

ABSTRACT

Niklas Juth: *Genetic Information – Values and Rights. The Morality of Presymptomatic Genetic Testing.*

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The focal point of this dissertation is the question of the value of and right to genetic information from presymptomatic genetic testing that may reveal risk of disease. This question is discussed regarding first parties, that is, the person on whom the test is performed, second parties, that is, blood relatives' of first parties, and third parties, such as insurance companies and employers.

In the second chapter, it is argued that the value of presymptomatic genetic testing for first parties ultimately rests on autonomy and subjective well-being. This shows the basis for some types of tests weaker than for others. Moreover, the way in which the test result is disclosed is crucial for the realization of the values. This renders some support for genetic counselling, the ethos of which is evaluated.

In the third chapter, autonomy is analysed. A conception of autonomy is developed, which is useful to analyse the novel idea in this area that autonomy is a value that should be promoted. In relation to this, various theoretical issues are addressed, e.g. about the possibility of measuring autonomy.

In the fourth chapter, the question of first parties right to genetic information is discussed. It is argued that the proper basis for such rights is the above mentioned values: autonomy and well-being. From this basis, it is argued that some limited rights to genetic information should be recognized.

In the fifth chapter, rights to remain ignorant about one's genetic constitution are discussed. Such rights are defended, e.g. from charges that considerations of Kantian ethics and autonomy speak in favour of a duty to know about one's genetic constitution.

In the sixth chapter, the question of blood relatives' rights to genetic information is discussed. It is argued that practical considerations speak in favour of leaving the decision to inform relatives to the tested person, except perhaps in very rare circumstances.

In the seventh chapter, the question of third parties', and primarily insurance companies', right to genetic information is discussed. It is argued that considerations of justice and well-being speak in favour of some regulation of insurance companies access to genetic information in conjunction with the protection and resurrection of social insurance systems.

Thus, there are some values of and rights to genetic information, mainly based on considerations of autonomy, well-being, and justice.

Keywords: morality, biomedical ethics, genetic information, genetic testing, presymptomatic, values, rights, autonomy, well-being, justice, genetic counselling, Kantian ethics, authenticity, privacy, confidentiality, insurance