Genetic Testing, Eugenics and Risk

> „ […] 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/Tancredi 1994, p. 176).

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 1990). Many critics regard the contemporary human genetic practices as a continuation of population policy, social cleansing and racist programs such as were practiced during the first half of the last century in their most violent and brutal form by the Nazis.

In the following, I wish to investigate the relationship between genetic diagnosis and the problem of eugenics. The key point here, however, is less whether contemporary human 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, p. 4). To what contemporary fears and foreseeable future developments does this label refer? What parallels and what differences in human genetic practices today can be discerned compared, for example, with the Nazi racist project or the US sterilization programs at the beginning of the last century? In other words, the question is as to the historico-political continuities and ruptures between "old" and "new eugenics" (Proctor 1992; Paul 1994).

When attempting to answer this question I proceed from two working hypotheses which likewise pinpoint 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, p. 146), of a continuation of "eugenic traditions on a higher technical level" (Schumann 1992, p. 62) or a "relapse into biologistic patterns" (Koechlin 1996, p.35). On the other, it is also not tenable to assume there has been a fundamental rupture between the old eugenics and

modern human 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, pp. 125-7; Winnacker 1997, pp. 143-8). Another line of argumentation appeals to changes in "motivational structures" (Junker & Paul 1999; 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 at 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 20th 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, by the new genetics the debate itself is replaced and the two poles that it once constituted. Today, molecular biology and genetic engineering function as informational sciences, regarding the DNA as a code that can be read and re-writen. 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 society/culture is itself getting more and more "risky" (Haraway 1991; Keller 1992; Latour 1995).[1]

The identification of individuals with genetic risks does not serve to pinpoint some ineluctably genetic 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 more easily to measure and to control. Genetic diagnosis offers a series of possible interventions to avoid or minimize

[1] 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 historican 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, p. 29).

risk. These cover such different strategies as taking medicines and psycho-pharmaceuticals, the use of genetic therapies or the control of life styles, choice of partner, reproduction decisions, etc. In this respect, the significance of predictive 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 to people to know about own genetic risk profile across a range of disorders, and for the design an 'individual 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, pp. 321-2; 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 the biotechnological possibilities of 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 bio-technologies becomes the object of free decision making and individual planning that makes this society inevitably eugenic: "The genetic manipulation of men confuses the spheres of freedom and necessity. The freedom to manipulate nature, providing copies or designing men following genetic blue prints produces at the same time the necessity to ascribe even our non-manipulated existence to a decision" (Nassehi, 1998, p. 57). If we want 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, pp. 196-7).

If the genetic tests function in terms of risks, then this marks a key criterion for distinguishing it from the "older" eugenic practice. This difference, or so I assume, may at the same time be the condition for the universalisation of eugenic goals. Precisely the construction of genetic risks creates the basis for re-coding eugenic practices that no longer aim on identifiable

individuals or collectives like the criminal subject or the "feebleminded", but on all and every single subject. This trend is evident in the two application areas for prognostic genetic testing. At present the main application area is that of antenatal predictions (prenatal diagnostics). Under the sign of genetic testing, any pregnancy fundamentally becomes a "risk pregnancy" or "pregnancy on trial", whereby allowing the embryo to live depends on proving freedom from genetic damage. The privacy of each individual's decision and the de-criminalization of abortion contrasts with the public view on the woman's body: prenatal diagnostics (likewise ultrasound and reproduction technologies) makes the "fetus" a subject by rendering it visible, open to assessment, and utilizable in separation from the mother. The pregnant woman is then called on to work actively to optimize the fetus' 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 "fetal environment" which must behave risk-minimizing to secure quality (Degener/Köbsell 1992; Weir 1996; see also Ruhl 1999).

It is foreseeable that in future the focus of genetic testing procedures might shift to persons already born (postnatal diagnostics). While genetic testing in this area was foremost used to detect very rare disorders, the decoding of the human genome and the isolation of genes that are associated with more 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 1995) 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 stigmatisation and exclusion that range from a denial of insurance coverage to employment difficulties (Draper 1991; Billings et al. 1992; 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 programs enforced by state institutions, relying primarily on repressive means, there we find apparatuses of risk, aiming at the productive enhancement of the individual human capital in the name of self determination and choice. Indeed, the term self-determination undergoes a significant transformation the more the self is conceived of as

grounded in genetic information. 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 the personal usage of genetic information, since this might be seen as an objective sign for lacking subjective competence or as an indisputable fact of irrational behaviour. 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, of 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. Alongside the doctor’s ethics under the Hippocratic oath, with regard to care and outer-determined support, in future will go hand in hand with self-determined and self-responsible ethics of the patient and citoyen in healthcare” (Sass 1994, p. 343).

We have to relate this appearance of a notion of “genetic responsibility” (Novas & Rose 2000, pp. 21-7) to a key representational shift that marks a departure from the classic form of eugenics. Political scientist Diane B. Paul has recently pointed out that the scientific discussions on inheritance and genetic illnesses were until recently conducted in bacteriological terms. Genes were often described as if they were bacteria causing illness and “genetic defects” prompted similar fears as some concealed epidemic. All the talk of “carriers” also referred to the danger of infection in line with the model of contagious illnesses. Paul states that ever since the 1970s the metaphorics of contagion has gradually dissipated. An important reason was the discovery of the variability of the normal to a degree hitherto unthinkable. Genetic investigations provided proof that mutations and genetic variations are extremely widespread across the population and in principle all humans are affected by genetic anomalies (Paul 1998).

It is certainly very difficult to provide a conclusive answer, but perhaps there is more than a merely coincidental link between the receding appeal of the bacteriological paradigm and the simultaneous emergence of immunology as a guiding biological science – as well as the “risk epidemic in medical journals” (Skolbekken 1995). Cultural anthropologist Emily Martin (1994) has demonstrated that the bacteriological discourse has for some time given way to an “immunologic” or at least been supplemented by it – the latter operates less via rigid conceptions of normality and fixed notions of health and illness than through a “flexible

normalism" (Link, 1997) and a "systemic" conception of the body (see Haraway 1991; Lemke 2000).

This immunological perspective allows to shift the focus from dangers to risks, from monitoring outer factors to controlling internal factors. In this respect, genetic defects do not always and in all cases lead to illness; the talk of "genetic risks" suggests instead that the symptom of the illness only arises when within the body's own "immune system" no "resistances" or "thresholds of tolerance" (see Kitcher 1996, p. 266) can be established. To this extent, the diagnosis of genetic anomalies no longer points to some inalterable fate, but is a medium for the call that a corresponding control regime be developed. Instead of genetic determination by contagion with "ill" genes and asserting there is a clear pathological identity that can be "read" from the genes, the immunological discourse constitutes the risk fields and factors which should allow a preventative diagnosis and flexible "treatment" of the matters diagnosed by genetic testing.

If this assessment of the link of the concept of genetic risk to an immunological discourse 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 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. For this reason, today it probably no longer suffices to point generally to the risk of eugenics, but this must instead be deciphered as a specific form of eugenics, as a eugenics of risk.

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