraging the breeding of "pure" Aryans and "negative" eugenics measures aimed at removing elements of society that were either considered to be "alien" or genetically disabled.

Since the aim of this essay is to assess how modern genetic technologies are applied today, and to depict potential dangers that genetic screening generates, this chapter will focus on outlining the laws and practices during the Nazi era that had been designed to discourage those who did not have good blood from having children, namely the negative eugenic policies which discriminated against the individuals deemed hereditarily ill. This inquiry is the basis in trying to reach a conclusion whether it is possible to identify the continuity between parts of Nazi medical and legal ideology and the way society today deals with genetic information.

During the Nazi era, law[2] was generally used as a central mechanism for the construction of a uniform society and achieving social goals. Thus, in 1933 the "Law for the Prevention of Hereditary Diseases" was enacted introducing mandatory sterilization in cases of genetic disorders. Fraser argues that the very core ideas of the Nazi state, the protection of the German *Volksgemeinschaft* and the elimination of its racial enemies, could only be achieved in and through law (Fraser, 2005, 29). According to Fraser, "*Volksgemeinschaft* is the community based on blood and written in the body of law, and the law delimits the subject not just in terms of merit and obligation, but also in the foundation of the blood and the body" (Fraser, 2005, 16). The law created a strong distinction between "us" and "them", meaning that "them" were "those deemed to be "hereditary ill", "alien" or "asocial"" (Bureligh and Wippermann, 1991, 305-306) . Thus it could be argued that Hitler was trying to legitimize anti-Semitism by medicalizing it. Fraser notes that the whole Nazi worldview was a eugenic one, informed by what was for them a scientific ideal of racial purity (Fraser, 2005, 31). An individual whose ability to procreate was deemed to pose a threat to the well-being of society was singled out (Fraser, 2005, 118). Furthermore, a special two-tier hereditary court system was established. In the first instance, the Hereditary Health Court was operating and consisted of a judge and two physicians. In the case of the appeal, the Hereditary Health Court of Appeals would reach the final decision about the application for sterilization. The sterilization could be undertaken even against a person's will if the Court decided that it had to be done.

In addition to the regulation of peoples' behaviour through law as a coercive mechanism, "law under National Socialism operated also as a kind of "taxonomical practice" that helps organize society into races that seem natural and biologically real" (Szobar, 2002). Law was thus not only used for regulating behaviour through punishment, but was also deployed for enforcing social hierarchies. Therefore, theorists like Ian Haney Lopez

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[2] I find it important to note that even though the inquiry into whether Nazi law was law in the first place is of a vital importance and at the heart of the debates about the Holocaust, such an inquiry is beyond the scope of this paper and I shall not deal with it. For the purposes of this paper, I will accept the argument of David Fraser that Nazism was perpetrated through and under law and that, as Fraser notes: 'Auschwitz was not a lawless time or place. Auschwitz was lawful, it was full of law - lawful prescriptions of „Aryan" and „Jew", lawful sterilizations and euthanasia to protect the blood, lawful orders, from lawyers to doctors, for the removal, isolation, and then extermination of those enemies of the State, those parasites who would infect the Volksgemeinschaft.' He also specifically refers to compulsory eugenic sterilization, claiming that it was in fact 'lawful'. (See D. Fraser (2005), 'Law after Auschwitz: Towards the Jurisprudence of the Holocaust').

emphasize that law during National Socialism also had a role of disciplining people in the field of gender and sexuality, functioning as a system of rules as well as a system of knowledge (Szobar, 2002).

It appears that in the sphere of reproduction, which presents the most intimate aspect of one's life, the power of decision-making was taken away from an individual and put into the hands of the state, which resulted in a blurred line between public and private lives. In such a way breeding became a privilege to benefit the *Volk*, and ceased to be the right to be exercised by all adults. It was not an individual who was important but the community. Ingo Müller, in his book "Hitler's Justice" mentions the case of an architect with suicidal tendencies, who was subject to sterilization despite being a father of healthy children and other obvious evidence pointing that the cause for his state was not hereditary (Műller, 1991, 124). In this case, Müller pinpoints to the ease with which a decision to sterilize someone was made. I refer to this case because it also reveals how insignificant the benefit of the individual in Nazi Germany was. Namely, in this case, the Hereditary Health Court of Appeals found that having suicidal tendencies was enough to conclude that sterilization was necessary because the purpose of the law was not to protect the individual, but the German people (Műller, 1991). It is precisely this notion of an overriding community importance and its "advancement" wherein a link between Nazi eugenic policies and laws and contemporary genetic interventions subsist.

