CONSENSUAL FOUNDATIONS OF THE POLICY OF PROTECTING THE GENETIC INFORMATION

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The paper offers an analysis of the policy of protecting the genetic information. This policy, based on counterbalancing the practical dimension of genetics with the protection of individual rights, exemplifies an action tied to directives which are based on the normative convictions fitting the concept of communicative rationality. To underpin his hypothesis, the author introduces the notion of genetic discrimination and offers a survey of empirical research in this field, as well as examples of the policy of protecting the genetic information from the perspective of communicative action theory.

Keywords: Human rights – Genetic discrimination – Policy of protecting genetic information – Communicative rationality – Critical theory

Introduction. The development of genetics and genetic engineering is linked to new opportunities in utilising scientific knowledge in numerous areas of human social activity – from macrostructural actions to the private choices of individuals. Never before has humankind been in the possession of such detailed language for describing the composition of its own body – and access to this language was granted by the Human Genome Project (Collins et al. 1993). On the one hand the discovery of the human genetic map opened up new possibilities, above all in disease diagnostics, while on the other it gave rise to such threats as genetic discrimination (Lemke 2013), attempts at improving man (Habermas 2003) and the patenting of the genome (Eckberg 2005), as well as a rebirth of eugenics (Sussman 2014). However, contemporary political institutions are drawing up mechanisms with the purpose of setting limits to the usage of knowledge within the scope of genetics, an example of which is genetic information protection policy. Analysing this policy from the perspective of the theory of communicative action reveals its consensual basis. The consensual basis of the policy can be seen on two levels – both in the international process of developing declarative norms, and in the local approaches to implementing these norms once they have been established. Subjects of the international community who have reached agreement through the unanimous adoption of an act designed to protect human genetic data then seek consensus among all social actors concerned. This consensus translates into a policy for the protection of genetic information, the harmonization of

which – at national and international level – is rendered possible through efforts to define a common goal, which becomes achievable through communicative action.

The Concept of Genetic Discrimination. Contemporary academic discourse uses the concept of genetic discrimination to describe how people with a potentially increased risk of disease due to a genetic basis are treated differently and unfairly (Lemke 2013, 23). This definition, widespread in the literature on the subject, is based on an understanding proposed in the early 1990s by Paul Billing's research team in the article *Discrimination as a Consequence of Genetic Testing* (Billings et al. 1992, 477). As Thomas Lemke writes, the definition embraces five groups of individuals (Lemke 2013, 23). These are:

– persons whose diagnostic tests have revealed a mutation of a specific gene responsible for the certain future occurrence of a disease that cannot be cured by methods available today, covering e.g. Huntington's disease;

– persons shown to have genetic predispositions increasing the likelihood of occurrence of a specific disease dependent on numerous factors, such as a tumour;

– persons with the genetic predispositions for the occurrence of a disease that can be cured with methods currently available, such as hereditary haemochromatosis;

– persons with a mutation of a specific gene responsible for the possibility of hereditary transmission of a disease, while this disease does not occur in these particular persons;

– persons diagnosed with a genetic disorder not manifested in physical symptoms, such as Gaucher's disease.

This definition also covers those people who, although they have not undergone genetic testing, have experienced differential treatment because of a history of disease in their family.

The concept of genetic discrimination applies not only to the present day, but also to a cultural phenomenon whose beginnings are related to nineteenth-century eugenic practices, while its radical manifestation peaked in the years of the Second World War (Adams 1990; Dowbiggin 2008, Kevles 1995; Lemke 2013). The scope of social practices linked to eugenics then affected a broad spectrum – from policy promoting segregation among individuals in regard to striving for offspring, through the sterilisation of mentally ill people in many modern European states and the United States of America, to the Nazi crime of genocide. Although today the mechanism of discrimination is similarly based on an unjustified conviction of a person's psychophysical otherness, constituting a deviation from the norm adopted by the subject expressing such a conviction, discrimination has never yet assumed such radical forms as it has in the era of genetic progress. Whilst eugenics concentrated on distinctive traits, contemporary forms of unjustified differential treatment are based on the genotype being perceived here as "different" or "incomplete" (Lemke 2013, 24). In his book *Perspectives on Genetic Discrimination*, Lemke demonstrates that it is precisely the conviction that a "genetic norm" exists that is the fundamental error of the mechanism on which discrimination is based (Lemke 2013, 112-113).

