ACTA PHILOSOPHICA GOTOBURGENSIA

18

GENETIC INFORMATION VALUES AND RIGHTS

The Morality of Presymptomatic Genetic Testing

Niklas Juth

ACTA UNIVERSITATIS GOTHOBURGENSIS

Genetic Information Values and Rights

The Morality of Presymptomatic Genetic Testing

ACTA PHILOSOPHICA GOTHOBURGENSIA

18

GENETIC INFORMATION VALUES AND RIGHTS

The Morality of Presymptomatic Genetic Testing

Niklas Juth

AKADEMISK AVHANDLING

för avläggande av filosofie doktorsexamen i praktisk filosofi,
som med tillstånd av humanistiska fakultetsnämnden
vid Göteborgs universitet
framläggs till offentlig granskning
lördagen den 4 juni 2005 13.00
i Lilla Hörsalen, Humanisten, Renströmsgatan 6, Göteborg.

ABSTRACT

Niklas Juth: *Genetic Information – Values and Rights. The Morality of Presymptomatic Genetic Testing.*
ISBN 91-7346-534-8

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

ACTA PHILOSOPHICA GOTHOBURGENSIA

18

GENETIC INFORMATION VALUES AND RIGHTS

The Morality of Presymptomatic Genetic Testing

Niklas Juth

ACTA UNIVERSITATIS GOTHOBURGENSIS

Distribution:
ACTA UNIVERSITATIS GOTHOBURGENSIS
Box 222
SE-405 30 Göteborg
Sweden

ISBN 91-7346-534-8
ISSN 0283-2380

Printed in Sweden by
Kompendiet, Göteborg 2005

To my Mother and my Father

Acknowledgements

First and foremost, I would like to express my deepest gratitude to my supervisor, Christian Munthe, who has provided me with invaluable comments and criticism, ranging from the smallest details to the broadest outlines, from philosophical content to formal presentation. In short, one cannot ask for a better and more thorough tutor.

At some points in one's life, one is hopefully lucky enough to meet someone that besides sharing one's professional interests becomes one's close friend. I thus want to extend my gratitude to Jonas Gren, who has been like a second supervisor, for his indefatigable willingness to discuss my ideas.

I am also grateful for the comments from the participants of the seminars at the Department in Philosophy at Gothenburg University, especially Petra Andersson, Karin Bengtsson, Tom Borvander, Ragnar Francén, Jan Lif, Pia Nykänen, Sven Nyholm, Ingmar Persson, Joakim Strandberg, Claudio Tamburrini, and Anders Tolland. In particular, I want to single out my friend Jan Lif for his assistance in practical matters, such as layout, in which I am hopelessly lost. I also want to thank Angus Hawkins for correcting my English. The responsibility for remaining weaknesses and errors rests entirely with the author.

When writing in applied ethics as a moral philosopher, you rely to a great extent on the expertise of authorities in the applied areas. For valuable insights in their respective field of inquiry, I want to thank Marcus Radetzki, Professor in Private Law, Marian Radetzki, Professor in Economics, and Jan Wahlström, Professor in Genetics. Once again, the responsibility for any remaining mistakes is entirely the author's.

Generous grants from Swedish Ethics in Health Care made this work possible, and I wish to express my sincere thanks, hoping that the results are up to the expectations.

Finally, I want to thank Helena for supporting me throughout this work. Thank you, love!

Contents

Chapter I
Introduction

1. Background

Contemporary genetics has brought about an immense and rapidly growing ethical discussion. The issues actualised by this discussion have attracted so much interest as to give rise to a separate niche of bioethics: gen*ethics*. Genethics has its own conferences, journals, and books. In 2002 this field of inquiry saw its first encyclopaedic publication: *A Companion to Genethics*, just as there are companions to epistemology, metaphysics, political philosophy, and other more classical areas of philosophy.

The background of this development is the recent progress of genetics. There was an eruption of achievements in the 1990s, consisting mainly of the mapping of the human genome, HUGO, and the continuous discovery of the relationship between particular genetic sequences and various diseases. Parallel developments in biotechnology have meant not only that these facts are known, but also that the presence of such sequences in a person can be detected by so-called genetic testing. Such achievements naturally give rise to expectations of even further progress. For one thing, if scientists have gained knowledge of the genetic basis of many diseases, there is perhaps an increased possibility of developing cures for or preventions of these diseases. As we will see soon, this possibility is yet to be realized for most genetic diseases. This fact is sometimes called the therapeutic gap, and this gap is one of the reasons why some of the initial enthusiasm over genetics has faded.

Despite doubts about the continuing pace of progress, even more distant possibilities of genetics than therapy for genetic disease have been discussed: for instance cloning and permanent modifications of the human genome, aimed at eliminating diseases altogether or maybe even improving human capacities for future generations, in so far as they are genetically determined.[1] This debate prompts us to ponder possible future developments, but they

[1] Harris, 1998, provides an accessible introduction to the ethical debate on subjects such as these. An intriguing discussion of these topics can also be found in Glover, 1984. Buchanan et al, 2000, addresses questions of justice relating to these possibilities.

often involve scenarios so uncertain that it cannot be determined today how credible their realization may be. Even so, these are the kinds of questions that seem to receive most attention in genethics, probably since they very clearly challenge many of our most fundamental beliefs about ourselves.

This book is about genethics. However, it hardly addresses non-realized possibilities at all, partly since others have done this so extensively and often meritoriously. Even though it is of utmost importance to anticipate ethical dilemmas that can arise in the future and questions such as these can be useful in order to test our deepest moral convictions, they should not block the view of present moral concerns. The technology that is relevant to the debate I will engage in already exists: *genetic testing*. Use is already being made of such tests in the health services of many countries to establish or further secure diagnoses and to estimate the risk of a wide range of diseases before onset.

More specifically, it is the latter kind of predictive testing, sometimes called *presymptomatic genetic testing*, that will be the focus of interest. Should these tests be performed? If so, why? Who should have the right to gain access to the genetic information that is the result of such tests? These are the kind of questions I want to discuss in this book. For those readers unfamiliar with ethical discussions, it should thus be noted that the discussion does not concern what can be done, or what is allowed by the state, or anything of the like. These are all interesting and important questions. But the concern here is what *should* be done. That is, given that this and that can be done, what reasons are there to actually engage in these activities? I will soon return to the manner in which questions such as these can be addressed in a systematic manner.

2. Questions and purpose

The topic I want to discuss is, then, different moral questions that arise in relation to presymptomatic genetic testing, questions regarding the value of and right to such testing. However, since the ways in which genetic material is extracted and analysed do not themselves create any immediate problems from an ethical point of view,[2] the very procedure of presymptomatic genetic testing itself is of minor interest per se. Rather, it is the information about the genetic constitution of people resulting from such testing that is the main area

[2] This is so, at least regarding genetic testing performed on adults, which is the focus of interest in this book (see this section below), unlike e.g. prenatal testing, where testing procedures (e.g. amniocentesis) gives rise to risk of harm.

of concern. Thus, my focus will be on the value of and right to genetic information from presymptomatic genetic testing. But even this has to be specified, since, as hopefully will become evident in the course of the book, genetic information as such, taken as an abstract object, cannot be of any value to anyone. It is the *use* of such information for various purposes that can be in various ways valuable to various parties. So whatever value genetic information has, it is derived from these possible uses.

