Dr. Thomas Lemke
Institut für Sozialforschung
Senckenberganlage 26
60325 Frankfurt am Main
Tel.: +49(0)69/756183-29
Fax.: +49(0)69/749907
www.rz.uni-frankfurt.de/ifs
www.thomaslemkeweb.de

Risk as Responsibility – Genetic Diagnosis, Moral Obligations and Consumer Choices

(Paper presented at the Vital Politics conference 5th to 7th September 2003, London School of Economics and Political Science)

My presentation is part of an ongoing research project that investigates the relationship between genetic diagnosis and the discourse of risk.[1] In my study I propose to make use of an elaboration of the concept of governmentality developed by the French philosopher and historian Michel Foucault. Following Foucault, I am especially interested in how genetic knowledge and genetic technologies are used in the government of individuals and populations, how medical practices and diagnostic tools do function as political technologies on the one hand and as moral technologies on the other hand.[2]

Since I do not have the time to develop this subject sufficiently let me concentrate on a strategic element in this "genetic government": the discourse of genetic responsibility. My thesis is that the discourse of genetic responsibility relies on the scientific and technological progress in genetics since the 1970s, but it also linked to the political success of neoliberal programs and transformations that increasingly individualize and private the responsibility for social risks. By presenting material from legal decisions in which genetic information plays a

[1] Please note: This manuscript is an uncorrected version that does not include references; please do not cite without permission.

[2] For more information see the project description under www.thomaslemkeweb.de.

crucial role I try to show the rise of new obligations and the displacement of rights that are brought about by referring to a "genetic responsibility".

Let me start with a short inquiry: What is covered by the notion of "genetic responsibility"? An internet research using the search engine "Google" shows more than 120 listings for "genetic responsibility". But since many references appear more than once the number of actual listings is much smaller. "Genetic responsibility" occurs in conference reports, advertisements for movies, extracts from lifestyle magazines, advise manuals offered by medical doctors etc. Since I do not have the time to provide you with some examples, let me jump directly to the analysis. The different sources show that the term "genetic responsibility" is used in two different meanings. On the one hand it refers to a scientific complex of causality or competence, on the other hand it is linked to a moral complex of culpability or duty. Genetic responsibility could mean: Genes are the origin for a condition, an illness or a certain characteristic, e.g. genes are responsible for cancer or sexual orientation. But genetic responsibility could also mean, that individuals deal with genetic information in a certain way, namely in accordance with moral values and in a reflexive mode.

These two semantic components of the discourse of genetic responsibility – the scientific and the moral one – are not simply defined by an additive relationship; the discourse of genetic responsibility does acquire its contours by a specific tension, that is generated by the particular combination of the two components. Repeatedly it has been remarked that especially genomic research is threatening traditional concepts of responsibility and individual autonomy. Contemporary biology with its search for genetic determinants for a multitude of attitudes and modes of behavior seems to subvert the substantial basis for responsible action: the possibility of individual decision making and choice. I do not think that this fear of genetic determinism is justified. What we observe today is not the reduction of individual responsibility by reference to genetic dispositions and inborn traits. The affirmation of genetic factors does not result in a position that negates or forecloses the responsibility of the subject; quite on the contrary, the new genetic knowledge is the central point of reference to expand moral duties, it does invent new modes and fields of responsible action.

In the following, I would like to show how the discourse of genetic responsibility expanded over the past 30 years. While genetic responsibility in the 1970s was articulated exclusively in the context of reproductive behavior and referred to the care for "healthy" children and the attention not to transmit "disease genes", today two other dimensions of responsibility are added. The moral duty for prevention of risk is complemented by obligations to communicate

and control genetic risks. Beyond the problem of transmitting "bad genes" to the next generations, we also find an anxiety of their possible effects for already living persons: Shouldn't relatives be warned about genetic risks in order to realize options for prevention or therapy? If there are no such options available shouldn't they know about genetic risks, seeking genetic counseling or testing options to make "responsible" decisions concerning their future? There is a second direction in which the discourse of genetic risk expanded since the 1970s. This new field of application does not concern the relation to others but the health behavior of the person himself or herself and the duty towards oneself. Not only in relation to others, to possible children or family members, but also towards personal genetic risks a responsible behavior, a responsibility for one's own health is requested. Genetic responsibility materializes in this case as demand for genetic diagnosis technologies and prevention procedures. In this perspective, only knowledge about the individual genetic risks allows for a responsible life. By presenting many diseases as genetic in origin, a "risk competent" or "mündiges" health behavior demands not only the acknowledgement of general risk factors like alcohol, smoking or lack of exercise but also necessitates a specialized knowledge based on the individual genetic risk profile.