Knowledge as a New Disciplinary Tool

My claim is that there are points of parallels between eugenic ideology and today's medical genetic ideologies and that certain aspects of medical care and practices can sometimes be accused to be potentially eugenic (Ledley, 1994). This continuity is apparent in the way medical genetics strives to "normalize" an individual body. Despite there being no laws today that expressly proscribe who should breed and who should not, I believe that genetic knowledge and genetic technologies, such as genetic reproduction counselling have the ability to shape our behaviour in accordance with what is perceived to be normal given the prevailing social standards. Before examining the ethical concerns arising from these attempts to "normalize" individuals, with which I will deal in the next chapter of this paper, I wish to outline an important distinction between eugenics and medical genetics. Notwithstanding that "medical genetics, unlike eugenics, does not presuppose the existence of any form of institutionalized social control" (Ledley, 1994), such as laws that govern our bodies, the increased availability of the genetic information and advancements in genetic technologies manage to shape our actions and have an effect on the ways in which we make decisions about our bodies and ourselves. The question then is, if not through law, how does medical knowledge manage to regulate human behaviour? Michel Foucault's analysis of governance and knowledge informs an answer to this question.

Foucault distinguishes several regimes of power, i.e. normative power (power over life), which is located in unofficial institutions, and juridical power (threat of death coming from the sovereign) (Foucault, 1981). Juridical power functions through prohibitions and punishments, coercion and constraints, and it prevents the individual from doing something. This power "operates mainly as a means of deduction" (Foucault, 1981, 136), meaning it punishes by taking away something. In contrast to juridical power, normative power is about social norms, not laws, and it strives to stabilize and normalize society through subjects' active engagement. For the present purposes, this normative power, and its two aspects, biopower and disciplinary power are of great importance. Normative power is an informal power which consists of unwritten rules, social norms as well as of fear of pressure, and is enforced but not by anyone particular. The first aspect of normative power – biopower - targets the population as a whole, and it is the way in which capitalist states exercise power over all aspects of peoples' lives; "biopower analyses, regulates, controls, explains and defines the human subject, its body and behaviour" (Danaher, Schirato and Webb, 2000). Biopower classifies normality and abnormality (Koch and Svendsen, 2005) by collecting data, evaluating successes and failures. Foucault claims that today we witness a shift from sovereign power to normative power, a shift from law to the norm as an instrument of social control. The second aspect of normative power - disciplinary power – targets the individual body and was, according to Foucault, at first apparent only in institutions such as prisons, but later it became a technique of social regulation and control. The author of this normative power is a capitalist society which strives to administrate life[3]. The primary interest of power ceased to be a defence of the sovereign and came to be the improvement and managing of life. Foucault does not state that there is no juridical power anymore, but it is not the only or primary way in which the power works. It is important to note that Foucault believed that the individual could resist this power. However, the limits of his theoretical framework come from the fact that he never elaborated on mechanisms that individuals had on their disposal in resisting this power[4].

In line with Foucault's thoughts, it could be said that it is precisely this normative power that opens the possibility for new ways of regulating peoples' behaviour according to available genetic information. In contrast to Nazi eugenic measures that were expressly embodied in the legal prohibitions, which then also led to self-policing of the individuals, today, more horizontal modes of power are employed for achieving social goals. While the top-down mode of governance was a concept applied for pursuing eugenic policies during the Nazi era, contemporary policing of human behaviour in relation to their genetic makeup is done in the name of human health, through self-regulation and self-censorship. Koch points out that despite there being no legal coercion, coercion is still present and exercised through informal means (Koch, 2004). Individuals are induced to behave in accordance with standards set by society. They self-regulate and become agents of their own normalization.

