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FROM SOCIAL PROBLEMS TO PRIVACY ISSUES

A Symptomatic Reading of the Discourse on Genetic Discrimination

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Thomas Lemke

From Social Problems to Privacy Issues

A Symptomatic Reading of the Discourse on Genetic Discrimination (This paper was first presented at the symposium »The ›Biological Turn‹ in Law: A Critical Appraisal« organized by Miguel Vatter and Marc de Leeuw at the University of New South Wales in Sydney on 23 October 2015.)

IfS Working Paper #9

Abstract

The term *genetic discrimination* has been coined to refer to a (negative) differential treatment of individuals on the basis of what is known or assumed about his or her genetic makeup. This paper critically engages with the current understanding of genetic discrimination. It shows that the distinction made between people who are symptomatically and asymptomatically ill as an essential element of the genetic discrimination discourse. Taking up Louis Althusser's interpretative method of »symptomatic reading« (Althusser and Balibar 1997), I seek to reconstruct and make explicit what is absent, omitted and repressed by the way the problem of genetic discrimination is framed and addressed.

The argument is structured as follows. I will first present a short genealogy of the problem, outline the concept of genetic discrimination and how it has become a research topic over the past twenty-five years. Second, the paper sketches the regulatory and legal responses to the phenomenon, focusing on Germany as an example. I will then discuss some characteristics of the debate on genetic discrimination, in order to show how it fails to address important areas of concern in consequence of its current focus and framing. The last section advances the thesis that it is necessary to reconsider and renegotiate the scope and the meaning of genetic discrimination in the light of new technological challenges, recent commercial dynamics and a revised understanding of genetic information following the Human Genome Project.

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Inhalt

Over the past twenty-five years, a series of empirical studies in different countries have shown that our increasing genetic knowledge leads to new forms of exclusion, disadvantaging and stigmatization.[1] The term *genetic discrimination* has been coined to refer to a (negative) differential treatment of individuals on the basis of what is known or assumed about his or her genetic makeup. Reported incidents include disadvantages at work, problems with insurance policies and difficulties with adoption agencies.

Today, many countries around the world have introduced laws designed to prevent discrimination against individuals due to their genetic properties. These legislation projects seek to guarantee the right to ›genetic privacy‹ and protect personal data against misuse. The notion of genetic discrimination, which was largely unknown only a few years ago, has now become a key term informing not only scientific work but also the regulatory and legal responses to what is conceived as a »new form of social prejudice« (Rifkin 2000).

This paper critically engages with the current understanding of genetic discrimination. I argue that the debate on genetic discrimination suffers from a juridical framing that focuses on institutional actors and privacy issues at the expense of a more complex and convincing approach. I will concentrate on the opposition of the symptomatic and asymptomatic ill as one essential element in the genetic discrimination discourse. Drawing on Louis Althusser's interpretative method of »symptomatic reading« (Althusser and Balibar 1997), I seek to reconstruct and make explicit what is absent, omitted and repressed by the way the problem of genetic discrimination is framed and addressed.

The argument is structured as follows. Firstly, I will present a short genealogy of the problem and set out what genetic discrimination is and how it became a research topic over the past twenty-five years. Secondly, I will sketch the regulatory and legal responses to the phenomenon, taking Germany as an example. I will then discuss some characteristics of the debate on genetic discrimination, in order to show how the current focus and framing of this discourse makes it difficult to address important areas of concern. The last part of the paper advances the thesis that we have to reconsider and renegotiate the scope and the meaning of genetic discrimination in the light of new technological challenges, recent commercial dynamics and a revised understanding of genetic information following the Human Genome Project.

[1] This paper takes up and expands arguments already developed in earlier publications (Lemke 2013; Lemke and Liebsch 2015).

