

Part II

Risk, population and identity

From eugenics to the government of genetic risks

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... we should not underestimate the dangers of a new eugenics. If biological tests are used to conform people to rigid institutional norms, we risk reducing social tolerance for the variation in human experience. We risk increasingly the number of people defined as unemployable, uneducable, or insurable. We risk creating a new biological underclass.

(Nelkin and Tancredi 1994: 176)

Introduction

In the ongoing discussion about the social and ethical impact of genetic testing the question of eugenics is a central issue. At the heart of these debates is the fear that there will be a re-emergence, return or a 'backdoor to eugenics' (Duster 2003). Many critics regard contemporary medical genetic practices as a continuation of population policy, social cleansing and racist programmes such as were practised during the first half of the twentieth century in their most violent and brutal form by the Nazis. Conversely, most geneticists dissociate present medical genetics from these practices since they employ a narrow definition that identifies eugenics with coercion and repression. In their view there is a fundamental rupture between past eugenics and contemporary medical genetics since the latter relies on consensus and choice.

In the following, I propose to displace this debate by introducing the notion of governmentality as developed by the French philosopher and historian Michel Foucault. Foucault defines government in a very broad sense as conduct or, more precisely, as 'the conduct of conduct'; the term in Foucault's use refers to all endeavours to guide and direct the government of others, but it also includes forms of subjectivation: the government of the self (Foucault 1982a: 220–221, 1991; Lemke 1997). The analytics of governmentality links political strategies to the subject's capacity to govern itself and the mobilization of truth to the production of particular moral subject positions. Following Foucault, I am interested in how genetic knowledge and genetic technologies are used in the government of individuals and

populations, how medical practices and diagnostic tools function as political technologies on the one hand and as moral technologies on the other hand.

As a consequence, the key point here is less whether contemporary medical genetics is eugenic or not, and more what we exactly mean by 'eugenics' today. By eugenics we used to understand 'the cluster of ideas and activities that aimed at improving the quality of the human race through the manipulation of its biological heredity' (Kevles 1992: 4).¹ To what contemporary fears and foreseeable future developments does this label refer? What parallels and what differences in present human genetic practices can be discerned compared, for example, with the Nazi racist project or the US sterilization programmes at the beginning of the twentieth century? In other words, the question concerns the historico-political continuities and ruptures between 'old' and 'new eugenics' (Proctor 1992; Paul 1994, 1998).

Medical genetics and eugenics: continuity or discontinuity?

When attempting to answer this question I proceed from a working hypothesis which proposes two lines demarcating the analysis: on the one hand, we cannot assume a more or less linear continuity of eugenic practices from the Nazis to the present. For this reason, I find it problematical to speak of 'old eugenics in a new guise' (Weikert 1998: 146), of a continuation of 'eugenic traditions on a higher technical level' (Schumann 1992: 62) or a 'relapse into biologicistic patterns' (Koechlin 1996: 35). On the other, it is also not tenable to assume there has been a fundamental rupture between the old eugenics and current medical genetics. Such a hypothesis relies on scientific improvements in molecular genetics declaring eugenic goals to be obsolete as a result of new scientific findings. They point to the fact that research in genetics showed that mutations and genetic anomalies are a widespread phenomenon in a population that renders senseless the project of 'purification' or 'amelioration' of the gene pool (Propping 1992: 125–127; Winnacker 1997: 143–148). Another line of argumentation appeals to changes in 'motivational structures' (Junker and Paul 1999; see also Wolff 1990). The claim is that there could no longer be any talk of eugenics if individual decisions on reproduction geared to self-determined options and the principle of voluntary choice take the place of collective concern for the gene pool or the project of an evolutionary improvement in humanity. Let us consider the two positions one after the other.

As regards the *continuity hypothesis*, it has to be remembered that nature today can no longer be regarded as some immutable constant, unlike during the first half of the twentieth century and the heyday of eugenics. It is problematic to claim that the recourse to heredity simply replaces the discourse of environment, shifting the attention from one side to the other side of the nature–nurture debate. Rather, the new genetics displaces the

two poles that once constituted the debate itself. Today, molecular biology and genetic engineering function as informational sciences, regarding the DNA as a code that can be read and rewritten (Kay 2000). As a result, the status of biology and the relation between biology and society is changed. It is therefore insufficient to state or to criticize the 'biologization of society', since the results of social science studies show that the dichotomy between nature and culture is itself getting more and more problematic (Haraway 1991; Keller 1992; Latour 1993).²