It is interesting to note that there is also a point of overlap between how internal conformity was achieved in Nazi Germany and today. Szobar notes that "even in Nazi Germany, the law had a constitutive function as well as a coercive one in that it enabled the formation of racial identity and the enforcement of racial policy" (Szobar, 2002). She notes that the informal pressures, such as community disapproval of relationships between Jews and Germans as well as social and economic discrimination encouraged

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[3] Foucault sees normative power as "an indispensable element in the development of capitalism and the one that is constantly exercised by means of surveillance rather than in a discontinuous manner by means of system of levies and obligations distributed over time". See M. Foucault, 'The Will to Knowledge: The History of Sexuality, Volume One, Harmonsdworf: Penguin 1981, 140.

[4] For example, notwithstanding the significant overlap between Foucault's and feminist thoughts on power, some feminist theorists such as Nancy Fraser argue that by reducing individuals to docile bodies and the effects of power, Foucault fails to acknowledge who resists the power. See Nancy Fraser, 'Unruly Practices: Power, Discourse and Gender in Contemporary Social Theory', Minneapolis: University of Minnesota Press: 1989.

mixed couples to end their relationship (Szobar, 2002). In the sphere of sexual and family relations it had an effect of shaping and governing peoples' behaviour in the way that was in conformity with the norms of National Socialism. In my view, genetic knowledge performs such a role. This suggests that in National Socialism, law was used to encourage individuals to self-discipline themselves, and today, the increased knowledge about our genetic makeup is doing the same task. Those social norms capable of regulating behaviour are not written down, but everybody knows them and shapes his or her behaviour according to them.

How then, if not through the law, do social norms manage to adjust subjects' behaviour according to the available genetic knowledge? I believe that the knowledge about the genetic code is enabling society to socialise people by using 'genetic risk' as a new mode of governing and disciplining lives (Rouvroy, 2008). I wish to unpack what this notion of the "genetic risk" means because it is important in ascertaining how a subject's behaviour is shaped according to the predictions about such risks, and to explain my claim about continuity. Understanding the genetic risk is also central for assessing ethical questions arising in genetic reproduction counselling which I will be discussing in the following chapter. In general terms, risk is an expression of probability, and in the effort to regulate the anticipated risks, we make risk assessments and modulate our behaviour according to those assessments. Risks can be regulated in different ways, from commands to encouragement to self-regulation. In the sphere of "genetic risks", many authors, such as Rouvroy argue that risk governance responsibility is ascribed to individuals (Rouvroy, 2008). Rouvroy explains that "genetic risk" functions as a "'technology of the self", encouraging people to get the most information they can about their genetic status, which then enables them to act "responsibly" towards their health and genetic health of their blood relatives (Rouvroy, 2008). Genetic tests make it possible to gather extensive information about the genetic profile of the individual, and, it is claimed that according to the information gathered, genetic risk can be calculated and genetic diagnosis established. Lemke argues that genetic diagnosis can offer possible interventions to minimize or avoid risk (Lemke, 2005, 97). I would disagree with Lemke in this latter part. Namely, I do not think risk can be completely avoided. Or to put it this way: avoiding one risk creates new risks. For example, if a woman with a genetic condition decides not to reproduce in order not to pass her "bad" genes, this will surely avoid the risk of passing them on, but could create a new risk such as emotional distress of not experiencing motherhood. In the context of regulation of genetic (and any other) risk, people and society engage in balancing loses and gains, and in deciding what is acceptable and what is unacceptable they take risks. In striving to normalize society by avoiding genetic risks, there is a danger of creating new risks, especially if the genetic results are taken at their face value[5].