1 The Genealogy of a Problem

In her dissertation, the medical anthropologist Janet Childerhose investigates how the problem of genetic discrimination has gained a prominent status in political and scientific debates in the United States since the 1970s (Childerhose 2008). She shows that the scope and definition of genetic discrimination have undergone several significant shifts and transformations over this period, drawing on archive material, interviews with key actors and organizations that shaped early public opinion as well as an institutional ethnography of relevant committees dealing with regulatory issues. Following Michel Foucault's reading of genealogy and Ian Hacking's understanding of historical ontology, she starts her investigation »from the position that practices of discrimination have not been sufficient for genetic discrimination to become a recognized problem« (2008: 11). As she points out convincingly, the rubric of *genetic discrimination* was not applied to the mass screening of African-Americans to detect sickle cell carriers during the 1970s (Duster 1990), nor to the practices of workplace screening in the 1980s for applicants for jobs in industrial sectors that entailed exposure to toxic chemicals especially affecting women and minorities (Holtzman 1989; Draper 1991). Instead, the controversies and critical debates tended to be interpreted as having exposed racial and ethnic discrimination. A ›reversed‹ or ›perverted‹ risk logic also became apparent whereby it was no longer dangerous working conditions or toxic substances in the labor process that were to be condemned but rather, the blame was laid on »supersensitive workers« (Daniels 2003: 548) who were less resistant than others to environmental risk factors and health-threatening working conditions. Another concern expressed in the early debates was the fear of a return to or a revival of eugenic practices – a focus missing in the contemporary debate on genetic discrimination (Childerhose 2008: 109–155)

The notion of genetic discrimination first emerged in publications in the mid-1980s (ibd.: 162–165), but did not yet possess a distinctive analytic profile that would systematically distinguish it from other forms of discrimination.[2] This definition was provided by the first empirical study to investigate the phenomenon of genetic discrimination, which was carried out in the early 1990s under the direction of Paul Billings (Billings et al. 1992). Billings and his team published an appeal in the *American Journal of Human Genetics* asking physicians and genetic counsellors to inform them about cases in which individuals suffered discrimination on account of their genetic makeup. A similar appeal was sent to physicians active in clinical genetics, as well as to support groups for those affected by genetic diseases. Billings and his co-authors documented a total of 41 cases of genetic discrimination. With only two exceptions, all of these concerned the insurance sector (health, life, and car insurance) or employment

[2] As Childerhose notes (2008: 163), the Social Issues Committee of the American Society of Human Genetics organized a meeting in November 1986 on genetic discrimination, explicitly linking the issue to genetic screening in the workplace and insurer access to genetic testing results (Rowley 1988). Around the same time, the term also figured in a book published by the legal scholar Lori Andrews (1987: 19).

(hiring, dismissal, training and promotion within companies). The study conducted by Billings and his colleagues evoked a strong reaction in the United States and stimulated a lively debate in the media and the policy area. It established a definition of genetic discrimination that was taken up in the following empirical studies and also shaped the legal and societal debate thereafter:

»[G]enetic discrimination is defined as discrimination against an individual or against members of that individual's family solely because of real or perceived differences from the ›normal‹ genome of that individual. Genetic discrimination is distinguished from discrimination based on disabilities caused by altered genes by excluding, from the former category, those instances of discrimination against an individual who at the time of the discriminatory act was affected by the genetic disease« (Billings et al. 1992: 477; see also the nearly identical definition in Natowicz, Alper and Alper 1992: 466).

Thus, Billings and his co-authors put forward a definition that relied on a strict distinction between genetic discrimination as opposed to discrimination based on disability and (chronic) illness. While the latter relates to phenotypic factors, that is, to observable characteristics, the former is based on the genotype, in other words the genetic makeup of the individual. Here, genetic discrimination occurs when an individual is treated differently because of actual or perceived deviances from the ›normal‹ genome. But the study not only came up with a systematic definition of genetic discrimination; it also invented a new epistemological figure. As Billings et al. regarded genetic discrimination as grounded in a non-manifest genotype conceived as ›different‹ or ›deficient‹: those affected by genetic discrimination are currently not (yet) ill but can be regarded as the »asymptomatic ill« (Billings et al. 1992: 479) who may in the future – or possibly never – suffer from a disease for which a genetic factor is considered causally responsible.

This pioneering work was followed by further empirical studies of genetic discrimination in the USA (see for example Geller et al. 1996; Lapham et al. 1996; Hall and Rich 2000; Klitzman 2010). However, practices of genetic discrimination are not limited to the United States and empirical studies have been conducted in the United Kingdom (Low et al. 1998; Mayor 2003), Canada (Bombard et al. 2007; 2012), Australia (Otlowski et al. 2007, Taylor et al. 2008, Barlow-Steward et al. 2009) and Germany (Lemke 2006; Lemke and Liebsch 2015).

The idea of an independent form of discrimination, based on genetic factors and to be categorically distinguished from discriminatory practices based on phenotypic characteristics, has dominated academic debates and encouraged empirical investigations. It has also informed legal responses to the issue.