Genetic Discrimination in Empirical Studies. The scale of the problem of genetic discrimination is reflected in the findings of empirical research studies conducted in Australia (Barlow-Stewart et al. 2009; Taylor et al. 2008; Otlowski et al. 2007; Otlowski et al. 2010), the United States (Billings et al. 1992; Geller et al. 1996; Hall, Rich 2000), Canada (Lemmens 2000), Great Britain (Low, King Wilkie 1998) and France (Browaeys, Kaplan 2000). The studies cover the sectors of health insurance, employment, adoption systems, education, military service and blood banks. They were initiated by a group of American scientists – the chemist Joseph Alper, biologist Jon Beckwith, lawyer Lisa Geller, physician Paul Billings and sociologist Peter Conrad – who were joined by numerous representatives of the social and medical sciences. The team's first publication appeared in 1992 in the *American Journal of Human Genetics*. Its authors analysed 41 cases of genetic discrimination, at the same time outlining three spheres in which this problem occurred: in the health insurance system, employment policy, and in the adoption program. Although it only covered a small sample of respondents, the project diagnosed a new social problem, at the same time inspiring further scientific teams worldwide.

The subject-matter of this paper, focusing on policy in the protection of genetic information in Australia analysed within the framework of social theory, leads one towards the research studies conducted there. They have been presented in two publications: *Investigating genetic discrimination in Australia: a large-scale survey of clinical genetics clients* and *Practices and attitudes of Australian employers in relation to the use of genetic information: report on a national study.* The former focuses on people who have experienced discrimination, while the second applies to employers' attitudes towards utilising the results of diagnostic tests in their employment policies. Such a juxtaposition illustrates the social awareness related to the range of issues in the unjustified differential treatment of people with a potentially increased risk of genetic disease.

In the article *Investigating genetic discrimination in Australia: a large-scale survey of clinical genetics clients*, the Australian team presented the findings of research covering 951 respondents (Taylor et al. 2008, 20). They were people who had been diagnostically tested in the years 1998 – 2003, with a medically ascertained defined risk of occurrence of a disease with a genetic basis. Of those invited to participate in the survey, as many as 10% had experienced genetic discrimination in the areas of insurance, employment, family, society and the health service. The research also revealed that barely 15% of the entire research population had knowledge of their rights in the event of experiencing discrimination, which illustrates the degree of awareness (Taylor et al. 2008, 20-27). On the other hand, the research presented in the report *Practices and attitudes of Australian employers in relation to the use of genetic information: report on a national study* covered employers' attitudes towards using genetic information (Otlowski 2010). Of the 1100 employers invited, 381 took part in the survey, and of these 179 opted to remain anonymous. In the group investigated, as many as 212 respondents declared that they ask people seeking a job about the state of their health, while 27 expressed approval for genetic testing as a means of health verification of the employees.

Research studies into discrimination play a large role in policy aimed at protecting genetic information, while their results can be of significance for the authors of legal acts. Conducted on the basis of public opinion by interdisciplinary teams comprising representatives of the social and medical sciences, and later used in the legislative process, they can prove the significance of dialogue for resolving civilizational problems. Connecting scientific and political institutions in this manner reveals the possibility of counterbalancing the instrumental rationality of market entities – through activities compatible with the concept of communicative rationality undertaken within a social structure. For representatives of specific disciplines sharing a common system of propositional attitudes with representatives of political institutions, this opens up the possibility of developing and implementing effective strategies for coping with crises related to the problem of genetic discrimination.