What lies behind this idea of genetic risk is, firstly that individual identity is reduced to the genome of the individual, and secondly that every individual seeks to have maximum information about his or her genetic make-up. The individual with a genetic disorder becomes a target audience, and is expected to make informed decisions and act as a responsible agent. It could also be the case that the individual does not want to know his genetic profile. Deftos warns that in contemporary society which puts so much value on the knowledge about our genetic make-up, individuals who do not want to have information about their genetic status could be regarded as "lacking moral competence" (Deftos, 1998). On the other hand, some authors, like Harris and Keywood argue that the right not to know does not even exist, that there is "*no prima facie* entitlement to be protected from true information about oneself" (Harris and Keywood, 2001). It follows that in the genetic era, Foucault's model of disciplinary power is exercised through the notion of a "genetic risk" as a new mode of governing lives, whereby discipline is enforced through the internalization of surveillance[6]. As a consequence, governing through genetic risks increases personal responsibility and accountability for bad luck on the one hand and absolves formal institutions from their responsibility in causing diseases and disabilities on the other hand (Rouvroy, 2008). In this sense Foucault claims that "society is designing unbound and subtle power mechanisms and that power is relying on techniques rather than law, on normalizing rather than statues, on control rather than punishment, and it is implemented at levels and in forms that spill over the state and its apparatus" (Rouvroy, 2008, 84).

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[5] Rouvroy argues that genetic truth discourses are often taken at face value, see Rouvroy, 'Human Genes and Neoliberal Governance: the Foucauldian Critique', New York: Routledge 2008, 3.

[6] Foucault uses the idea of Bentham's model prison, Panopticon, as a metaphor to explain how the automatic functioning of power can be assured. The idea is that the individual knows he or she has been watched all the time so even if the individual has not actually been watched, he or she could be watched and thus behaves as though someone has been monitoring. The individual internalizes the norms and behaves according to them: See generally Michele Foucault, 'Discipline and Punish: The Birth of the Prison', Harmondsworth: Penguin, 1979.

I believe that discussing ethical questions that arise from genetic reproduction counselling is first and foremost important because it involves a very intimate and central aspect of individual's right. In addition, the accumulation of knowledge about human genetics and transformation of what is perceived normal has a consequence that, as Emily Jackson notes, genetic testing is being applied today to a wider population then it was the case before (Jackson, 2010, 427). Namely, we all have faulty genes and thus genetic testing could be "potentially relevant to all of us" (Jackson, 2010, 427). Moreover, Khoury, Linda McCabe and Edward R.B. McCabe point out that genetic screening will more frequently be used to determine individual susceptibility to common disorders. Consequently, this will result in widening the net of potential users of genetic screening and counselling. Due to the fact that many fertility clinics acknowledge the importance of their role in assessing *any*[7] kind of genetic risk, more and more individuals will be under social pressure to engage in genetic screening and counselling[8]. It could of course be argued that this only gives more options to potential users, who are then free to decide whether they want to engage in risk assessment procedures. However, the question is whether they are truly free in deciding whether to use or not these genetic technologies. Furthermore, the knowledge of the human genome also has the capacity to shape identities, behaviours and expectations, and to alter the identity of the individual.

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[7] I put an emphasis on the word "any" because it struck me that some fertility clinics do really engage in assessing any kind of genetic risks. Bearing in mind that we all have faulty genes, such a broad concept of genetic risk strengthens the argument that we are all potential users of genetic screening and genetic counselling services. Consequently, as Ettorre notes, "this changes our status of being healthy to being an asymptomatic ill person who self-enrols in continuous medical surveillance and monitoring process (Elizabeth Ettorre, 'The Sociology of the New Genetics, Conceptualizing the Links Between Reproduction, Gender and Bodies in A. Petersen and R. Bunton, 'Genetic Governance: Health, Risk and Ethics in the Biotech Era, Routledge 2005). See for example Fertility Clinic IVF Australia, http://ivf.com.au/fertility-specialists/ivf-australia-genetic-counsellors - accessed November 18, 2013.

[8] It is also possible that fertility clinics will be exposed to an increased number of litigations for not warning their clients about genetic risks, especially with regard to donated gametes.

All those factors contribute to the importance of assessing the ethical implications[9] that genetic reproduction counselling has in contemporary society.