There are many parties for which information about a person's genetic constitution can be valuable and, thus, of interest. Foremost, the person herself can have an interest in acquiring such knowledge. One might want to know if one has a genetic predisposition for some disorder in order to either take measures for preventing its outbreak, or just for making ones future plans with consideration to this. This person, on whom a presymptomatic genetic test for some disease can be performed, i.e. the first party, will in this book most often be called the index-person, or the individual, and sometimes the proband, patient, or client, depending on the vocabulary of the text under discussion. These terms should then be considered as synonymous.

By its very nature, genetic information about ourselves also discloses genetic information about others, namely those with whom we share our genes: parents, siblings, children, and other blood relatives.[3] In consequence, just as an individual may have an interest to know about her own genetic constitution, relatives of this individual may also have an interest in knowing this, since it can say something about the probability that they themselves have a genetic predisposition of developing some condition. Knowledge of this kind may also be relevant for reproductive decisions, such as whether or not to have children at all or whether or not to use procedures such as prenatal diagnosis. For this reason, one might feel obligated to reveal such information to the partner one is planning to procreate with. These kinds of parties will be called relatives or second parties.

If we widen the scope from the first party perspective even further, genetic information about a person could be of interest to business associates, employers, insurance companies, health institutions, researchers and society in general. Business associates may have an interest in knowing these things, for instance in order to decide whether or not it is worthwhile to establish long-

[3] Of course, to a large extent, our genes are (qualitatively) identical with those of almost all living organisms.

time contracts. Employers have economic reasons for knowing about it: why hire and train someone if you know that she probably is going to be permanently disabled in a few years or on sick leave for long periods. Insurance companies have an interest in genetic information that reveals increased risk of disease in order to protect themselves from economic loss. And so on.[4] Let us call these kinds of parties third parties.

Against the background of the various interests at stake, it should hardly come as a surprise that the issue of which parties it is that have a right to genetic information has become a growing subject of controversy among geneticists, medical professionals, sociologists, historians, economists, and philosophers.[5]

The questions I want to discuss in this book are thus:

(i) What is the (derived) value of genetic information from presymptomatic genetic testing for first, second, and third parties?

(ii) Do any of these parties have some kind of right to genetic information from presymptomatic genetic testing?

And, consequently:

(iii) How should conflicts of interests/rights between various parties be handled? [6]

It should be noted, even if perhaps obvious, that the questions of the value of and right to genetic information from presymptomatic genetic testing are somewhat different regarding the first person and other parties. The value-question of the first person is the question of what value the person can realize for herself by (receiving the information from) genetic testing, while

---

[4] See VII.1 for further third party interests.

[5] Contributions from a wide range of experts and scientists on the subject have been published in Chadwick et al, 1997.

[6] The conflicts that will be the focus of concern are the ones between the index-person and relatives (chapter VI), and the index-person and third parties (chapter VII). However, various types of conflicts arising as a result of presymptomatic genetic testing will be discussed before that (see e.g. section II.3.4).

the value-question of other parties is the question of *the value of receiving the information from the genetic testing of the individual who go through with testing.* Similarly, the right-question of the first person is the question of the right have a genetic test performed on herself (and receiving the information from this), while the right-question of other parties is the question of *the right to receive the information from the genetic testing of the individual who go through with testing.*

Furthermore, questions of values and rights can regard the ethics of individual conduct or the ethics of institutions. This book will deal with both these kinds of questions, but depending on the more specific question at hand, emphasis will be put on one or the other. For instance, when discussing negative and positive rights of individuals (IV.2 - IV.3), the emphasis will be on institutional questions, since institutions often determine the scope of such rights or are the parties with the corresponding obligations towards the individual right-holder. In contrast, when discussing the duty to know about some genetic information about oneself, the question is most naturally interpreted as one about the morality of individual conduct. Similarly, the question of obligations to reveal genetic information to relatives is more of a question of the morality of individual conduct (VI.3),[7] while questions of insurance companies access to genetic information is obviously related to institutional questions of regulation (VII.1 - VII.5). However, I make the assumption that questions of institutional setting are moral ones too, in the sense that it can rationally be argued what kind of policy or regulation that *should* be implemented.

While kept apart from other areas of genethics, the scope of my inquiry is thus still quite broad. For this reason, some additional limitations are necessary in order for the discussions not to be too sketchy. In any intellectual investigation, there is always a trade-off to be made between scope and depth, and the trick here is to ensure that depth is not bought too much at the expense of scope. I believe that the limitations to be explained serve this purpose.

First, as already indicated, I will primarily focus on genetic testing that can be performed today. This means that I will ignore presymptomatic, or other,

---

[7] Even if there are questions of the extent to which institutions should enforce individuals to do their moral duties. Therefore questions of the role of institutions will not be ignored in these contexts either (see e.g. VI.3.1.2).

genetic testing that is not testing of what is conventionally seen as diseases. In the future, various tests for individual properties that are not diseases might be developed. For instance, one might have testing revealing the propensity of developing musical or athletic skills, and so on.[8] These "science fiction" - questions, although intriguing and important, will be ignored. This means that, without exception, whenever I write "genetic information", this is equivalent to "genetic information about future risk of disease".

Second, as also already indicated, I will deal exclusively with *presymptomatic* genetic testing, which means roughly testing that reveals increased risk of genetic disease before symptoms emerge or before onset (see I.4.1).[9] This means that genetic testing that is used for the purpose of establishing or securing diagnosis, i.e. diagnostic genetic testing, will be ignored. This limitation is due to the moral problems of diagnostic genetic testing often being less serious than they are for presymptomatic genetic testing. The most obvious reasons for this is that diagnosis establishes the existence (or non-existence) of a disease that the patient actually suffers from, while presymptomatic testing only can establish increased risk of some disease, i.e. that the person tested *may* become ill in the future. However, some of the moral problems are common for diagnostic and presymptomatic testing. For instance, they both reveal the genetic constitution of relatives, and both kinds of testing will make it more difficult to get private health insurance. In the cases that the problems are the same, the arguments of this book will be relevant for both, then. However, the focus will be on presymptomatic genetic testing.

Third, I will not address ethical questions specific to genetic screening-programs. At least two things separate pure[10] screening-programs from the kind of genetic testing discussed in this essay: 1) Health care as a societal institution, rather than the individual or the family, takes the initiative for having tests performed. 2) There is no prior knowledge of an increased risk common to all the individuals approached in this way. Genetic screening gives

---

[8] See e.g. Harris, 1998, and Buchanan et al, 2000.