Policy in the Protection of Genetic Information. Contemporary societies respond to the problem of discrimination presented above with policy for protecting genetic information. Following the institution in 1997 of the Universal Declaration on the Human Genome and Human Rights, bodies of international law – organisations and states – assumed the role of guarantor of the observance of law in this respect. In this context the change in policy following World War II is remarkable. Focused on drawing up a system for protecting human rights, it seems to be a guarantor preventing the reoccurrence of eugenic practices in the politics of the countries of the West. Despite a number of initiatives undertaken within the international community, the process of counterbalancing the market exploitation of scientific progress and protecting the rights of individuals remains open the whole time, while the changes taking place within it depend on how the practical dimension of genetics develops. International policy in the Protection of Genetic Information is established by the provisions of the International Declaration on Human Genetic Data, adopted after international consultations by acclamation by the General Conference of UNESCO on 16 October 2003. Declaration formulates the principles that bind "in the collection, processing, use and storage of human genetic data, human proteomic data and of the biological samples from which they are derived [...] in keeping with the requirements of equality, justice and solidarity, while giving due consideration to freedom of thought and expression, including freedom of research." This act gives special status to human genetic data, which it describes by distinguishing their attributes. These attributes are: the ability to define individuals' genetic predispositions, the ability to influence human offspring, the cultural dimension and the status of human genetic data as an information medium, the significance of which may be identified following genetic testing. This act calls for ensuring the appropriate level of protection both for the data and for the biological samples from which the said data may be obtained. It defines the purposes and procedures in the collection, processing, use and storage of the data. In particular, this covers diagnostics, health care, scientific research and forensic medicine, as well as criminal and other legal proceedings.

Bearing in mind the legal provisions established at the international level, states are endeavouring to draw domestic policies for the protection of genetic information. Some of them, such as Austria, Belgium or France, have introduced a statutory prohibition against insurance agencies using the results of genetic testing (Lemke 2013, 32). On the other hand, attempts to draw up more comprehensive regulations have been made by the United States, both at a state and a federal level, and by Germany. The Genetic Information Nondiscrimination Act of 2008, enacted on 21 May that year in the USA, applies to unequal treatment – in the area of health insurance and employment – based on genetic information, which is defined not only via diagnostic testing, but also family medical history (Lemke 2013, 32). The first title of this three-part legal act regulates the issues of entitlements, the covering of costs, and the guarantee of compensation paid in the event of damage in the insurance sector. The second title on the other hand regulates the issue of employers being forbidden to use genetic information when taking decisions regarding employment, promotion at work, work conditions and the form of job contract, as well as employee privileges. As with the American law, the German law on genetic diagnostics of 1 February 2010 also regulates the usage of information of this kind in the context of social insurance and employment. This law not only prohibits genetic discrimination, just as the American law does, but also obliges the medical services to inform persons interested in undergoing diagnostics about the possible social dangers related to genetic testing, and also to provide counselling in this respect (Lemke 2013, 33).

A form different to the statutory regulating of protection for genetic information was adopted by Australia. A report was compiled there that was intended to be not only the basis for amendment to legislation, but also an impulse for social change. The *Report on the Protection of Genetic Information in Australia* (Breen, Weisbrot, Opeskin et al. 2003) was published on 28 March 2003. This two-volume document, containing a set of recommendations regarding the ethical, legal and social aspects of the development of genetics was drawn up by a team of the Australian Law Reform Commission and the Australian Health Ethics Committee. The project's organisers created conditions enabling communication between interested bodies. Thus when formulating their set of recommendations, they were guided by opinions voiced within fifteen open forums, two hundred meetings, and three hundred written motions (Breen, Weisbrot, Opeskin et al. 2003). These opinions, confirming the significance of the development of genetics – from the first publication on the subject of DNA structure to the Human Genome Project – demonstrate contrasting ways in which the significance of this progress is understood (Breen, Weisbrot, Opeskin et al. 2003). On the one hand, societies give their approval for new forms of diagnosis and treatment, while on the other they express concern about genetic information being exploited for discrimination of the individual. These tendencies, though characteristic of today's civilisation, come to light above all in states where progress in genetics finds large-scale practical application on the medical market.