Lemke claims that "Liberal "eugenism", despite its rejection of authoritarianism and its proclaimed respect for individual choice and human diversity, shares several features with "old" eugenism. Liberal eugenism efficiently "imposes" specific expectations of human normality and functioning that are unconsciously or consciously endorsed by individuals disciplined by the imperative of genetic self-knowledge, genetic risk avoidance etc."(Lemke, 2002). Following Lemke's argument, it could be said that the genetic knowledge we possess today, the burgeoning thrust of society to know even more about our genes and this new mode of governance – governance through knowledge, which I discussed in the previous chapter, opened up the scope for potential abuses given its effects on the ways in which we make decisions about our bodies and ourselves. In this section, I want to address the ethical concerns arising from those "expectations of human normality and functioning" that Lemke talks about. I wish to explore those issues in connection with genetic reproduction counselling[10].

In the sphere of reproduction, genetic testing followed by genetic counselling is currently being used to detect genetic disease either prior to or during pregnancy. Thus, in my opinion, it is essential to consider what the aims of genetic counselling are and what significance is attributed to the individual voice in deciding whether to engage in genetic reproduction counselling, as well as during genetic counselling.

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[9] It is worth noting that there is an important distinction in the approach to bioethics between postmodernism and mainstream bioethics. Namely advocates of postmodernism criticise the mainstream bioethics on relying too much on clear and distinct divisions such as right and wrong, health and disease, normal and abnormal as well as on individuality and rationality. Postmodernism on the other hand claims that there are multiple truths, none of which have the ultimate authority, and that there is no possibility of reaching a definite solution. Further discussion on this issue is beyond the scope of this paper but for deeper insight into the differences between mainstream and postmodern bioethics see Margit Shildrick, 'Beyond the Body of Bioethics: Challenging the Conventions' in Margit Shildrick and Roxanne Mykitiuk, 'Ethics of the Body Postconventional Challenges', Cambridge, MA: MIT Press, 2005.

[10] It should be noted that the fears that genetic information could be misused is present to a large extent in relation to health insurance and employment. Namely, based on the genetic information, individuals deemed to have genetic diseases could be denied access to employment and insurance. However, those issues extend beyond this paper and I shall not deal with them in the following sections. See for example A. Rouvroy, 'Human Genes and Neoliberal Governance: A Foucauldian Critique', New York: Routledge, 2008, Chapter 2.

Fertility clinics around the world offer genetic counselling services to those who are deemed to be at risk of reproducing genetically "abnormal"[11] children. They make promises of bringing healthy beautiful babies into this world[12]. I wonder what kind of messages those promises send. I surely do not assert that having a healthy baby is a bad thing but I do believe that such messages and invitations to undergo genetic screening do increase the pressure on those with genetic conditions either to undergo genetic screening or not to have children. Clark for example claims that even "an offer of prenatal diagnosis implies a recommendation to accept the offer" (Clark, 1991). On the other hand, Jackson claims that "it is not obvious that the existence of external influences necessarily undermines the legitimacy of a particular choice" (Jackson, 2001). I do agree that external influence does not undermine the legitimacy of decision making *per se*. However, since in practice it is hard to distinguish when the external influence did diminish the legitimacy of an individual's decision, I believe that counsellors should strive to be ethically neutral in order not to jeopardize the counselees' freedom of choice. We should surely not underestimate the capacity of social norms to govern our behaviour. It is not uncommon that genetic teams in infertility clinics emphasize the importance that those individuals who are aware of the presence of certain family health conditions undergo genetic testing and act according to the results of those tests. Petersen argues that individuals are not only expected to want to use genetic reproduction technologies in order to make socially responsible decisions, but that prenatal genetic technologies are even seen as "driven by consumer demand" (Petersen, 2003). Thus individuals designated as being at risk are expected to behave as responsible agents and engage in the offered genetic screening services. This will inevitably result in changing individual's self-perception and put pressure on women with genetic conditions not to have offspring. Ettorre notes that genetic counselling has a similar function as psychoanalysis in that "it makes visible genetic elements of an individual and makes one's biological destiny evident." In making those genetic elements visible, individuals perceived as being at risk are expected to exert their responsibility and to take steps in order to mitigate and minimise genetic risks (Ettore, 2005). If they do not act according to those expectations, it is very likely that they will be

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[11] When referring to abnormal, I mean that which is considered different from what is usually founded in communal beliefs and is not normal according to today's society standards.

