Biological lottery and social solidarity

The impacts of genetic diagnosis

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The political and social dimensions of modern technologies of genetic diagnosis are generally analysed in an unequivocal manner. This is a misleading view. An argument is developed in this essay to review two different and alternative future scenarios. The first reflects on the possibility that the use of genetic diagnosis may lead to the questioning of welfare states in advanced industrial societies. The second contends that, because of the social uncertainty brought about by these new techniques, emerging agreements of solidarity can be achieved in those countries without national systems of health.

Genetics, especially human genetics, has a dark side to it. At the beginning of the 20th century, when eugenics swept through Western countries, there was a clear link with genetic research. Eugenics led to the discrimination of those who were already in weak social positions, or simply to crimes. Later on, in the 1960s, research in the genetics of intelligence was used to deal a hard blow against compensatory education and other type of social policies. Many people wish to refresh our memories so that, in the times of the Human Genome Project, we can avoid history repeating itself.[1] Others, like the authors of *The Bell Curve*, seem to insist on its revival.[2]

To state that research on the biological origin of human differences has been used against the social demands of the least favoured is a simple reference to an historical truth. It therefore seems reasonable at present to attempt to prevent possible negative social impacts of the use of genetic information. This is precisely what is being done by the ELSI programme (NIH-DOE Working Group on Ethical, Legal and Social Implications) in the United States and the ELISA project (Ethical, Social and Legal Aspects of Human Genome Analysis) in the European Union.

History, however, is neither linear nor cyclical. In what follows we discuss two alternative (and opposite) future scenarios concerning the social and political impact of genetic information (genetic diagnosis and genetic tests). To achieve this we will use the works of John Rawls on justice and Peter Baldwin on the welfare state in Europe. Although this analysis may be to a large extent speculative, we consider it important given the present discussion about welfare states in many European countries.

The majority of the social issues that are raised by the use of genetic diagnosis are related to so-called 'genetic discrimination'. According to an increasingly general use, genetic discrimination is defined as that which takes places against an individual or against the members of a family in relation to real or perceived differences with respect to the 'normal' genome. A distinction is therefore made between genetic discrimination and discrimination due to handicaps. The case studies collected by Billings and his colleagues show that in the USA genetic discrimination is already a fact, not just a theoretical possibility.[3]

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Genetic tests can be used for four main purposes: identification of carriers, prenatal diagnosis, pre-symptomatic diagnosis and DNA profiling. The social impact of these tests can be organized depending on whether they are used in clinical or non-clinical contexts. The main areas (non-clinical) in which genetic discrimination could take place are in the contracting of insurance and in the labour market.

Insurance companies can calculate their risks with a higher degree of precision if they take into account the genetic diagnosis of their clients. In this context the possibility exists that certain individuals (and their families) are denied access to health insurance (life or disability) due to their probability of developing certain illnesses. In the labour sphere a worker might be discriminated against due to claims that, because of the risk of developing an illness of genetic origin, they can be absent quite often, be less productive than their colleagues or require a larger proportion of medical care (for which the insurance company will demand a higher contribution from the company). The latter possibility is an extension into the workplace of the discrimination regarding insurance.

First scenario: the end of solidarity in Europe

The possible social impact of genetic diagnosis in non-clinical contexts can be conceptualized as a redefinition of the terms in which, traditionally, certain private contracts have been established. In European countries the existence of national health systems (and other social protection institutions) minimize the social impacts of genetic diagnosis. This is obvious in the case of health insurance, but is also true for labour contracts: one of the main motivations for employers to demand access to genetic test results of their employees is related to their need to take out insurance policies with private companies which calculate the cost from previous experiences with the company in question. But there is one question that is also relevant: Can genetic information also redefine the terms in which social contracts, such as the national health system of universal coverage, are established?

In his elaboration of his concept of justice, Rawls lays out a hypothetical situation that he calls the 'original position', a contemporary version of the traditional 'state of nature'. The individuals who find themselves in this 'original state' are covered by a 'veil of ignorance'. This veil only allows for knowledge on the 'general facts of human nature' and hides practically any other kind of information: status, social class, abilities and intelligence, cultural level or life plans. Rawls assumes that a group of people who would find themselves in this situation would reach an agreement regarding the principles of justice that should rule social life: (a) every person has the right of access to a fully sufficient system of equal basic liberties which are compatible with a similar regime of liberties for everyone; and (b) social and economic inequalities must fulfil two conditions: (i) they must be associated to positions and posts open to all under the conditions of fair equal opportunities, and (ii) they must provide the maximum benefit for the less favoured members of society.[4]