2 Legal and Regulatory Responses: The German Case

The academic discourse and the empirical studies dedicated to the problem of genetic discrimination have not gone unheeded. Since the early 1990s a series of legislative initiatives and opinions have been issued by inter- and supranational organisations and commissions aimed at protecting individuals against genetic discrimination. Thus, article 6 of the *Declaration on the Human Genome and Human Rights* of the UNESCO reads: »No one shall be subjected to discrimination based on genetic characteristics that is intended to infringe or has the effect of infringing human rights, fundamental freedoms and human dignity.« At the European level, explicit bans against discrimination based on genetic characteristics are contained within the *European Convention on Human Rights and Biomedicine* of the European Council (1997) (article 11) as well as in the *Charter of Fundamental Rights* of the EU (2000) (article 21).

Many countries around the world have passed genetic non-discrimination regulations to restrict or ban the use of genetic information in employment and insurance (Bombard et al. 2012; Joly, Braker and Le Huynh 2010; Rothstein and Joly 2009; Knoppers, Godard and Joly 2004). The laws are intended to protect individuals against unfair differential treatment in the fields of employment and insurance based on genetic information, and to respond to the fears of individuals currently dissuaded from undergoing genetic testing in both clinical and research settings. Some countries have adopted a prohibitive approach banning the use of genetic test results by the insurance industry on principle (for example Austria, Belgium, France). Others have opted for moratoria which require the insurance industry to refrain from demanding genetic tests and bans the use of test results for insurance contracts for a specified period of time (United Kingdom, Finland, the Netherlands) (Van Hoyweghen and Horstman 2008; Joly, Braker and Le Huynh 2010: 361–3; see also McGleenan and Wiesing 2000).

Germany could be described as a »late developer« in the field of genetic information regulation (Ireni-Saban 2010: 366). After several years of debate the *Genetic Diagnostics Act* (*Gesetz über genetische Untersuchungen bei Menschen*, GenDG) was finally passed by the German Parliament and came into effect on February 1, 2010. The focus of the Act is on the right to information and self-determination with the aim of protecting individuals against abuse of their genetic information (Backhaus 2011; Lander 2011).

The Act explicitly states (§4) that no person may be discriminated against or disadvantaged because of genetic characteristics. It generally prohibits insurers (§18) and employers (§19) from demanding a genetic examination or being supplied with the results of any previously conducted medical genetic examination. The Act also underlines the obligation of medical professionals to inform individuals thoroughly, for example about the risks of the examination and the patient's rights (§9). According to §10 genetic counselling is obligatory for an individual seeking genetic testing.

The Genetic Diagnostics Act focuses especially on the use of genetic information by employers and insurers. Insurance companies are prohibited from requesting clients to undergo genetic tests prior to the conclusion of insurance contracts. Furthermore, they are not even allowed to receive or use genetic information given to them voluntarily by the individual. However, the prohibition of use does not apply if the agreed benefits in life, disability or pension insurance policies would exceed 250,000 euros or 30,000 euros in annuities. This exception is justified in terms of a declared need to protect the insurer against adverse selection. Likewise, the intention with regard to employment relations is to prohibit employers' consultation of genetic screening results for their hiring decisions. But again, exceptional cases are acknowledged: genetic tests are permitted in the context of preventive occupational medicine examinations, in order to identify susceptible employees who are less resistant than others to environmental risk factors and health-threatening conditions of work (Eberbach 2010; Kröger 2010).

In the following, I do not propose to explore in detail the many regulatory deficits, practical difficulties and normative contradictions that characterize the Act (see for example Eberbach 2010; Backhaus 2012; Heinemann and Lemke 2013). Rather, I intend to shift attention to the fundamental premises about genetic discrimination on which this Act and legal regulations in other countries are based. The empirical studies and legal regulations have stimulated an important debate on the societal impact of the new genetics. However, it has also become increasingly evident that the current understanding of genetic discrimination that informs both scholarly investigations and legal texts entails a variety of conceptual, normative, and analytic difficulties.

3 Essential Features and Limitations of the Debate

So far, the history of the debate on genetic discrimination might sound like a success story. Empirical knowledge has been generated to analyze and assess a societal problem. The results of the studies have informed the wider public leading to new legal arrangements designed to address and prohibit certain undesirable effects of the increasing genetic knowledge. So far, so good. But something has got lost along the way, indeed, the success turns out to be a failure in some important respects. It is rather ironic that two problematic aspects are internally linked. There is a tendency to generalize the topic and extend its significance from selective minorities to include everyone as potential victims of genetic discrimination. This is coupled with a limitation that seriously restricts the scope of genetic discrimination, as it is conceived as only affecting asymptomatic individuals at risk of genetic disease.