My thesis is that these two new dimensions of genetic responsibility might undermine guarantied rights and the freedom of choice concerning genetic tests. The discourse of genetic responsibility tends to substitute the recourse to rights by establishing imperatives of duty towards oneself and others.

Firstly, the duty to inform relatives about their genetic risks may contrast with the protection of privacy and the confidentiality of the doctor-patient relationship. Moreover, the imperative to warn others could erode their right not to know about genetic risks.

Secondly, new forms of discrimination, exclusion and paternalism might arise in a social and political conjuncture in which genetic information is getting more and more irresistible. In this climate it will probably be judged irresponsible not to make use of genetic technologies and diagnostic devices. Seemingly paradox, the main point of reference for responsible action might not the individual will or the principle of self-determination but on the contrary the personal decision could be questioned in terms of a lack of "responsibility" or an excess of dependency.

The extension of the discourse of genetic responsibility from the focus on reproduction to the interest on communication and control of genetic risks could empirically be demonstrated by an analysis of medical advice books and self help manuals from the 1970s onwards. I will leave out this material since here I am more interested in the fact how the logic of genetic

responsibility already shapes legal decisions and how it gets hold in institutional settings. I would like to present two legal cases that were recently decided in the US and that serve to illustrate that there are clear signs that the duty to inform relatives as well as the imperative of genetic self-responsibility are about to be institutionalized.

I.

Genetic risks are characterized by a central ambiguity. Genetic information does not only concern the individual, but may also indicate health risks for relatives and family. This particular quality of genetic information produces a certain problem: Under what conditions are physicians legally obliged to disclose genetic information that is medically relevant to potentially affected relatives? There are different regulatory frameworks to deal with the problem of confidentiality in the context of genetic information. In France any direct transmission of genetic information to other persons or institutions is forbidden, while in the UK and in the US as in many other countries the right of confidentiality is principally guarantied, but it may be restricted under certain conditions. While all regulations protect the privacy of genetic information, there remains a lot of legal uncertainty to set out situations in which such information may be disclosed without liability.

Two cases in the US, where high courts ruled that doctors are obliged to warn children of a patient that may be at risk genetically for acquiring the disease of their parent, illustrate a creeping tendency to establish a duty to warn family members about genetic risks. Since the reasoning in both cases is quite similar, I only refer to the Safer v. Pate case that was decided in 1996 by an appellate court in New Jersey (the other one was decided in Florida one year before).

Donna Safer's father was treated for cancer in the 1950s and 1960s. He was hospitalized in the beginning of the 1960s for colon cancer and died in 1964 when she was 10 years old. In 1990, Donna Safer was diagnosed with colon cancer herself. After obtaining her father's medical records, she filed suit in 1992 against the estate of her father's doctor (who had died in 1969). She alleged that her father's physician knew or should have known of the hereditary nature of the disease and she saw a violation of a duty to warn her of the risk to her health while her father was treated. According to Safer, a timely warning would have enabled her to take preventive measures to reduce her risk.

While the trail court denied the plaintiff's motion of judgment, the appellate court came to another conclusion. Like the Florida Supreme Court before, the New Jersey court concluded that the physician's duty went well beyond the patient to the children themselves. The court

held that there is a legal duty to warn those at risk of avoidable harm from genetically transmissible conditions. A very important reason for this judgment was the fact that the court treated genetic risks just like any other type of medical risks, thereby assimilating genetic risks to infection risks. According to the court there was "no essential difference" between "the type of genetic threat at issue here and the menace of infection, contagion or threat of physical harm … The individual at risk is easily identified, and substantial future harm may be averted or minimized by a timely and effective warning" (Safer v Pack 1996, p. 1192). In this perspective, the transmission of genetic risks by parents appears to be quite similar to the problem of a possible infection and as there is a duty to warn relatives in the case of contagious diseases the same must be true for genetic risks. It is the epistemic rapprochement of genetic risk to other forms of medical risk that allows for a normative extension of genetic responsibility.