The possibility of establishing a social contract similar to that proposed by Rawls would depend, among other factors, on the ignorance vis-à-vis the life trajectories of those involved. Or to put it differently: the choice of the social justice mentioned above would depend on every person being able to imagine being in the social position of any other. This point is vital for the existence of a public compromise, explicit or implicit, that would make possible the systems of solidarity that characterize advanced industrial societies. Let us assume that genetic diagnosis will be able to give us information with a high degree of precision with respect to people's lives, their possible illnesses, their longevity, their capacities and the characteristics of

their personality. The problem would then be as to whether the use of this genetic information could lead individuals to stop considering it possible to be in the position of any other person. If such a thing should happen, the present solidarity systems could lose a large part of their foundations.

Let us turn to an example of the argument. In the Netherlands, insurance companies and the government came to a temporary agreement with a peculiarity worth highlighting: the use of genetic tests is not radically prohibited but it is restricted. Companies cannot demand genetic information when 'real necessities' (such as access to health care) of individuals or their families need to be covered. Beyond this threshold, depending on the social and financial circumstances of the individual, the prohibition prescribes. Regarding this agreement criticisms were raised arguing that an injustice was being done to the individuals 'free of defects'.^[5] For a long time individuals with genetic 'defects' that were impossible to detect have been insured. Now, new technology for genetic diagnosis opens the possibility of questioning the terms in which these types of contracts have been established. In this way private insurance can lose its character as a mutual aid to risk and stop fulfilling some of its social functions. The problem laid out concerns the social impact of genetic technology and if putting it into practice would question wider forms of civil solidarity. Genetic diagnosis would make individuals transparent, would lift the Rawlsian veil and would reopen the debate about traditional modes of solidarity in Europe.

Second scenario: the public and universal health system reaches the USA

A large number of John Rawls's arguments have been taken up by Peter Baldwin to explain the construction of some European welfare states. According to Baldwin, the welfare state should not be understood as the redistribution of income, but of the costs needed to confront the risks and uncertainties inseparable from contemporary society. The characteristics of the more developed welfare states-according to Baldwin-consisting in sharing globally all types of risks, made equality possible not only in the formal sense of civil and political rights, but also provided minimum common protection in practical terms.^[6]

The welfare state arises, according to Baldwin, when coalitions and categories at risk help themselves. That is, in certain historical circumstances it has been in the self-interest of a sufficient number of citizens to socially distribute the costs of risks associated to situations of illness, disability, old age, unemployment or paternity. If Baldwin's argument is correct, and as genetic information reduces the uncertainty with respect to future life changes, genetic diagnosis could be a factor in the questioning of solidarity contract⁵ in our society (first scenario).

The above can also serve to think about a diametrically different hypothetical situation to the one analyzed until now. In the USA, in fact, the study of problems related to the use of genetic diagnosis by insurance companies and in the workplace had led some sectors to think about the need to put into practice a 'basic health programme'. In the second recommendation of the 1993 report of the working group on genetic information and insurance¹ of the ELSI programme (Ethical, Legal and Social Implications of Human Genome Research) it is claimed that the only practical and effective method to avoid discrimination with reference to health based on genetic results is to put into practice a programme that would allow universal access to basic health services.^[7]

Indeed, many people could reach the same conclusions as the constituents of the ELSI programme. The hypothesis that we put forward is whether the possibility of suffering genetic

discrimination in access to health insurance could convince a large number of North American citizens (with capacity to influence politics) of the chance to establish a national health system of universal coverage. That is, genetic diagnosis could eliminate uncertainty about possible future illnesses but at the same time would create a new uncertainty: the possibility of being discriminated in insurance and labour market. An individual must seriously consider undergoing, or not, genetic diagnosis. Genetic information would be a double-edged sword and one of the social consequences of research in human genetics could lead to the questioning of present US health system.

Our main aim has been to show the way in which one same general argument can be developed in two completely different ways. In the analysis of the social consequences of genetic information. To recognize the complexity of the interaction between technology and society must be, none the less, a shock against mental laziness, not an excuse for inaction. Genetic diagnosis can help achieve higher social well-being, but the possibility of discrimination can do away with the faith put into this technology. Genetic information can reduce (though not always) uncertainty regarding our future health, but also lays out a set of new situations over which men and women will have to make decisions.

Notes and references

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7. ELSI, Genetic Information and Health insurance (Report of the Task Force on Genetic Information and Insurance; NIH-DOE Working Group, National Center for Human Genome Research, Bethesda, MD, USA, 1993).