[9] The last clause is important, since not all diseases are defined symptomatically.

[10] Screening-programs can be more or less pure, depending on the level of individual initiative and prior knowledge of increased risk. For instance, screening of populations for which there are some indication of increased risk (although low), e.g. screening-programs among Ashkenazi Jews for Tay-Sachs (see I.4.1), is less pure than screening of populations for which there are no such indications, e.g. general screening for phenylketonuria (see I.4.1).

rise to an array of problems of its own.[11] The genetic testing I will discuss are thus the ones initiated by the individual (including, perhaps, her family), commonly motivated by some prior suspicion of or concern for having genetic susceptibility for some disease. I will also almost entirely ignore genetic testing for purposes of research, although I will have something to say about this (see VII.6.2).

Fourth, I will only discuss presymptomatic genetic testing on adults, who can reason and make decisions themselves. I will not discuss moral questions that can arise particularly as a result of genetic testing on children, foetuses, or fertilized eggs. I will thus not discuss the ethics of prenatal or preimplanation genetic diagnosis (PGD),[12] even though many serious genetically determined diseases affect the individual early on in life.[13] This means that so-called late onset-disorders will be the focus of attention. However, adults may perform genetic testing in order to make reproductive decisions. These tests include testing for diseases that can cause disease or risk of disease to their children. But testing for these diseases will, then, only be dealt with to the extent that they concern the presymptomatic genetic testing on adults. Once again, some of the arguments put forward in the book will be of relevance for these other issues, but they will not be the focus of interest.[14]

Fifth, I will not discuss ownership of genetic information in the form of DNA patenting, although I am aware that this issue can be cast in terms of rights. This is also the kind of question that requires a lengthy inquiry of its own.[15]

Naturally, the main purpose of this book is to take a stand on the questions formulated above. While doing this, I will evaluate some influential contributions on the subject. However, the purpose is not to map an entire discussion, since such a project would be futile given the exponential growth of the literature on the subject. Rather, I will try to take a stand on some of the

---

[11] For discussions of the ethics of genetic screening, see the anthology of Chadwick et al, 1999, and Munthe, 2002.

[12] See Munthe, 1996, and 1999, for a discussion of these issues.

[13] For instance, Tay Sachs disease and Lesch Nyhan syndrome (see I.4.1).

[14] For instance, some reasoning on the duty to know will be of relevance to the question of when PGD is morally justifiable.

[15] The question also has been meritoriously discussed elsewhere from an ethical point of view (Wilkinson, 2003, p 182-221).

suggestions that have been made by influential writers. These suggestions have ranged from the more theoretical to the more practical, as will be the case with this book. Of course, some issues will receive more attention than others. Sometimes, this will be given an explicit motivation. Other times, I have let my own interest in a certain issue determine the extent to which I discuss it. I am therefore partly relying on the beneficence of the reader, and hope she or he will not be too disappointed to find that their own favourite problem has received less attention than others.

However, I have further more subordinate, yet important, secondary purposes. One such motive is to remedy the present focus on more futuristic questions in genethics. In order to take a stand on the issue of improving the genome of future generations, we have to take a stand on the moral justifiability of genetic testing, since genetic testing is a prerequisite for genetic therapies and modifications. Even though the questions of presymptomatic genetic testing that will be addressed in this book have been discussed for at least the past two decades, they are still controversial and far from solved. This book is thus entering an already existing debate, a debate that will continue long after this book. This is important to emphasise: this is neither the first nor the last word on the subject, but a contribution to an ongoing discussion. However, since there is no collected account of the questions with a scope comparable to this book, it fills a gap in the literature.

Another motive is to resurrect the interest for some traditional values in biomedical ethics that has been argued obsolete or insufficient for practical purposes. I am primarily thinking of autonomy. When writing about the right to know of one's genetic information, Göran Hermerén makes the following statement: "Both those who wants to know and those who do not want to know, may appeal to the principle of autonomy and have done so" (Hermerén, 1999, p 145). This is no doubt true. On the basis of this observation, the following line of reasoning may seem attractive: "If the autonomy of different parties clash, the conflict cannot be resolved merely on the basis of autonomy; other ethical considerations have to be introduced." (Hermerén, 1999, p 142)[16] Another similar example is Laurie, who claims that:

---

[16] Similarly, Parker, 2001, when discussing genetic testing, writes: "Respect for patient autonomy... call for both testing with and testing without consent... The usefulness of biomedical ethics... as a tool for decision-making... is limited." (p 453)

> The principle of respect for patient autonomy – which has been described as the guiding ethical principle in health care and which has received unprecedented recognition by the laws of most Western states - is... ill-equipped to provide a comprehensive solution to the problems posed by familial genetic information. This is because the focus of an autonomy-based argument is largely on the individual and her ability to control aspects of her life. The 'group' nature of claims concerning family information poses a serious conceptual threat to this paradigm. (Laurie, 2002, p 4)

These statements are united in their scepticism towards autonomy as an appropriate concept, principle or value for addressing the moral issues of genetic testing. However, against Hermerén it can be held that conflicts of autonomy can be solved if there are two different senses of autonomy at work and one is the more reasonable,[17] or if autonomy is a question of degrees and one of the parties has more autonomy at stake than the other. In the course of this book, I will argue in favour of both these points. Against Laurie it can be held that there is nothing unique about genetic information, and that the present problems can be addressed with classic tools from moral philosophy, such as autonomy, including problems of relatives' right to genetic information. I will also argue in favour of these points.

This suggests that we should perhaps take another round with autonomy before discarding its viability or practical usefulness altogether, especially since autonomy "has been described as the guiding ethical principle in health care and which has received unprecedented recognition by the laws of most Western states" (Ibid.). Of course, it may be more thrilling to say that common conceptions are wrong, but some principle of charity seems to bid us to try to interpret widespread opinions as reasonably as we can before discarding them. So again, a subordinate purpose of this book is to try out classical biomedical values of autonomy (and well-being) again. In fact, if there is any thesis in this book, it is that the only relevant basic ethical concerns regarding almost all moral problems of presymptomatic genetic testing are concerns of autonomy[18] and well-being.[19]

---

17 Hermerén, 1999, seems to be aware of this when writing: "we cannot simply take it for granted that "autonomy", used on both sides of the controversy, is used in the same way." (p 145)

18 Primarily conceived of as a value, which is something of a novelty. See chapter III.

Finally, I do hope that this book can provide valuable reading for primarily two different groups: moral philosophers interested in health care and health care professionals interested in moral issues. Therefore, some passages may seem superfluous or shallow on the verge of misleading for some readers, but perhaps difficult verging to obscurity to others. For instance, the short account of genetics below probably will seem superfluous to some geneticists, while maybe coming through as excessively detailed in the eyes of the layperson. And similarly, the passage on method below will most likely not shake the foundations of any moral philosopher, but may be thought tricky or controversial for others. However, the passage on method is primarily directed to those readers who are not well acquainted with moral philosophy, so that they at least have a general grip on how questions like the ones posed in this book can be tackled. And the passage on genetics is primarily directed to those readers who are not well acquainted with genetics, so that they can have a fuller appreciation of the more practical problems of the book. Bearing this in mind, you might be more patient when some passages seem too lengthy or too laconic.