The identification of individuals with genetic risks does not serve to pinpoint some ineluctably biological fate; nor does it signify something which is beyond control. On the contrary, it refers to a privileged field of interventions. Like environmental risks, genetic risks could be calculated, but – in contrast to the former – they appear to be easier to measure and to control. Genetic diagnosis offers a series of possible interventions to avoid or minimize risk. These cover such different strategies as taking medicines and psychopharmaceuticals, the use of genetic therapies or the control of lifestyles, choice of partner, reproduction decisions, etc. In this respect, the significance of genetic diagnostics is above all in monitoring the potentially infirm and controlling the factors which could lead to the emergence of pathological states. The introduction and spread of genetic tests will dramatically improve the scope of information available for those who wish to enhance their 'quality of life' by avoiding illness and deviance from the norms:

The logical progression of this type of development is a situation in which it would become common for people to know about their own genetic risk profile across a range of disorders, and for them to design an 'individually tailored' set of behaviours. Someone with an inherited susceptibility to coronary thrombosis and musculo-skeletal problems, for example, may decide never to eat high-fat foods nor play impact or contact sports. Another person with a quite different 'genetic read-out' may become particularly wary of entering smoky rooms, or being exposed to bright sunlight.

(Davison 1996: 321–322; see also Rose 2000)

Let us go on to the second position, namely the *assumption of a discontinuity* between eugenics and human genetics. With the erosion of the borderline between nature and society and new biotechnological possibilities for the diagnosis of the genetic composition of individuals, the problem of eugenics does not disappear but on the contrary it becomes inescapable. Paradoxically, it is exactly the fact that reproduction by means of the new biotechnologies becomes the object of free decision-making and individual planning that makes this society inevitably eugenic:

The genetic manipulation of humans confuses the spheres of freedom and necessity. The freedom to manipulate nature, providing copies or designing

human beings following genetic blue prints produces at the same time the necessity to ascribe even our non-manipulated existence to a decision.

(Nassehi 1998: 57, translated by TL)

Whether we like it or not, even the seemingly ‘non-eugenic’ decision against genetic diagnostics and selective abortion has a eugenic quality, since it is based on a (normative) decision: the decision that it is better not to decide. The choice of a ‘natural’ genetic make-up for an individual is only one option and one ‘selection’ among others, in any case it is an option – neither fate nor unchangeable (Kitcher 1996: 196–197).

Risk discourse and genetic testing

It has been well documented that the notion of risk occupies a central place in professional medical literature (Skolbekken 1995), in health policy documents (Hayes 1992) and in the new public health (Petersen and Lupton 1996). Genetic risk has recently become equally important. My own research shows that the number of medical articles that deal with the term ‘genetic risk(s)’ in the title or abstract of the MEDLINE database increased rapidly from the end of the 1960s to the beginning of the new millennium. While only 4 articles are listed for the period from 1967 to 1971, ten years later 67 ‘genetic risk’ articles were published (1977–1981); another ten years later the count is 211 (1987–1991), while it goes up to 1082 for the period from 1997 to 2001. The strategic concentration on genetic risks in medical research and clinical practice is also visible in the two application areas for genetic testing.

At present the main application area is that of prenatal diagnostics (and – to a lesser extent – preimplantation diagnostics). Under the sign of genetic testing, any pregnancy virtually becomes a ‘risk pregnancy’ or ‘tentative pregnancy’ (Rothman 1987), whereby allowing the embryo to live depends on the result of a test that rules out genetic abnormalities. The proclaimed privacy of each individual’s decision and the decriminalization of abortion contrasts with the public pressure to (re)produce ‘normal’ children. The pregnant woman is conceived of not only as two people, but also as two patients with separate or even hostile interests. She is called on to work actively to optimize the foetus’ health – and to avoid anything that could damage it. If, on the one hand, the woman (e.g. through claims for damages filed against the doctors responsible) is guaranteed a right to a healthy (i.e. ‘undamaged’) child, then, on the other, she is degraded to the status of ‘foetal environment’ which should engage in risk-minimizing behaviour (Steinberg 1996; Weir 1996; see also Ruhl 1999).