The report's authors attempted to draw up a perspective reconciling the utilisation of scientific innovations with the practice of protecting the individual's rights (Breen, Weisbrot, Opeskin et al. 2003). This perspective focuses on setting out the framework of a

system of legal control over projects being implemented, in keeping with the ethical values protecting human subjectivity. In wording their set of recommendations, the authors of this report concentrated on investigating existing regulations, and then drew up proposals for their modification and, in some cases, expansion to embrace new regulations. These recommendations take into account federal, state and territorial legislation, market interests, social opinions and pressures, and the forms of public supervision. All these aspects prove the significance of drawing up a compromise, one that reconciles opposing values, leading at the same time to social understanding. As the project's authors emphasise, the drawing up of regulations in policy for the protection of genetic information, implementing the principles of social justice, cannot therefore focus solely on the rights of the individual. It requires the working out of such a perspective that reconciles a broad spectrum of values by which specific social players – market entities, scientific and political institutions, bodies involved in the protection of health and life, and individuals – are guided.

With regard to the *Report on the Protection of Genetic Information in Australia*, an important role is played by the recommendations regarding the implementation of specific norms, not only legal but also ethical. The reform devised by its authors reformulates the classic process of preparing legislative changes by expanding it to embrace a set of strategies: codes of good practices, sectoral codes, educational programmes and a programme for the coordination of governmental collaboration. The report's main assumptions cover:

– establishing a Human Genetics Commission of Australia in order to guarantee high-standard information on the development of human genetics for the government, industry and society;

– amending legislation that allows for genetic discrimination;

– harmonising legislation related to the protection of individuals' privacy in regard to genetic information, while simultaneously enabling the authorisation of doctors to disclose a patient's information to their immediate kin in order to prevent a serious threat to the said patient's life, health or safety;

– legal protection of samples of genetic material;

– setting up legislation penalising the taking of samples from – or conducting of genetic testing on – a given person without their consent or the authorisation of an entitled state body;

– ensuring that the standards of the National Health and Medical Research Council are observed in human genetic research;

– developing new support systems for the Human Research Ethics Committee;

– ensuring better sources of information on good research practices for scientists;

– drawing up principles regarding the functioning of scientific databases in the field of human genetics;

– broadening the accreditation standards of the national Association of Testing Authorities to embrace an ethical dimension, with the simultaneous assumption that only accredited institutions may conduct research in human genetics for medical purposes;

– authorising the Therapeutic Goods Administration to regulate research plans in human genetics which directly address society;

– establishing a strategy reflecting the growing demand for counselling services related to genetics, as a priority for Australian governments;

– prohibiting the collection and usage of genetic information by employers, with the exception of stringently defined situations;

– introducing a broad range of safeguards against insurance agencies using genetic information for purposes not defined by contract;

– conducting tests to determine fatherhood only with the consent of the person concerned, and in the case of a child who cannot take such a decision, with the consent of both legal guardians or on the basis of a court order;

– such tests to be conducted only by accredited laboratories;

– guaranteeing and developing standards for an acceptable minimum in regard to sharing genetic information for legally defined purposes by judicial institutions, while simultaneously respecting regulations regarding the collection, usage, storage and destruction of forensic materials.

Too short a time has passed, since the undertaking of the initiatives presented here that comprise policy in genetic information protection, for possible social changes to have been observed. None of the scientific teams has as yet conducted comparative research that would compare the scale of the problem of genetic discrimination before and after these initiatives were launched. The results available, on the other hand, are insufficient for assessing the effectiveness of genetic information protection policy. Difficulty in making such appraisals is indicated in the article *The use of legal remedies in Australia for pursuing allegations of genetic discrimination: Findings of an empirical study*, which is evident from the fact that the authors barely managed to present three cases that resulted in effective prosecutions of deeds satisfying the criteria of genetic discrimination (Otlowski 2007, 14). It would also seem premature to posit the hypothesis that there was a lack of knowledge on the available means of prosecution to explain the ineffectiveness of this policy, based on the findings of research regarding awareness of one's rights in the event of experiencing discrimination (Taylor et al. 2008, 20-27).