3. Method

How is one to settle disputes over the value of and right to genetic information? Is it "just a matter of opinion", where no standpoint is superior to another, or is there some systematic way of evaluating different standpoints? In the following, I will briefly present how I think moral questions in this area, and in morals in general, should be tackled. That is, I will present, in very general terms, a method for dealing with questions such as the one's discussed in this book in a rational manner.

This book belongs to the area of *applied ethics*, which is the area of moral philosophy that discusses concrete or particular moral problems. More precisely, the investigation belongs to the realm of biomedical ethics, which is the area where moral problems that arises in, or as a result of, biomedicine are discussed. As mentioned in the outset of the book, it is also a book in

---

[19] A striking example to the contrary is, I believe, conflicts between first and third parties, where moral considerations of justice becomes highly relevant. See primarily chapter VII.

genethics, that is, the area that discusses moral problems that are brought about by genetics and its application.[20]

The area of applied ethics is often distinguished from *normative ethics*, in which general theories of what makes an action right, a state of affairs valuable, a person worthy, and so on, are discussed. However, there is no sharp line between applied and normative ethics. This is so, since both these areas of investigation discuss questions regarding the plausibility of moral standpoints, but applied ethics discusses more particular ones and normative ethics more general ones. So the difference is one of degree rather than kind. Moreover, standpoints on a more general level can affect standpoints on a more particular level, and vice versa (I will return to this shortly). So, even if one wants to make a distinction between the areas, one has to concede that they are interrelated.

Besides applied and normative ethics, moral philosophy consists of *metaethics*, which is the area of investigation that discusses questions like the meaning of moral terms, for instance 'right', 'wrong', 'good', 'bad', and so on, and whether moral judgements can be true and false or, at least, rational or well-founded. So, loosely speaking, while applied and normative ethics deals with questions regarding the content of morality, metaethics deals with questions regarding the nature of morality.[21]

I will try to remain neutral on metaethical questions as far as possible. However, I will make one exception to this. I will presuppose that one can rationally argue in questions of morals, that is, I will assume that moral judgements are in need of justification and can be subject to criticism. A minimal part of this presupposition is that moral judgements can stand in logical relations to one another in the way, I guess, that one normally takes it for granted that they do. For instance, if some person claims that a particular action is right, and someone is denying this very claim, the conjunction of these statements is contradictory. Another example of logical relations between moral judgements is that general normative principles in conjunction with

---

[20] Perhaps, not all genethics is a part of biomedical ethics, since one may be reluctant to call some issues in genethics medical, like the question of enhancement of properties that are (partly) genetically determined. However, since I will only discuss genetic disease, this book more clearly falls within the confines of traditional biomedical ethics.

[21] However, there is no sharp line between normative ethics and metaethics either, for instance since one tries to argue in favour of moral standpoints in normative ethics, that is, one tries to justify them, which must presuppose some idea on how moral judgement are to be justified.

particular factual statements can yield particular normative judgements. For instance, from the general moral principle "murdering innocent is always wrong" and the particular statement "performing action A is to murder someone innocent" one can conclude that performing A is wrong.

However, logical consistency seems insufficient for accepting some set of moral judgements. In order to accept our moral judgements, we would also like some kind of reason for, or justification of, or argument in favour of these judgements. In the absence of some self-evident Moral Truth from which we can deduce our more particular judgements, the favoured way of accomplishing justification in morals is by testing our considered judgements about particular cases against moral principles, and vice versa. Thus, we go back and forth, sometimes revising particular judgements, and, on other occasions, general principles, until we, ideally, reach a state of "reflective equilibrium".[22] This is a state where the moral and other judgements of an ethical theory are not only coherent in the sense of logically consistent, but also closely knit together, explaining each other. In this ideal state of coherence, the more particular judgements are explained by the more general moral principles that, in turn, are supported by the particular considered judgements. The general thought is that moral judgements are justified by being a part of such a reflective equilibrium.

This justificatory ideal opens up for various kinds of rational discussion of moral problems. First, it opens up for the possibility of questioning arguments for irrelevance. An argument is irrelevant if it does not show what it intends to show, that is, even if one accepts the premises of the argument in question, the conclusion that they intend to support is not supported. For instance, one may accept the following premise: "The European Monetary Union makes war in central Europe less likely." However, this does not support the following claim: "Sweden should join the European Monetary Union", at least not without some additional premises (for instance that one should join a union if one contributes to its end of making war less likely and the membership of Sweden would contribute to this end). This is one kind of criticism that will be adopted in this book. For instance, Kantian premises cannot be used to argue in favour of general duty to know about one's genetic constitution, despite what has been claimed, or so I will argue (see V.3.1). So even if one

[22] The idea was originally introduced by Rawls, 1972, p 48-53, and is developed and discussed by Tersman, 1993.

accepts the premise (Kantian ethics), the conclusion (a duty to know) does not follow.

Second, the ideal of coherence opens up for criticism of the plausibility of general moral principles, due to them, or their implications, being at odds with our considered, more or less particular, moral judgements. For instance, one may reject libertarianism due to the fact that it seems to imply that we should not enforce a duty to help those without the necessary means to survive. Also this kind of criticism will be adopted by some arguments in this book (for instance, see VII.5.2.2).

Another way of testing the plausibility of moral principles by seeing if it is at odds with our moral judgements is to try them out in thought experiments. This method is very common in moral philosophy, and the point of them is to extract and isolate the features of a situation that is relevant. For instance, one may want to ask if genetic information is necessary for autonomous decision-making when this information is relevant for the decision in question. To prove this wrong, it requires a *possible* situation where it is the case that some genetic information is relevant and the person making the decision does not have it (or willingly refuses it), but nonetheless is making an autonomous decision. This kind of situation does not have to be common. In fact it may never have happened or will never happen. In order to reject the claim that some connection is necessary, it is enough to demonstrate that the opposite connection is possible. Thought experiments can thus have an important role to play in moral arguments. However, they will be used less frequently in this book than is sometimes the case in more principled discussions of "pure" normative ethics, since this discussion deals with more concrete moral problems. Nevertheless, this kind of criticism will be adopted by some arguments in this book too.[23]

Third, the ideal of coherence opens up for the criticism of the plausibility of particular moral judgements, since they are at odds with some general principle one is reluctant to give up. For instance, one may give up the particular moral judgement that a certain act of torture is wrong, if one believes that this instance of torture is the only way to save thousands of human lives, due to one accepting the general principle that inflicting pain on someone is less bad than failing to save thousands of human lives. Also this

[23] In fact, I will present an argument similar to the one adumbrated here (see V.3.1). However, this argument does not refer to any far-fetched possibility, but to very credible scenarios.

kind of criticism will be adopted by some arguments in this book. For instance, a kind of theory of justice will be criticised, since it can favour particular moral judgements that are at odds with the general principle of justice that bids us to take more consideration to those worse off (see VII.5.3).