Let us now analyze in more detail two essential elements of the prevailing discourse on genetic discrimination: the strict distinction between those who are asymptomatically

and symptomatically ill, and the clear-cut separation of genetic and non-genetic diseases and tests.[3]

As I have already shown, the first definition of genetic discrimination by Billings et al. introduced the distinction between phenotypic and genotypic discrimination. According to this point of view *genetic* discrimination represents an analytically distinct, unique form of discrimination, distinct from the disadvantaging and exclusion of the disabled or the chronically ill. This assumption has guided empirical studies of and legal responses to genetic discrimination so far, but should be questioned for various reasons. First, this presupposition informs a narrative that considers practices of genetic discrimination to represent a radical new form of exclusion and stigmatisation. The distinctive feature of genetic discrimination is that it allegedly operates at the level of the genotype and replaces visible – phenotypic –classification patterns by invisible ones. Accordingly, there is thought to be a danger of a new social class being created, consisting of people who are for the most part excluded from career paths, training prospects, and insurance opportunities, due to their genetic characteristics, and thus socially marginalised. The problem with this critical formulation is that specific factors producing inequality are treated in isolation from one another; thus, it is not able to examine the systematic links between forms of exclusion, marginalisation, and disadvantaging that already exist: against the disabled or the chronically ill on the one hand and those against individuals affected by genetic risks on the other.[4]

Secondly, a strict demarcation between genotype and phenotype is not helpful when trying to grasp the fears and experiences of those affected by genetic diseases or risks. In empirical studies on genetic discrimination, few substantial arguments can be found to justify a systematic differentiation of two isolated and principally separated forms of discrimination and groups of persons concerned (asymptomatic ›risk persons‹ versus symptomatic patients). In everyday life and in experiences of stigmatisation or disadvantaging based on genetic knowledge, the distinction between asymptomatic and symptomatic individuals is more difficult to sustain than many scientists and policy makers assume. This point is illustrated convincingly by the results of an empirical study based on 64 interviews with individuals who had, or were at risk of developing, Huntington's disease, breast cancer and Alpha-1 antitrypsin deficiency: »Patients and family members here tend not to see this differentiation as distinct or sharp, and rather, often perceive these realms as blurring. In part, these disorders may have intermediate ›grey areas‹ – e.g. possible (but not definitive) and/or non-specific symptoms. [...] Thus,

[3] There are other important features that I cannot address for reasons of space: the focus on practices of institutional discrimination (especially insurances but also employers) at the expense of other fields of discrimination, for example in the domain of the family (see Bombard et al. 2008: 287; Lemke and Liebsch 2015) and the tendency to exclude reproductive issues and eugenic concerns (see for example Duster 1990).

[4] »By focusing on mechanisms of genetic discrimination and inequalities of access to genetic treatment and enhancement technologies, the use of the underclass metaphor loses much of its analytic potential. Sociologically, theories of the underclass point to cumulative dynamics of social disadvantage, geospatial and social forms of segregation and exclusion, and above all marginality and structural barriers to participation in the mainstream.« (Kelly 2005: 147)

the distinction between symptomatic vs. asymptomatic may not be wholly clear, and individuals may face discrimination due to symptoms that are not yet recognized as caused by a genetic disorder. [...]. Moreover, symptomatic and asymptomatic individuals are frequently members of the same families and disease communities. Fears of discrimination against symptomatic family members may heighten anxieties among their asymptomatic family members, affecting the latter's decisions.« (Klitzman 2010: 80; see also Lemke/Liebsch 2015)

The strict division between the symptomatic and the asymptomatic ill is intimately connected to the opposition of genetic and non-genetic tests and diseases. While the distinction between the symptomatic and the asymptomatic concerns the clinical domain only, the latter opposition extends beyond the medical sphere. Again, we observe a tendency to isolate and separate one set of practices from the other, as the juxtaposition does not allow the investigation of how forms of genetic discrimination are linked with sexist and racist practices and mutually reinforce one another (Wolf 1995).[5] There are several problems associated with this oppositional framing that neatly separates the genetic from the non-genetic. First, it is evident that public debates and legal regulations assume a unique epistemological and normative status for genetic factors, which also shape non-discrimination legislation. This idea of »genetic exceptionalism« (Murray 1997) relies on the erroneous assumption that genetic and non-genetic information, testing procedures, and diseases can be clearly separated from one another (Alper 2005: 171). According to this idea, individuals affected by genetic risks should enjoy particular legal protection, since they are supposedly not responsible for their genetic constitution and genes are conceived of as being the basis of human identity.