[12] See for example IVF Australia, http://ivf.com.au/fertility-specialists/ivf-australia-genetic-counsellors, accessed November 20, 2013.

deemed irresponsible members of society[13].

Once engaged in the genetic counselling session, it is undisputable that counselees should be provided with the information about genetic risks. Nonetheless, the way in which such information is presented to those being counselled risks, as Nagl points out, that development in genetic technology could have the implication of "silencing of the patient's voice in medical discourse" (Nagl, 2005). The proclaimed principle in genetic reproduction counselling is the principle of non-directiveness[14]. It is broadly accepted that genetic counselling should be non-directive and guarantee that the informed decisions of those being counselled are made on a voluntary basis. Yet, I believe that the capacity of genetic information to regulate our behaviour in an informal way through social pressure questions the proclaimed freedom of choice.

In contemporary society, the proximity to the standards of normality and perfection became an important aspect of social acceptance, and in my belief, this is where the most obvious link between the practices of eugenics and medical genetics today can be recognised. A lot of emphasis is put on the "progress" and "normalization" of the individual body, resulting in the transformation and categorization of society according to available knowledge about human genetics[15]. Fraser's argument that the Nazi regime and its medical professionals perceived eugenic practices, which brought enormous suffering and death, not as self-professed barbarism but as an advancement of civilization and "progress", supports my claim about the continuity of the two ideologies. Clearly, the greater knowledge about human genetics we possess nowadays has opened the potential not only for prejudices and discriminatory practices of those with sub-optimal genetic material, but has also influenced the ways in which we are expected to relate to our bodies and society. Thus, the proclaimed

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[13] Abby Lippman, for example, claims that in North America it is generally assumed that women are obliged to produce a healthy child, which makes it hard for women who are told to be at risk "to refuse measures that are advertised to be risk-reducing". See A. Lippman, 'Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities', American Journal of Law and Medicine, Vol. 17 NOS.1&2, 1991.

[14] For example, the Ethical Guidelines of Australian Health Ethics Committee, which identify ethical principles that must inform the conduct of clinicians and researches and the procedures in the use of assisted reproductive technologies, inter alia proscribe that clinics should provide and discuss information in a way that is appropriate to, and sufficient for informed decision making, and more importantly that the information should be given without any unnecessary inducement. See http://www.nhmrc.gov.au/guidelines/publications/subject/Genetics%20and%20Gene%20Technology, accessed 20 November 2013

[15] Foucault noted that eugenics was integral to the effort to transform life. See M. Foucault, 'The History of Sexuality, Volume One: An Introduction', Harmonsdworf: Penguin, 1981.

principle of non-directiveness and the freedom of choice do not mean absence of power. On the contrary, power has just changed its shape and functions in a different way, through disciplinary practices which require us to meet standards imposed on us by society and then being internalized.

I do not deny that we are necessarily connected and dependent on other people and community, but as Isabel Karpin notes “the only question is where power resides in these interconnected selves” (Karpin, 2010, 151), and what does power aim to achieve. In emphasizing the importance of the informed choice and proclaiming non-directiveness as its main principal, genetic counselling seeks to protect itself from being accused of having eugenic motivations. However, it seems that by declaring the non-directive model of genetic counselling as a prevailing model, our society only appears to be liberal in dealing with issues of reproduction. Despite such a proclamation, it can be argued that our society is repressive and ascribes more importance to the welfare and the “normalization” and stabilization of society then to the individual needs, rights and values. For instance, it appears to me that in genetic reproduction counselling, fertility clinics are more in favour of eliminating any genetic disorder and achieving the ultimate goal of “normalizing” society then providing help and support to the individual.