One can also criticise the plausibility of particular moral judgements due to them resting on dubious empirical facts. This strategy will also be adopted sometimes. For instance, it will be argued that the judgement that insurance companies should be prohibited from using genetic information rests on the questionable empirical assumption that this prohibition is an efficient means for protecting people with increased risk of genetic disease against lack of insurance (see VII.2.2).

Of course, when general principles and particular judgements are at odds, there is always a choice of which one of them one should give up. When making such a choice, a lot of factors come into play. For one thing, our basic moral intuitions do. We sometimes think that if a moral theory has implications at odds with a certain particular judgement, this speaks strongly against that theory due to the intuitive force of the particular judgement. On the other hand, when the intuitive appeal of a general moral principle is strong enough, we sometimes think that the particular judgement that first seemed attractive should be abandoned after all when in conflict with the principle in question.

However, this does not mean that moral intuitions, although important, should be treated as data that cannot be revised. We would also like our theories not to be arbitrary, or ad hoc, in the sense of making distinctions without explaining why the distinctions are made and should be considered relevant. For instance, one might originally have the intuition that genetic relatedness is of moral relevance in the sense that we have stronger obligations to those who we are genetically related to. However, as I will argue, if we find that there is reason to question the moral relevance of genetic relatedness and if we can defend the particular moral judgements that we, on closer inspection, want to retain without resorting to the relevance, but only to more general or uncontroversial moral principles, there is no reason to ascribe the distinction between genetic relatives and non-relatives any moral relevance in itself (see VI.3.2.1). This relates to the fact that general theoretical virtues, such

as simplicity and power,[24] also play a role in choosing between moral judgements in conflict. In the choice between two alternative explanations, we prefer the simpler and more powerful one, at least if it does not force us to revise our most considered judgement too much.

The last kind of criticism directed against a moral judgement or a moral argument is that it rests on concepts, notions or conceptions that are incoherent or too vague for us to be able to evaluate the judgement or argument in question. In order to tackle such incoherence or vagueness, conceptual analysis will be necessary. This relates to the distinction between, on the one hand, ideals, which defends moral standpoints, and, on the other hand, concepts or conceptions, that is used to formulate moral standpoints. Proponents of ideals should be careful to define the concepts they make use of, so it is clear enough what the ideal actually says. And concepts should be defined generally enough as to permit the formulation of different ideals. This last point is important, so that one avoids making moral disagreements into terminological ones.

I will thus not only be analysing moral arguments, but the concept used in these arguments. Most thoroughly, autonomy will be analysed, and a conception of autonomy will be presented (see chapter III).[25] The reason for giving the analysis of autonomy such a conspicuous place in this book is that it is one of the concepts most adopted but at the same time less scrutinized in the debate of the value of and right to genetic information.

So, the ideal of justifying moral judgement with reference to their coherence provides us with a toolbox, or method, of possible rational arguments in morals. The ideal allows us to question the plausibility of moral judgements by arguing that they are at odds with other considered judgements, both more general and more particular ones. The ideal also allows us to question moral judgements resting on irrelevant premises, dubious empirical assumptions or an incoherent or unclear conceptual basis.

---

[24] Roughly, a theory is simpler than another if it generates the same body of particular judgements using less general principles, and a theory is more powerful than another if it can be used to cover more previously unattended cases. See Kagan, 1989, p 11-15, for an elaboration of the importance of theoretical virtues in moral theory.

[25] The concepts of well-being (see II.4) and rights (see IV.1) will also receive some extra attention.

Perhaps needless to say, I will not defend any full-fledged coherent moral theory in this book. In this regard, I will not satisfy the ultimate ideal of the reflective equilibrium. Rather, I will use the methodological toolbox offered by this ideal in order to scrutinize arguments in the debate of the value of and right to genetic information. While doing this, I will often take a stand on the issues discussed.

4. Genetics

In this section[26] I will present a brief account of the science and technology that has made genetic testing possible by presenting some basic genetic terminology (see I.4.1). Future possibilities offered by genetics will be further elaborated in section I.4.2. Even though speculation about the very distant or very unsure future lies beyond the scope of this book, some scenarios as to what may become possible in the more immediate future will be relevant for the discussion to follow, especially on the societal level.[27]

However, before this I wish to counter a common but fundamental misunderstanding: a gene in itself can never give rise to the properties of an individual and can only affect an individual given a particular biochemical environment. Contrary to this claim, there seem to be a widespread view, at least among lay people, that human nature is identical with, or determined by, the genes of humans. This view is refuted by modern genetics, as we will see. The view, presented in so loose a fashion, can of course be interpreted in several, more or less reasonable, ways. The view that the genes of a person constitute her nature is sometimes called genetic essentialism and the view that a person is a product solely of his genes is sometimes called genetic determinism (Launis, 2000, p 309). I will not uphold this distinction, but use the term genetic essentialism for both.[28] As will become clear in the following,

---

[26] This section draws heavily on chapter 2 in Radetzki, Radetzki & Juth, 2002. It has gained tremendously from the expertise of Jan Wahlström, professor of clinical genetics at the Sahlgrenska University Hospital in Gothenburg. All responsibility for the content and its flaws is the author's.

[27] This level will primarily be discussed in chapter VII.

[28] Strictly speaking this presentation of genetics only rebuts genetic determinism. Nonetheless, it makes substantial interpretations of genetic essentialism highly unlikely to be valid, since genetics shows that phenotypic properties (which are the most likely candidates of being essential) are the result only of an interaction between genes and the environment. It thus seems unlikely that properties of genes (the DNA) are essential properties of a person (if there indeed are such essential properties at all).

modern genetics shows that genetic essentialism is based on gross misunderstandings of the significance of biological inheritance. The environment is not something that becomes significant, so to speak, after the creation of the biological individual with all his properties. Environment is there as a determining factor from the start at all levels: the chemical and biological as well as the social, economic and cultural (moreover, the latter levels affect the former, for instance by the impact our technology has on nature). Environments thus always have a crucial significance for the properties of any individual. The biological individual is consequently a product of the interaction between genes and environment.

4.1 Some basic genetic terminology[29]

What is a gene? What kind of information is genetic information? How can this kind of information reveal anything about a person's susceptibility to certain diseases?

Genes have two main functions. They provide a mechanism for inheritance between generations and a mechanism for the development of the biological individual. The latter process can now be explained to an increasing extent.