The two court decisions do institutionalize a legal duty of the physician to warn, if he or she knows or should have known that the patient's children are exposed to a genetic risk that is related to the disease diagnosed in the patient. In both cases it was held that there are legal obligations that go beyond the concrete relationship between the physician and his or her patients towards the patient's children. This tendency to establish a duty to warn in the context of genetically transmissible diseases results in some serious problems. Firstly, it might be asked if the establishment of such a duty of disclosure does not undermine the right not to know about genetic risks. Probably, there are family members that do not want to be warned of their increased genetic risks. How is it possible to exercise a right not to know if the doctor is legally obliged to inform the relatives? So the often cited right not to know about genetic information might lack any substance in a society that gives priority to unconditioned information and that assumes that responsible persons are only those that actively seek genetic information. This reasoning is stated quite clearly in a report on genetic screening that was published by the Nuffield Council on Bioethics: „As a starting point, we adopt the view that a person acting responsibly would normally wish to communicate important genetic information to other family members who may have an interest in that information, and that a responsible person would normally wish to receive that information, particularly where it may have a bearing on decisions which he or she may be called upon to take in the future" (Nuffield Council on Bioethics, 1993, p. 49).

Let me just mention some more problems that will arise in the context of a medical duty to warn relatives of genetic risks. The disclosure of this kind of information may have negative effects on family relations and lead to severe tensions between family members. Also, the

genetic information might be used by third parties. Employers and insurance companies are certainly interested in this kind of information and there is a danger that it will be used for discriminative purposes.

This brings me to the second court decision that I would like to present: the Chevron- v. Echazabal case that was decided by the Supreme Court of the US in 2002. Let me first lay out the facts of the case. The plaintiff, Mario Echazabal, worked since 1972 at a Chevron oil refinery in El Segundo, California as a laborer, helper, and pipefitter for various contractors, mainly in the coker unit. In 1992 he applied to work directly for Chevron at the refinery's coker unit. Chevron determined that Echazabal was qualified for the job and offered to hire him contingent on the results of a physical exam. The company doctor, however, declared Echazabal unfit for the job because blood tests showed liver abnormality. The company assumed that further exposure to toxic substances in the refinery might pose a risk to his liver. Nonetheless, Echazabal was permitted to continue working at the company as employee of Chevron's contractor. He sought treatment and was ultimately diagnosed with Hepatitis C that remained asymptomatic since then. In 1995 he again applied for a job at Chevron, and again his demand was turned down after a medical exam. This time the company directed the contractor who employed Echazabal to take him out of that position, which it did in 1996. This action was taken even though Echazabal's liver condition never caused injury or accident to himself or anyone else at the refinery. In 1997 he filed suit, charging that Chevron's decision violated the Americans with Disabilities Act (ADA). He also presented testimony by two medical experts in liver disease that working in that factory would not put him at any greater risk than any other employee (NCD 2003, pp. 5-6; Chevron v. Echazabal 2002, pp. 1-3).

After a District Court granted summary judgment for Chevron and a Circuit Court reversed this decision, the case was presented to the Supreme Court. The Supreme Court addressed in its decision issues central to the ADA. During the examination a liver function assay was used that resulted in the identification of a biological marker that according to the employer disposed Echazabal for liver impairment. As a consequence, he would face further damage if he experienced chemical exposures characteristic of refinery work. At the heart of the ruling is the court's interpretation of the direct threat provision of the ADA. A direct threat is defined as a significant risk of substantial harm that cannot be eliminated by reasonable accommodation. An individual may be refused employment if a direct threat can be established.

The previous ruling in this case by a Circuit Court held that the direct threat defense was not available to Chevron because Echazabal only presented a risk to himself. As a commentator remarked, "the court reasoned that a direct threat only applies when the individual's condition poses a direct threat to others. In other words, the court affirmed the notion of health as a discretionary right in which the individual may chose to assume certain risks so long as they do not have the potential to harm others. The Supreme court decision rejects this reasoning and reverses the circuit court's judgment. Individuals who pose a risk exclusively to themselves may be excluded from a job as long as the employer relies on reasonable medical judgment" (Lomax 2002, p. A 505). The company thereby sought to "protect" an individual such as Echazabal from himself. The court decision denies employees the right to decide whether or not to accept the risks posed by a particular job and restates a paternalistic logic that the company knows what's best for the employee or potential employee. Ironically, it was exactly this paternalistic logic that should have been abandoned by the ADA regulation.