Important observations regarding genetic information protection policy are also presented in Polish source literature on the theory and philosophy of law and on international law. Marta Soniewicka indicates the problem of a lack of unambiguous definitions related to genetic information as the fundamental difficulty in introducing legislation in this respect (Soniewicka 2010, 152). In this context, she emphasises the problem of isolating genetic information from other information regarding a person. A consequence here may, in Soniewicka's opinion, be the ineffectiveness of provisions regulating the issue of protection of genetic information, provisions only declarative in character, while selected provisions of international law constitute an example of this. A different view is taken by Atina Krajewska, who tackles the issue of the scope of the individual's autonomy in European legal space in the context of genetic information, outlining the individual's entitlements (Krajewska 2008). However, both the work of the Australian research team and

the Polish publications are further steps on the way to assessing the effectiveness of policy in protecting genetic information.

Theoretical Perspective. Genetic exceptionalism, which characterizes contemporary policy in the protection of genetic information, establishes ethics as the normative system that determines the directions of legislative practice, defining the limits of a social agent's activity. The set of issues related to discrimination, and the initiatives of modern-day institutions, do not apply to objective scientific knowledge but rather to ways in which it is utilised in areas of humanity's social activity. Such an assumption situates the subject-matter at hand within the context of the impact that the development of genetics is having on culture, which requires critical analysis of the consequences of development in these fields of knowledge for the legal, economic, aesthetic and ethical order of late modernity. This analysis requires enduring theoretical foundations. In the context of policy for the protection of genetic information, embracing the self-destructive dialectic of enlightenment (Horkheimer, Adorno 2010) or war of everybody against everybody (Foucault 1998) seems unjustified, since neither of these takes into account the entire spectrum of positions taken by social agents, or their activities. Analysis of the examples presented leads one towards a consensual perspective, and it could also find support in the theory of communicative action (Habermas 1999).

The development of genetics is affecting the shape of the social world of late modernity. Scientific progress in this field is accompanied by the rising significance of market entities implementing and using the findings of research, and growth that is based on the strategic activity model. Its impact on society may be counterbalanced by the policy of modern institutions, where one of the areas is the protection of genetic information focused on the prevention of discrimination. Australia's rational policy in the protection of genetic information is based on an attempt at coordinating claims, in regard to their validity, put forward by specific social agents undertaking measures related to the development of genetics. Based on the process of counterbalancing the practical dimension of genetics with the policy of protecting individual rights, it constitutes an example of a measure tied to directives based on the normative convictions appropriate for the concept of communicative rationality, which leads to protection against an increase in the significance of the model of strategic action in social life, with regard to the development of genetics.

The example of the report on the protection of genetic information in Australia proves the hypothesis proposed in this work, which is to some extent aligned with Jürgen Habermas' theory of communicative action. This German philosopher's fundamental theory is based on reasoning in favour of adopting the communicative action model as the fundamental tool for social analysis (Szahaj 2008, 118). Its goal, which is to understand the contemporary world, is based – as Andrzej Kaniowski writes – on Max Weber's concept of the world's disenchantment. The translator of Habermas' work emphasises that "if the modern world we live in is shaped as a result of what Weber called the disenchantment of the western world, then we will not understand this world without a theory of rationality constituting at the same time a theory of society" (Kaniowski 1999). *The Theory*

of Communicative Action therefore locates the concept of rationality in the perspective of transformations of the modern understanding of the world, to then concentrate on the relations between the theory of rationality and social theory in regard to two planes: the metatheoretical and the methodological (Habermas 1999). Its goal, as Andrzej Szahaj writes, is to indicate the relations between the situational meaning of speech acts and the meaning of the words in the context of the world of life, as well as the role of communicative action in the context of reproduction of the world of life, so as to relate the instruments developed through formal analysis to empirical studies (Szahaj 2008: 118). In the context of the example presented here of Australia's genetic information protection policy, those aspects of Habermas' work applying to his definition of the communicative action are of fundamental significance. Of this concept, Habermas writes:

I speak of communicative actions when the action orientations of the participating actors are not coordinated via egocentric calculations of success, but through acts of understanding. Participants are not primarily oriented toward their own success in communicative action; they pursue their individual goals under the condition that they can coordinate their action plans on the basis of shared definitions of the situation. For this reason, negotiating a situation's definition constitutes a significant component of the interpretative accomplishments required in a communicative action (Habermas 1999, 773).