All living organisms consist of cells. Cells are biochemical systems that contain, among other things, a long molecule: the *DNA* (the genetic vocabulary in italics is collected and explained in table I.1). DNA, or deoxyribonucleic acid, is built up of a sugar phosphate backbone with nitrogenous bases (A, G, C and T), which, because of their chemical constructions, can be combined in varied but limited ways. A *gene* is a part of the DNA that, in the appropriate chemical environment, via RNA (ribonucleic acid), creates a protein – i.e., this part of the DNA interacts chemically with its environment and the product of this interaction is a protein. This is in fact the definition of a gene: a unit of DNA, which codes for one specific protein. The proteins "do the work" in the cell. Among other things, they decide the function of the cell, whether it is to be a heart cell, liver cell, nerve cell, etc. The chemical process is complicated, and scientists are far from fully grasping it yet.

---

[29] This very rudimentary account of genetics is part of the standard view of the functioning of genes and the literature is of course vast. An accessible, while fairly detailed, account can be found in Connor, Ferguson-Smith, 1997.

The general idea, however, is that the genes are a part of the construction of the *phenotype*, i.e. the individual.[30] This takes place through a number of steps: gene (DNA), RNA, protein, cell and so on. Each one of these steps is sensitive to influence from environmental factors and, sometimes, other genes. This means that the impact of a single gene on an individual is difficult to determine. Geneticists know more about the chemical construction of the DNA than they know about the impact of genes on the cell and even less about the impact on the whole organism (Buchanan *et al*, 2000, p 349).

Sometimes genes are randomly changed, due to external influence (for instance, radioactivity or foreign chemical substances) or because they fail to make an exact copy of themselves when the cell divides. Such a change of genes is called a *mutation*. Sometimes mutations damage the genes permanently, damage that eventually causes disease.

Genetic disorders differ with regard to how many of those who carry the gene that actually contract the disease in question (*penetrance*) and how grave the symptoms are (*expressivity*). Some genes always give some specific symptoms and some only increase the risk that some of a variety of symptoms will emerge.

A gene consists of two parts or *alleles*, one inherited from the mother and one from the father. All genes in the nuclei of our cells are organised in longer "packages" called chromosomes. Humans have 46 chromosomes, 23 from each parent. The likelihood of receiving a given allele, the part of the gene one gets from one of the parents, is 50%. With respect to its biological function an allele can be *dominant* or *recessive*. If it is dominant, one allele alone is sufficient to contract the disease or the risk of the disease, i.e. you need only inherit the genetic abnormality from one parent. If the allele is recessive you have to inherit it from both parents. If you inherit a recessive genetic abnormality from one parent only, you are a healthy carrier of the genetic abnormality. This means that you can pass on the gene to your children, who may become sick if the other parent is also a carrier (the likelihood in this case is 25%).[31] Some genetic diseases, such as haemophilia, are inherited through

---

[30] Sometimes the properties of the phenotype are defined as the properties that are directly perceptible. However, in modern biology, it is more of a "garbage can category" which is used to refer to all the non-genetic properties of the biological individual, such as height, blood type, taste in music and so on (Buchanan et al, 2000, p. 354).

[31] The matter is really more complicated because of the phenomenon of "crossing over", which splits up and combines chromosomes in arbitrary ways.

genes located on the sex chromosomes, so the impact of the gene is determined by the person's sex (usually the gene is located on the X chromosome, so that males get the disease and females are healthy carriers).[32]

Table I.1 Explanations of some basic genetic terms

Term	*Explanation*
Allele	The part of the gene one gets from one of the parents
DNA	The chemical carrier of our inheritance. Short for deoxyribonucleic acid, a long molecule shaped like a spiral staircase, built up of sugar phosphate as the sides of the staircase, with nitrogenous bases acting as the steps.
RNA	Mediates the chemical "message" from the DNA to the cell. Short for ribonucleic acid. Consists of one side of a DNA step.
Gene	A part of DNA that (via RNA), in suitable circumstances, produces a protein.
Phenotype	The perceptible properties of an individual.
Mutation	A change in the DNA of an organism.
Penetrance	The extent to which a gene manifests itself in a certain population.
Expressivity	The strength with which a gene manifests itself in an individual.
Dominant	The property of a hereditary condition caused by a gene, the inheritance of which from one of the parents is enough for this condition to develop.
Recessive	The property of a hereditary condition that will develop only if the gene causing it is inherited from both parents.
Chromosome	A part of the DNA (much longer than a gene). The human cell contains 46 chromosomes, organised in pairs, 23 from each parent.
Sex chromosomes	The pair of chromosomes that decides the sex of the organism. In humans a female has two X chromosomes, a male has one X and one Y chromosome.
Modifying gene	A gene that affects the penetrance and/or expressivity of another gene.

[32] Genes that are not located on the sex chromosome are called autosomal while those that are so located are called sex-linked.

In the medical and legal literature, a distinction is often made between three kinds of genetic testing. *Presymptomatic genetic testing* aims at identifying a single gene disorder in order to predict whether the tested person will develop a disease or not (the genetic testing vocabulary in italics is collected and explained in table I.2). Another kind of genetic testing tries to establish whether the tested person has an increased risk of developing certain diseases that are generally caused by a combination of environmental factors and one or a number of genes. This kind of genetic testing is called *predictive genetic testing*. Sometimes individuals are healthy carriers of genes, which can be inherited by following generations and cause diseases there. Tests for these genes are called *genetic carrier detection*.

In this context it is important to mention that one can obtain access to genetic information using other methods besides genetic testing. To an investigator with a proper understanding of genetics, the family's or relatives' medical history can reveal if a person has a risk of genetically based disease. Family information, rather than genetic testing, can thus sometimes be used in order to acquire relevant genetic information. Therefore, one should not focus exclusively on genetic *testing*. Genetic information is, in itself, neutral with regard to method used in order to reveal it. However, in this book, focus will almost entirely lie upon risks for genetic disease revealed by genetic testing, i.e. some sort of biochemical test.

As indicated above, some genetic diseases or risks of diseases are *single gene disorders*, that is, they are the result of the abnormality of one particular gene. Examples of such diseases are some special forms of cancer, cystic fibrosis, Huntington's disease and sickle cell anaemia. A short description of two such diseases will follow.

- Huntington's disease is a dominant single gene disorder that causes severe and progressive physical and neurological deterioration. The symptoms usually become apparent when the affected person is 35-45 years old. Symptoms are lack of coordination, lack of balance and an unsteady walking gait, drastic changes in behaviour such as unmotivated outbursts of rage and increasing physical and mental dysfunction. The disease is not lethal in itself but the symptoms cause

other problems, and the person usually dies from these side effects within 15-20 years. The sick individual will be in increasing need of care and will in the end be totally dependent on constant help. Though the genetic cause of the disease is known, no treatment exists for this disease. Medical treatment aimed at slowing down the process of deterioration does not exist, although there is research to develop ameliorative and preventive medical measures.