Apart from the epistemological problem of neatly separating the genetic from the non-genetic, there is also a normative quandary. As genetic discrimination and discrimination based on phenotype or on already manifest symptoms are evaluated differently in legal terms, it is necessary to ask what criteria are used to justify such a differential treatment of persons who are equally affected by discriminatory practices. Furthermore, there is the danger that the exceptional legal status of genetic discrimination simply ›normalizes‹ all non-genetic forms of discrimination. If in the widest variety of different social areas the disabled and the (chronically) ill are regularly discriminated against compared with the able and the healthy, this appears legitimate to the extent that special protection exists for persons who are affected by practices of genetic discrimination. Put

[5] As certain ethnic groups are differently susceptible to particular genetic illnesses, there is a danger that members of minorities will be associated with such genes and treated as if they were ill, even if they do not bear the particular genetic mutation. For example, sickle cell anemia in the United States is considered a disease of African-Americans, although it is to be found just as frequently among population groups from the Mediterranean rim (Duster 1990: 24–28, 45–51). The practice of »gender verification« at international sports competitions is a striking example of the linking of genetic discrimination and sexism. This procedure has for a long time been used to determine the sex of female athletes. It resulted in a series of women with seemingly »male attributes« (for example females with androgynous insensitivity, XY gonadal dysgenesis) who were excluded from the competition. Only women and not men have to have their »gender« verified, and suffer the possible consequences of »failing« such a test.

differently: the focus on the legal impermissibility and moral reprehensibility of genetic discrimination isolates other forms of discrimination, plays them off against one another, and threatens to augment the social acceptance of practices of non-genetic discrimination.

Hence, the distinction between genetic and non-genetic information can hardly serve as the basis for legal differentiation and may have problematic social implications. It is not intelligible why, for example, the use of biochemical methods that make it possible to draw inferences about a person's genetic disposition is permissible for discriminatory purposes, while DNA tests that produce the same results are forbidden. It would seem not only impractical but also unfair to prohibit an insurance company from considering a genetic analysis for a complex disease, while the results of a non-genetic test for the same disease may be relied on. This approach entails a legal double standard in which people with positive genetic diagnoses receive more protection against discrimination and data abuse than those whose findings are based on non-genetic methods.

However, legal protection does not need to result in genetic data being isolated from other (predictive) medical information. Genetic discrimination is the result of an increasing extension of the concept of illness and disability and the expansion of existing practices of contempt, stigmatization and exclusion to those categorized as the »asymptomatic ill«. According to this perspective, strategies to counter genetic discrimination have to be supplemented by profound institutional reforms and comprehensive regulations that protect individuals who are already ill or disabled more effectively against social exclusion and disadvantage. Otherwise we run the risk that the distinction between genetic and non-genetic will lead us to ignore the more fundamental issue of how (predictive) medical information can be used in general to categorise people, to assign them characteristics and traits, and to exclude them from certain benefits (see Wolf 1995).

4 Current Developments and Future Trends

As I stressed in the introductory part of my presentation, Janet Childerhose in her dissertation investigates the debate on the (possible) negative consequences of undergoing genetic screening and testing since the 1970s. She convincingly shows that the notion of genetic discrimination is »plastic« (2008: 10), as it captures the diverse and often conflicting interests and concerns of a heterogeneous bunch of actors involved in the process of identifying and addressing problems tied to genetic testing and screening in the past forty years. By enacting this genealogical perspective, Childerhose counters the still dominant interpretative pattern that argues that the problem of genetic discrimination was ›discovered‹ in the context of the human genome project and increasing genetic knowledge in the 1990s (see e.g. Frankel 1999; Parthasarathy 2004), resulting

finally in the call for more comprehensive safeguards and legal protection. Childerhose calls this narrative »the genetic privacy story« (2008: 60). In her view, it represents a limited and distorted account of the complex and shifting problem of genetic discrimination as it »overlooks how concerns and political interests unrelated to genetic privacy have shaped the problem and driven activism on it« (Childerhose 2008: 61).