Patterson and Satz note that the overriding assumption is that being born with a disabling genetic condition is a bad thing and that the task of genetic counselling is to give information to those deemed to be at risk and encourage them to take steps that would minimize or remove those risks. If this is truly the overriding assumption of our society, it is hard to imagine that counsellors could detach themselves from such beliefs and truly act according to allegedly embraced principle of non-directivenes. Patterson and Satz give an example of the couple with Achonodroplasia who did not perceive their “condition” as negative and wanted to have a child with Achonodroplasia. The case depicts how hard it is for counsellors to step aside and start thinking in a way that is different from their usual way of thinking, and how the model of non-directiveness in actually problematic in practice. Counsellors regularly present only negative images of disability in initial prenatal counselling sessions, which present a “constructed reality grounded in the scientific and medical definition of a given genetic condition" (Patterson and Satz, 2005). Consequently, this necessarily significantly influences the decision of counselees. Moreover, Patterson and Satz observe that during their training, counsellors rarely have the opportunity to experience disability from different perspectives (Patterson and Satz). Thus they hold on to their beliefs which mirror the prevailing beliefs of society, according to which a disabling genetic condition is necessarily a bad thing. Wendell suggests that we should value disabilities as differences, which would enable people to see that not every disability is necessarily a bad thing (Wendell, 1996, 84). However, Gilligan warns that since our society is fixated at normality, difference easily becomes deviance, which is often perceived as a sin (Gilligan, 1982). This indicates that even though evaluating disabilities as differences is more neutral, the reluctance of our society to appreciate differences and its obsession with normality and perfection does not create an environment in which choices about reproduction are ultimately one's own choices.

If the fundamental bias of the counsellors is against abnormality, it means that they strive to achieve "normality". Jackson argues that women whose fertility is perceived to be a social problem often receive strong messages from the negative attitudes of health professionals not to reproduce. It could be argued that by sending messages to people with genetic disabilities not to reproduce, society is aiming to reduce social problems by reducing the number of people with disabilities. Even though decisions were meant to be made on an informed and voluntary basis, the emerging genetic knowledge has the effect of putting the individual under pressure to make socially desirable decisions, and, as Lemke states, to produce "normal" children.

I am not suggesting that the countries which use genetic screening today are like Nazi Germany, but there are some points of continuity in the ideas of advancement, improvement of nature and of science as a way to a better future. The conditions in which reproduction decisions are made are capable of creating an environment in which individual autonomy and choice are sacrificed for the communal good. Petersen notes that "with increased surveillance and intervention, the notion that genetic counsellors can, and should be value-free and non-directive will be more and more difficult to sustain" (Petersen, 2007). I wonder how explicitly counselees are informed about positive experiences of the people who live with disabilities. In a society such as ours, where being born with a disability is seen as a tragedy, those positive experiences are easily overlooked. Thus, I believe that only by striving to understand and respect perspectives of people with genetic conditions and disabilities would free our society from the quest of "normalization" and perfection of human body and we could then say that the principle of non-directiveness is truly embodied in the genetic counselling practices. Otherwise, as the law was used to "protect" society during Nazism from those deemed "unfit", so today it could be said that the increased genetic knowledge requires individuals to sacrifice their beliefs, convictions and wishes for the collective good. If not on a conscious level, then surely at the level of the subconscious.

I believe that acting upon the unfavourable opinion of someone, rather than using a straight-forward prohibition, is potentially more dangerous from traditional command-and-control projection of power. It does not only bring uncertainty but also creates the notion of the genetic risks that are not beyond the control of the individual (Rouvroy, 2008, 67). I agree with Douglas who notes that "the construction of risk individuals, risk couples, risk pregnancies etc. makes it easier to moralize on deviant behaviour and to assign guilt and responsibility". This corresponds to the idea that Koch and Svendsen have put forward (Koch and Svendsen, 2005). They assert that the wish for the proper use of genetic knowledge has created a notion of ethical responsibility which individuals exert towards themselves and their relatives. However, I disagree with their claim that precisely genetic information passed to counselees makes them autonomous individuals who voluntarily make responsible choices about their health and the health of their relatives[16]. Biomedicine is powerful in creating social identities and Shildrick rightly notes that health care today "is as much about control, containment, and normalization as it is about treatment" (Shildrick, 2005, 17). The actions of the designated individual are expected to conform to the expectations of society which attaches great importance to the normalization of the human body. Rouvroy argues that "when the social or the "average man" becomes the standard against which normality and deviations are articulated, the "normal" is increasingly defined by reference to standards external