- Experts believe that about 5-10% of all cancer is caused by hereditary factors. Some are believed to be dominant single gene disorders, with reduced penetrance. One example is the mutation called BRCA1, which can cause breast or ovarian cancer. A carrier of BRCA1 has a risk of approximately 80 per cent of developing cancer in adulthood.[33] What you really inherit is then not cancer, but a severely increased risk that you will develop some forms of cancer. As opposed to Huntington's there are, however, methods of treating cancer. There are also preventive measures, such as regular controls in order to secure early diagnosis and, in effect, improve chances of successful treatment, and prophylactic surgery (i.e. removal of tissue or complete body parts before symptoms start to appear).

The reason to single out these genetic disorders, i.e. Huntington's disease and cancer due to BRCA1, is that they will be much used as examples in the discussion to follow. For both these diseases, presymptomatic genetic testing exists. Due to this, they are performed in a clinical setting and have received much discussion and research. However, as we will see in chapters to come, they differ in morally important ways. For instance, there are some medical measures to take for breast cancer, unlike Huntington's. Moreover, there are other kinds of genetic diseases that, due to their different nature, should be treated differently. This will also become evident in the following discussion.

Other single gene disorders that will be referred to in the following are:

- Cystic fibrosis is a recessive disease with grave respiratory problems and increased sensitivity to infection, the symptoms of which can be treated to an increasing extent.

---

[33] Even if this high figure has been contested. See Shattuck-Eidens et al, 1997.

- Duchenne muscular dystrophy is an X-linked recessive trait, thus affecting only boys (girls can be healthy carriers), with onset in early childhood and symptoms of deteriorating muscles, especially in shoulders and pelvis.
- Fragile X syndrome is an X-linked that can lead to a wide variety of symptoms, foremost different degrees of intellectual disability, but also connective tissue problems, attention deficit disorders, autistic behaviour and hand-biting. The penetrance on females is usually much milder. Male carriers of a premutation that as a full mutation gives rise to fragile X can develop FXTAS, a deteriorating neurological disorder, with onset in late middle-age and old age and symptoms similar to Huntington's.
- Krabbe's disease is a recessive disease, which seriously upsets metabolism, with onset in infancy, and symptoms of muscular tensions and uneasiness when touched. Leads to death within a few years after birth.
- Lesch-Nyhan syndrome is an X-linked recessive trait, with onset in infancy and symptoms of mental handicap, self-mutilation, and renal calculi. Leads to death within a few years after birth.
- Marfan syndrome is a dominant trait, which leads to damages on the connective tissue, and typically is connected to characteristics such as heart and eye defects.
- Phenylketonuria is a recessive disease has its onset in infancy and leads to early death unless prevented by giving the patient a special diet. This is thus one of the few genetic diseases that can be prevented.
- Sickle cell anaemia is a recessive disease, which leads to lack of blood cells and thus damage the body's uptake of oxygen.
- Tay-Sachs is a recessive trait, which seriously upsets metabolism and causes progressive neurological abnormalities, with onset in infancy. Leads to death within a few years after birth.

In fact, there are many single gene disorders (about 8000 have been detected), though all of them are rare. Only a minority of these diseases have their onset in adult years. For an even smaller minority, there are any preventive measures, palliatives or cures. Presymptomatic genetic testing can be used to detect some of these diseases today and, in principle, such tests can be developed for all

these diseases, once the genetic mutation responsible for the pathology has been identified.

Other diseases are *polygenetic*, that is, they are the result of multiple genes with different loci, each with a small but additive effect. There are probably no polygenetic disorders that result solely from the genes involved. Most likely, they are all the product of several genes in interaction with environmental factors. These diseases are thus also called *multifactorial*. From this point on, therefore, both polygenetic and multifactorial diseases will be called multifactorial. The term polygenetic will instead be used to refer to the genetic element that is causally active in a multifactorial genetic disease. The inheritance of multifactorial diseases is more complex, and therefore more difficult to predict, than single gene disorders. Predictive testing for multifactorial diseases can therefore only, at best, reveal the risk of disease.

Many of the more common diseases are multifactorial: cardiac diseases, alcoholism, diabetes, (some forms of) Alzheimer's disease, schizophrenia and many other diseases can, but do not have to, be a result of a complicated interaction between environmental factors and genes. They might also be the result of environmental factors only, in the sense that there is no reference to the malfunction of a gene in the explanation of the disease. In other words, genes are neither a necessary nor a sufficient cause of these diseases. Genetic testing is therefore an imprecise tool for determining the risk of such diseases.

In this context, it should also be mentioned that specific combinations of genes could have a positive effects on health, even if in other combinations they cause disease. Some individuals thus have inherited "disease genes" that decrease the risk of contracting infectious diseases, such as malaria, tuberculosis and dysentery (Diamond, 1999, p 201).

Table I.2 Types of genetic diseases and tests, with explanations

Types of genetic diseases and tests	*Explanation*
Presymptomatic genetic testing	Genetic testing before onset of disease to establish the existence of single gene disorders which are very likely to cause disease. Sometimes used as a term for both presymptomatic and predictive genetic testing.
Predictive genetic testing	Genetic testing before onset of disease to establish the risk of developing a polygenetic or multifactorial disease.
Genetic carrier detection	Genetic testing to establish whether the individual is a healthy carrier of (recessive) genes that may cause disease in offspring.
Single gene disorder	Disease due to damage to a single gene.
Polygenetic disease	The genetic basis of diseases due to damage to several genes in combination with environmental factors.
Multifactorial disease	Disease due to several genes at different loci in the DNA molecule that interact with environmental factors. Here used for both polygenetic and multifactorial diseases.

The line between single gene and multifactorial inheritance is not very sharp, however. This is so, due to the existence of genes that influence the penetrance and expressivity of single gene disorders: *modifying genes*. In these cases there is a "main gene" that causes the symptoms, but there is a modifying gene that affects the onset of the symptoms, and their severity. Not all damage to a gene that usually causes disease actually results in disease, since modifying genes also influence the penetrance of the damaged gene. Thus, the damaged gene causes only an increased probability of becoming ill (one example is the cancer case mentioned above).

The fact that single gene disorders may have reduced penetrance makes the common distinction between presymptomatic and predictive genetic testing a bit hazy. It is easy to get the impression that a positive result from presymptomatic genetic testing shows without doubt that the tested individual will become ill (at least if he lives long enough). This, as we have explained, is not necessarily the case. The following remark also speaks against the

distinction: all predictive genetic testing is presymptomatic (is done before symptoms emerge) and (almost) all presymptomatic testing is predictive (reveals different degrees of risks). Due to this, I will not uphold the distinction between presymptomatic and predictive genetic tests for the rest of the book, but I will call all these tests presymptomatic.

At this point we can see problems with the classic dichotomy between inheritance and environment. The gene is active in a chemical environment, which influences the gene and can be influenced by external factors. The gene itself can therefore be seen as an easily influenced environmental factor among others. This is why modern genetics makes the prospect bleak indeed for many forms of crude genetic essentialism, according to which we are nothing but our genes, and genetic determinism, according to which we are products of our genes alone. The environment always plays a crucial role for the health and development of the individual. Indeed, the more genetic science unfolds the complexity of heredity and the link between genotype and phenotype, the less meaning is left to the idea of a distinction between environment and heredity.