As Szahaj writes, these actions are coordinated by shared knowledge, the validity of which is accompanied by mutual bonds (Szahaj 2008, 120). They form the foundation for the arguments cited in the process of communication, in which the person speaking gives as their statement a reference to the worlds distinguished (Szahaj 2008, 120). These references may be subjected to an objective appraisal by the interlocutor, which constitutes a source of motivation for adopting a specific stance (Szahaj 2008, 120). Although the concept of communicative action is not the same as the procedure of achieving understanding (Szahaj 2008, 120), Habermas' theory is based on an assumption that establishes language as the medium enabling their rational finalisation (Szahaj 2008, 120). Likewise, he attributes language with the role of medium in the social coordination of actions (Szahaj 2008, 120). This work finds an example of such action specifically in the Australian policy for the protection of genetic information. Thus in this context the significance of Habermas' work has a dual dimension. On the one hand he introduces a typology of actions that may be identified in the context of issues related to genetics, while on the other the social theory presented in it allows for analysis of the social world which takes into account the attitudes of all social actors.

The study outlined here is based on Habermas' theory, with a focus on the consensual basis for the policy of genetic information protection, which aims to harmonize the objectives expressed in international declarations. Harmonization entails that the communicative action undertaken by the subjects of the international community can become the basis for shaping this policy. The consensus reached at the international level in the establishment of the Universal Declaration on Bioethics and Human Rights and the Interna-

tional Declaration on Human Genetic Data, which was preceded by committees and debates, is reflected in the process of shaping local consensus, which is an argument that supports the presented hypothesis. Although the initiatives presented here differ with regard to the way they are implemented in local policies of genetic information protection, they are linked by virtue of the attempt to achieve a goal that is common for the entire international community – namely to balance the practical dimension of genetics with the requirements of human rights. Habermas' theory makes it possible to show the significance of the issue in question, considering the use of new possibilities offered by scientific knowledge in many spheres of social human activity. These actions can be instrumental, strategic or communicative. Showing how policies aimed at protecting genetic information constitute a response of Western societies to new forms of discrimination, as an example of an extreme form of action aimed at the realization of particular goals, reveals the crucial role of consensus in defining the limits when it comes to applying genetic knowledge. The way that these constraints are shaped is illustrated by this study, which devotes special attention to the Australian project – a project that is unlike any other in the way that it attempts to implement the consensual approach.

The importance of focusing on the process through which the policy of genetic information protection is shaped is explained by the constructivist paradigm, which "sees the world as a project under construction, as becoming rather than being" (Adler 2002, 113). As John Ruggie writes:

At bottom, constructivism concerns the issue of human consciousness: the role it plays in international relations, and the implications for the logic and methods of social inquiry of taking it seriously. Constructivists hold the view that the building blocks of international reality are ideational as well as material; that ideational factors have normative as well as instrumental dimensions; that they express not only individual but also collective intentionality; and that the meaning and significance of ideational factors are not independent of time and place (Ruggie 1998, 52).

By adopting this assumption, constructivists focus on the role of policy in the process of socialization, viewing the process of its creation as an opportunity to strengthen the shared system of norms. Without this system, the rules of law established in the field of bioethics would be merely empty slogans.

Conclusion. The purpose of policy in the protection of genetic information is to establish boundaries on the use of knowledge deriving from genetics and genetical engineering in areas of human social activity, from macrostructural actions to individuals' private choices. Based on a process of counterbalancing the practical dimension of genetics with the policy of protection for individual rights, it constitutes an example of action tied to directives based on normative convictions appropriate for the concept of communicative rationality, which leads to protection against growth in the significance of strategic action models in social life in the context of the development of genetics. Although

contemporary social sciences do not yet have research which would enable an appraisal of this policy's effectiveness or an analysis of its contribution to social change, the case study presented finds the process of counterbalancing the practical dimension of genetics with the policy of protecting individual rights as very significant for modern states. What are the cultural foundations of this genetic exceptionalism characterising these actions? Is this not an attempt at protection from the self-destructive dialectic of enlightenment, yet simultaneously an attempt to defend the individual from becoming affiliated to the technical domain of mastered nature?

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