It is foreseeable that in the future the focus of genetic testing procedures might shift to persons already born (postnatal diagnostics). While genetic testing in this area was primarily used to detect very rare disorders, the

decoding of the human genome and the isolation of genes that are associated with common diseases like cancer or heart disease raise the possibility of providing predictive information to many more people. Although in most cases genetic diagnostic procedures do not enable one to predict with certainty whether a person will develop a certain disease in the future they have already contributed to producing a new category of subjects: individuals 'at risk' (Billings et al. 1992; see Kenen 1996) who in the framework of genetic examinations and tests have been diagnosed to run the risk of certain illnesses which they may perhaps or may not possibly contract in the future. As surveys in several countries have shown, these 'risk individuals' or 'asymptomatic ill' are already confronted with real forms of genetic discrimination in the present. The perceived genetic variation from the 'normal' human genotype may result in forms of stigmatization and exclusion that range from a denial of insurance coverage to employment difficulties (Billings et al. 1992; Low et al. 1998; Thébaud Mondy 1999).

The risk discourse does not depend on the authority of the state but on the autonomy of the individual. Instead of eugenic programmes enforced by state institutions, relying primarily on repressive means, we observe today apparatuses of risk, aiming at the productive enhancement of the individual human capital in the name of self-determination and choice. A pluralism of authorities induces and encourages individuals to take responsibility for their own decisions concerning health and reproduction. Health experts and bioethicists teach and persuade us to make 'rational' and 'informed' choices that are based on genetic knowledge. They claim that genetic factors regulate or influence important diseases of civilization like obesity, cancer, schizophrenia, depression, Alzheimer's disease, diabetes, high blood pressure and coronary heart diseases (Clark 1997; Wertz et al. 2003). Medical advice literature reminds its readers that their 'genetic destiny' is in their own hands. Here the right for health gives place to an imperative to get as informed as possible about genetic risks:

Know your family history, be cognizant of your ethnic origin, determine your genetic susceptibilities, opt for necessary gene tests, take preventive actions, establish appropriate surveillance, and seek preemptive treatment where applicable. In this way, you can exercise control over your genetic destiny, secure your health, and – in more ways than you yet realize – save your life.

(Milunsky 2001: xv; see also Teichler-Zallen 1997;
Bland and Benum 1999)

Genetic responsibility and the government of the self

Genome analysis and genetic diagnostics do rely less on a deterministic relationship between genes and diseases but generate a 'reflexive'

relationship between individual risk profiles and social requirements (Lemke 2004). The reference to personal responsibility and self-determination in the biosciences makes sense only if the individual is more than a victim or prisoner of her or his genetic material. He or she is conceived not as a passive recipient of medical advice, but as an active seeker of information and consumer of genetic testing devices and health care services (Petersen and Bunton 2002). This strategy produces and exploits the imagery that future diseases, disorders and disabilities can be foretold and prevented by examining the individual genome. If indeed there were a direct relationship between genotype and phenotype in the sense of genetic determinism, then it would be more difficult to uphold the appeal to individual autonomy. By contrast, the construction of risk individuals, risk couples, risk pregnancies, etc. makes it easier to moralize on deviant behaviour and to assign guilt and responsibility (Douglas 1990). The definition of risk spaces enables therapies and forms of prevention to come to bear in a non-medical and a supra-individual sense and raises predictive genetic diagnostics to the status of a social medicine (Rose 2001).

The concept of information is crucial in this context since it serves simultaneously as the 'code of life' and as the 'key to freedom'. If the body is nothing other than a genetic programme, then disease points to a communication problem. In this light, the emergence of an illness indicates a functional disturbance which can in principle be avoided to the extent that sufficient risk management is undertaken. Genetic enlightenment (as the deciphering of the 'dark' code) therefore also entails a precise notion of *Mündigkeit* (maturity), which is linked to 'informed decisions' based on the knowledge of one's own genetic risks. In this perspective, the use of genetic diagnosis is not up to individual freedom or personal choice. The will not to know about your genetic make-up or risk profile could be regarded as no will at all: the sign of a deficient or illegitimate will, or even (why not?) the first symptom of a genetic 'disorder'. We might witness a process in which it will be more and more problematic to opt against genetic information and the transmission of this knowledge since this might be seen as an objective witness for lacking moral competence or as an indisputable fact of irrational behaviour (Deftos 1998; Petrila 2001).