By presenting evidence from a biological marker, Chevron relied on a medical opinion that is based on future possibilities. The same is true for genetic susceptibility testing. Since the ADA is often cited as offering individuals protection from genetic discrimination, one might ask the (speculative) question if the decision would have been different in this case. According to the Supreme Court it is acceptable to exclude individuals from a job who pose a risk exclusively to themselves as long as the employer relies on reasonable medical judgment. This condition might be fulfilled by genetic susceptibility testing that successfully claims medical and scientific credibility. As a consequence, it is conceivable that future workplace exclusion might be based on genetic susceptibility testing that establishes a substantial genetic risk of the individual to himself.

Apart from its effect on disability rights, the Chevron v. Echazabal decision may have important implications for environmental health research (Lomax 2002, p-A 504). While research in this field traditionally concentrated on identifying external risk factors that pose health problems to employees, more and more scientific emphasis is put on recognizing internal risks or personal susceptibilities that are based on the genetic make up of individuals. As a consequence the "old" risk logic is completely reversed. The scientific interest no longer focuses on bad working conditions or toxic substances that are used in the labor process but on susceptible employees that are less resistant than others to risk factors and health threatening conditions of work.

II.

Let me conclude. In my presentation I did distinguish two semantic components of "genetic responsibility". The first complex refers to scientific questions of causality and competence, while the second includes moral questions of duty and culpability.

I also referred to what I called the expansion of the discourse of genetic responsibility. In the 1970s, the domain of genetic responsibility was limited to reproductive behavior, that was problematized to control disease and disability in the next generation. Genetic responsibility in this context means to act in such a way as to guarantee the birth of healthy children and to prevent the transmission of "bad" genes. Today, genetic responsibility is increasingly addressed to the individual, as responsibility towards the self. It means prevention of diseases by the prudent management of genetic risks, by informed choices of life style options that are based on genetic information. Genetic responsibility here means the active demand for genetic information and the interest in genetic testing opportunities.

Finally, let me say a few words on a subject that seems central to me in this context: Which social and political transformations are responsible for the expansion of the discourse of genetic responsibility? My assumption is that the recent discourse of genetic responsibility depends on two conditions of existence that originate in the 1970s: The first is a scientific-technological one, the second a social-political one. The first condition of existence can be found in the increase of genetic knowledge and the proliferation of new technological interventions, that were only created in the beginning of the 1970s. The 1970s were a crucial decade in that genetics was introduced into medical practice, especially in the field of diagnosis. In the US and other industrialized states genetic knowledge was used in screening programs for certain diseases, new reproductive technologies were developed and prenatal diagnosis became part of medical care for pregnant women. The second condition of existence for the discourse of genetic responsibility is the crisis of the Keynesian state or the welfare state and the successful implementation of neoliberal policies from the mid-1970s on. The massive financial support for the decoding of the Human Genome and public acceptance of human genetic research are part of a comprehensive transformation that is increasingly individualizing and privatizing the responsibility for social risks. The individual is expected to conduct a forward-oriented risk management. This is not only the case in the field of health, but also in employment policies, crime prevention or old-age insurance. The retreat of the state goes hand in hand with an appeal to personal responsibility and self-care and the promotion of self-regulatory competencies among individual and collective subjects. Put differently: The contemporary discourse of genetic responsibility is embedded in a more global – neoliberal – discourse of responsibility, that shapes our society today. It has nothing

to do with an increasing knowledge that engenders new duties and obligations but forms an integral part of a neoliberal strategy that is obviously very successful in so far as it effectively conceals the constraints and inequalities that characterize the discourse of genetic responsibility. By dismantling the mechanisms of social security and shifting responsibility for human misfortune from the public to the individual domain the dominant discourse of responsibility actually removes the material conditions for acting responsible as it minimizes the possibilities of free decision making and real choice.