Following this diagnosis, I have proposed a »symptomatic reading« (Althusser and Balibar 1997) of the prevailing genetic discrimination discourse focusing on one essential element of this discourse: the strict distinction between the symptomatic and the asymptomatic ill, genetic and non-genetic tests and diseases. This method of interpretation not only exposes absences, omissions and limitations; it also seeks to establish how a specific problematization addresses and frames the problem of genetic discrimination in a distinctive way. The opposition on which I have focused is an integral part of a more comprehensive constellation that has dominated the scientific and legal debate on genetic discrimination since the 1990s. Another important element is the *genetic privacy story*, which claims that genetic discrimination affects everybody, not only a minority of individuals who are carriers of rare mutations, as each single citizen is exposed to genetic risks and/or might pass them on to the next generation. Further aspects are the focus on practices of institutional discrimination (especially insurance but also employers) at the expense of other fields of discrimination (for example in the domain of the family) and the tendency to exclude reproductive issues and eugenic concerns. As I have tried to show, this particular framing makes it impossible to account for many forms of stigmatization, negative classification or disadvantaging which mobilize genetic knowledge, and it tends to obscure the continuities between discriminatory practices.

Ironically, the call to distinguish genetic discrimination from other types of disadvantaging and exclusion and subject it to special legislation has a paradoxical impact. Prohibiting the ›inequitable treatment‹ of individuals with an ›abnormal‹ genetic constitution reinforces the cultural belief in the exceptional status of genetic factors, something which the legal regulation was supposed to counter in the first place.

Exposing this particular frame and its limitations is today more urgent than ever. The proposal to enlarge and deepen the understanding of genetic discrimination beyond a legal account focusing on privacy issues is necessary if we want to grasp contemporary forms of negative differential treatment on the basis of genetics; furthermore, the field of genetic knowledge is characterized by an enormous technical, scientific and commercial dynamics that makes it quite obvious that in the foreseeable future the problem of genetic discrimination will be framed and negotiated differently. Two developments are particularly relevant.

First, it is important to note that the problem of data protection, confidentiality and privacy goes far beyond the clinical context. It is a central issue in biomedical research, the operation of biobanks and the uptake of direct-to-consumer genetic testing, all of which pose new challenges in safeguarding genetic privacy and non-discrimination

(Greely 2007; Prainsack 2008; Heeney et al. 2010; Tutton 2014).[6] Let me just briefly point to the problems of data protection involved in DTC-testing. While the diagnostics industry usually guarantees the protection of genetic data, the guarantees are always incomplete and fragmentary. Many enterprises invite their consumers to share genetic information with friends, family members and the wider public on the internet. Moreover, law enforcement agencies might force those offering genetic services to disclose information to them about their clients in order to prevent terror attacks or fight crime (on this point, see Kollek and Lemke 2008: 209–222; Harvey et al. 2012).

Secondly, new disciplines have emerged since the turn of the millennium, for example epigenetics, systems biology, and proteomics, all of which need to be included in the discussion on genetic discrimination (Joly et al. 2013: 12). They reflect a growing recognition of the limits of genetic determinism in the biosciences. The reductionist concept of genetic regulation that reigned in the past finally seems to have been superseded by a more complex understanding of biological development. In this perspective, genes should no longer be conceived as determining agents but more accurately as actors in an extraordinary complex biological network. Increasing genetic knowledge has demonstrated that, in most cases, a DNA sequence is not coupled to a single feature or a specific function (see The Encode Project Consortium 2012). As a result, research interest has shifted from individual genes or DNA sequences to the functional interaction of a multitude of genes or proteins and their interdependence with developmental or environmental factors. In the light of this new development, it is less relevant for insurances or employers to focus on genetic information alone, since in most cases it is the combination of genetic information with lifestyle data, medical records and family history that are supposed to make it possible to predict future diseases. This does not necessarily mean that the prognosis that the phenomenon of genetic discrimination will lose its significance in the future is correct (see for example Prainsack et al. 2008: 35). Rather, we can assume that the areas of concern and the points of intervention of the discourse on genetic discrimination will continue to be transformed and readjusted, as was the case in the last forty years. New and different fields of stigmatization, disadvantaging and differential treatment are likely to emerge. These fields will attract more attention, and the systematic links between the genetic and non-genetic, symptomatic and asymptomatic aspects of discrimination will gain more currency in the future. However, one constant most certainly remains unchanged: determining what *genetic* and *discrimination* might mean in this context will remain a challenge.

[6] See for example the assessment by Otlowski et al. (2012: 448): »Of particular concern are newly emerging domains where GD [genetic discrimination] is anticipated to occur, including personalized medicine, pharmacogenomics, and direct-to-consumer testing.«

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