Paradoxically, it is exactly the invitation to engage in self-determination and the imperative of a 'genetic responsibility' (Hallowell 1999; Novas and Rose 2000: 21–27) that renders individuals more and more dependent on medico-scientific authorities and their information. The right to health is realized in the form of duty to procure information, and only those who act responsibly draw the correct, i.e. risk-minimizing and forward-oriented, conclusions from this range of information.³ As a consequence, it is possible to use the experiences with eugenic practices in the past as an instrument to expand moral obligations and duties in the present, as the British Medical Association (BMA) in its report on *Human Genetics: Choice and Responsibility* demonstrates:

Awareness of abuses practised in the past in the name of ‘eugenics’ creates an understandable reluctance for health professionals even to think about telling patients who suffer from hereditary conditions that they have special ‘duties’ to other people or society. The most common ‘duty’ historically assigned to such patients was that of remaining childless. The BMA maintains, however, that *all patients* have duties of some sort, which may include voluntarily disclosing information to other people who may be affected. Obligations must not be placed on one group – to share information, for example, or limit their reproductive choices – which are not applied to other citizens.

(BMA 1998: 11–12; added emphasis)

The success of this responsabilization strategy depends on a change in the technologies of the self, aiming at ‘rational’ subjects with ‘due foresight’ who (wish to) use genetic diagnostics and submit to the resulting decisions or inquire into the specific options which arise. Genetic testing might contribute to constituting a ‘homo geneticus’ (Gaudillière 1995: 35) who submits to practices of self-control and personal management of the body – which comprises an embodiment of risk technologies that goes well beyond processes of exclusion or mechanisms of repression. The old eugenic programme to achieve ‘racial hygiene’ which primarily worked by means of coercion and constraint is more and more replaced by the government of genetic risks geared to optimization of human capital in the name of self-determination and individual freedom of choice. This ‘genetic responsibility’ establishes a new body politic, which calls on us to be as economic as possible with our own body, health or ‘quality of life’:

We might say that the political dilemma of eugenics is being solved in the genetic risk society by leaving behind the authoritarian model and replacing it with individualized freedom and responsibility. In the genetic risk society, we may rest assured that most people will make their choices in accordance with the common responsible social rationality.

(Koch 2002: 100)

If this assessment of the link of the concept of genetic risk to a discourse of responsabilization is accurate, then this would entail a fundamentally different meaning being given to eugenics. The notion of the ‘purity’ of the body of the population which needs to be restored or (re-)created becomes ever more insignificant. As, in principle, everyone is affected by genetic risk and potentially ‘ill’, current eugenic practices no longer focus on ‘purification’ of a collective genetic pool, but on ‘government’ of individual genetic risks. Precisely the construction of genetic risks creates the basis for recoding eugenic practices no longer aimed at specific individu-

als or identifiable collectives like the criminal subject or the ‘feeble-minded’, but at each and every single subject. For this reason, today it is probably no longer sufficient to point generally to the risk of eugenics. It might be more accurate to decipher a specific transformation form of eugenics: a eugenics of risk.

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Notes

- 1 For the history of eugenics see Kevles (1985), Schmuhl (1987), Proctor (1988), Adams (1990), Weingart et al. (1992), Kühl (1994); for a bibliographic account of the literature on eugenics, see Beck (1992).
- 2 However, this does not mean that the (human) genome is a ‘social construction’, rather the distinction line between the social and technical on the one hand and the natural and biological on the other is itself undergoing a profound transformation. As the historian of science Hans-Jörg Rheinberger remarks:

[Molecular biology] makes us realize that the result of its scientific conquest is not to supersede, but to change our natural history, that the very essence of our being social is not to supersede, but to alter our natural, that is, in the present context, our genetic condition. We come to realize that the *natural* condition of our genetic makeup might turn into a *social* construct, with the result that the distinction between the “natural” and the “social” no longer makes good sense. We could say as well that the future *social* conditions of man will become based on *natural* constructs. The “natural” and the “social” can no longer be perceived as ontologically different.

(Rheinberger 2000: 29)

- 3 Hans-Martin Sass, a medical ethical philosopher, therefore calls for an ‘ethos of duty’ in handling genetic information:

Leisure time behavior, place of work, or genetic predisposition, or a mixture of all three factors determine the respective individual risks to my health . . . Some can be eliminated, others reduced, or the stage at which they become acute delayed. The patient becomes the partner in preventing or delaying major health risks. The doctor’s ethics under the Hippocratic oath, that is characterized by care and outer-determined support, will in future be complemented by a self-determined and self-responsible ethics of the patient and citizen in health-care.

(Sass 1994: 343, translated by TL)

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