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[16] Koch and Svendsen draw their conclusion from observing the practice of cancer genetic counselling. Thus, their observations necessarily have limited application to reproduction genetic counselling, where the fears of associating such practices are far greater.

to the individual" (Rouvroy, 2008, 103). It seems that despite not having laws proscribing sterilization and special courts that would apply them, society is still capable of preventing those who are "unfit" from continuing its kind. And again, medical science is taking part in the construction and maintenance of this taxonomy (Fraser, 1989, 30) creating classes of "us" and "them". Rouvroy claims that despite the claim that genetic counselling is left to individual choices, those choices become the precise medium through which a new form of governance is exercised, taking citizens' bodies as both vectors and targets of normalization (Rouvroy, 2008, 82). Instead of using prohibition, we use unofficial channels to regulate, and society sends strong messages that there are those who are "normal" according to its standards and "abnormal", and that we should do whatever is possible to prevent spreading the genes of those deemed to be "abnormal" or at least help them mitigate the abnormalities.

The nature of the counsellors' advices is inevitably value-laden but what is needed in my opinion is the following: firstly the acknowledgement that many factors shape the representation and perception of genetic information, and secondly critical questioning of the basis on which their beliefs are made. Society should foster an environment in which exercise of reproductive choice is practically possible and effective, not just illusory and theoretical. As Shildrick argues, "the real test of bioethics is whether it is able to operate adequately in practice" (Shildrick, 2005). Thus genetic counsellors should be appropriately trained how to communicate genetic information, and should be given the opportunity to listen to the views of people living with what most counsellors would call abnormalities. This would give them another perspective and understanding of the needs of those to whom they offer their services, and would result in responding to counselees with greater respect. I agree with Wendell's viewpoint according to which "not every disability is a tragic loss and that not everyone with the disability wants to be cured" (Wendell, 1996, 88). Besides, implementing social measures that would improve care of those with disabilities, instead of offering genetic screening programmes and solutions, seems to me as a more humane approach.

Conclusion

The aim of both eugenics and genetics is to control and regulate the behaviour of the population either through formal channels e.g. law, or informal, i.e. encouraging designated persons to self-discipline and behave in the way society expects them to. The aim of this paper was to depict how genetic knowledge as a disciplinary device, challenges the population to be healthy and, to show its capacity to control and influence self-perception. Such control does not conform to our ideas about democracy and equality, and we must ensure that our rights to make final decisions on such matters as reproduction are respected. If humanity is not ready to respect those rights, we are surely not ready for the ever increasing genetic knowledge we are coming to possess. If we are to learn from past mistakes, we should be cautious in the way genetic reproduction technologies are deployed. We should also be aware and openly discuss their potential ramifications, and the ways they influence choices about our bodies. In order not to generate stigmatization and discrimination based on genetic makeup of the individual, open debate, fostering tolerance and an honest dialogue between scientists, counsellors, practitioners, counselees and the public about ethical questions arising from the use of the genetic information is highly needed[17]. Commitment to the principle of non-directiveness and ensuring that decisions about our bodies are made on a voluntary basis is of the utmost importance. In addition, raising public awareness and awareness of counsellors that their decisions are often value-laden is crucial in ensuring this goal. Insights from people with genetic conditions or disabilities could be of a great value in raising such awareness and it would take us closer to the goal we should be striving to achieve. Namely that decisions we make about our bodies are not imposed on us as duties we have to bare but are reflections of our own value systems and choices.

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[17] An idea of using theatre to encourage engagement and discussion of broader public on ethical and other implications of genetic testing applied in Canada in 2005 seems like a good example of how the goals of tolerance and mutual understanding can be fostered. For more details on Canadian theatre, see Isabel Karpin, 'Taking care of the 'health' of preconceived human embryos or constructing legal harms' in Isabel Karpin ' The 'Healthy' Embryo: Social, Biomedical, Legal and Philosophical Perspectives', Cambridge University Press, 2010, 154-156.

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