4.2 The possibilities of genetics

Thus far, the account of genetics has dealt with its past and present achievements. In this section I will discuss the potential of this science in the immediate future with regard to prediction of disease and premature death.

The rapid development of genetics has encouraged the opinion that the genetic basis of a growing number of diseases will be revealed. The received wisdom seems to be that increasing genetic insights will also increase the possibility of foreseeing disease and length of life. Indeed, this opinion seems to have been the very fuel that has kept much of the debate on genetic testing going. However, as already indicated, scepticism in this regard has been growing recently.[34] The mapping of the human genome – the HUGO project – has recently been concluded and revealed that human beings have far fewer genes than previously thought (about 30,000 rather than 100,000).[35] The

---

[34] See for instance Kristoffersson, 2000, whose article questions the ability of genetics to make adequate predictions of risk for multifactorial diseases.

[35] This has been questioned too. Geneticists at the Johns Hopkins University now seem to believe (private communication) that the number of genes is somewhere in between (about 70,000). This would probably make the scepticism here adumbrated slightly less likely. Whatever conclusions one is inclined towards, one can be sure that the final word has not yet been said.

resulting conclusion does not seem to be that things are simpler than we had expected, but rather the opposite; the connection between health and genes is more complicated than previously imagined. This is because fewer traits of the phenotype than assumed are the result of a single gene. Instead, they are the product of a complex interaction between different genetic[36] and (other) environmental factors, i.e. they are multifactorial (Wahlström, 2002a). If this analysis, based on the HUGO project, turns out to be correct, there might not be many meaningful predictions we can make about a person's susceptibility to diseases on the basis of genetic testing alone (Göring *et al*, 2001).[37]

The difficulty of making adequate predictions of multifactorial disease on the basis of genetic testing alone is thus explained by the fact that a number of genes, together with various environmental factors and an element of chance, interact to change the protein and cause disease. Because all of these factors interact to cause a disease it is difficult to determine the contribution of any one factor in isolation. To make predictions on the basis of genetic information alone is therefore difficult, to say the least.

This is well illustrated by a common type of diabetes, which is multifactorial.[38] Today 12 different genes are considered to affect whether a person will develop the disease or not. This implies *at least* 531,144 possible combinations of alleles.[39] Since different genes have different penetrance and expressivity, and since the environment also influences the risk of diabetes, it is easy to understand why genetic testing will have marginal value as a predictive instrument in this case.

---

[36] The complexity here is a result, among other things, of the facts that many genes can be involved in the explanation of a certain trait, that a few genes are sufficient for a wide variety of possible combinations of inheritance (three are enough to yield 64 possibilities), and that some genes affect the penetrance of other genes to various degrees.

[37] Göring et al are genetic statisticians. They emphasise the difficulty of determining the contribution of a single gene to a trait by statistical methods. In other words: we cannot account for differences in phenotype in terms of differences in genes when a certain trait of the phenotype is multifactorial. This is because the penetration of the DNA loci investigated will always be overvalued with regard to the trait investigated (they can even be completely independent).

[38] I wish to thank Jan Wahlström for bringing this example to my attention.

[39] The reservation "at least" is made due to the Mendelian conjecture that there are two alleles in each gene (one from the mother and one from the father), which can be similar in two ways (AA or aa) or differ in one way (Aa=aA). There are reasons to believe that there may be more alleles in a gene, which makes this a cautious estimation of possible combinations.

Geneticists, to be sure, believe that more single gene disorders will be identified. Presymptomatic genetic testing will probably be developed for those of these diseases that are late onset. However, such diseases are rare and there is reason to believe that the ones not discovered yet are even more rare than those already discovered (otherwise they would probably have been discovered before). The most common and most widespread diseases caused by genetic factors are multifactorial. Moreover, a majority of these are explained more by differences in environment than by differences in genes (Kristoffersson, 2000, p 5499). We have already seen why there are strong reasons for doubting that genetic testing could ever be used for adequately determining well-specified risks of most multifactorial diseases. The future potential of genetic risk-analysis must therefore be judged with quite some caution. Visions of how genetics can alter our lives and society to its very foundations (Silver, 1997) may thus never be realised.

Having said this, it is nevertheless important to note that the science of genetics is still rather young, and the technology underlying the boost in this field during the recent decades even more so. It is a known fact about the history of science that many developments generally considered to be incredible, or even inconceivable, in the scientific community, have been realized. Our ability to foresee scientific progress is weak even in the short term, since groundbreaking developments are often considered credible only when they are almost a fact. In the mid-1930s, the father of atomic theory, Ernest Rutherford, expressed his conviction that the theory would never have practical applications. About a decade later, the first atomic bomb exploded (Glover, 1984, p 14). The common opinion among geneticists was that cloning of larger mammals was not possible, at least not in the foreseeable future, until someone in fact achieved it (remember the famous sheep Dolly). However, at the same time, it may also be argued that account of genetics underlying an ethical discussion of mainly contemporary practices should not rest on hypotheses concerning developments that are possible, but highly unlikely.

Further considerations, however, seem to lend some support to the opinion that reliable presymptomatic genetic testing will be developed for multifactorial diseases to a larger extent than the sceptics seem to believe. *First*, not even the sceptics deny that there will be a clearer understanding of the connection between genes and the common diseases (Kristoffersson, 2000, p. 5501). This conjecture is strengthened by the suspicion among some geneticists that the HUGO project's way of counting genes may have led to an

underestimation of the number of genes (see above). Because of this, it is more likely that a larger number of multifactorial diseases have a simpler pattern of inheritance than the diabetes case mentioned above. As a result, the prospect for reliable and adequate presymptomatic testing seems less bleak. *Second*, the construction of the biochip or DNA chip has helped to raise expectations of better insights about how genes interact to affect the human organism (Helgesson, 2001).[40] *Third*, it has been claimed that the environment in developed countries has been improved and homogenised, which leads to reduced risks of disease due to the environment. This may mean that genes will take on increasing significance as a medical risk factor (Rasmusson, 2001). However, one should not disregard the remaining variation in the inner biological environment of each individual and the basic statistical considerations mentioned above (Göring et al, 2001) that, in combination, leaves a basic scepticism regarding the practical possibilities of collecting the very knowledge necessary as a basis for any prediction about future health on the basis of information about the structure and content of a person's DNA.

Besides tests on DNA (genes), however, there are other tests that are the result of progress in genetics and that might be used to predict disease or the risk of disease before onset, namely tests on RNA or the protein product. As mentioned in the previous section, the basic doctrine of genetics is that the gene (located on the DNA molecule) creates the protein via RNA. An analysis of the protein product is often used in order to establish a diagnosis, even for single gene disorders.[41] Two international research areas, "functional genomics" and "proteomics", are studying the relationship between damage to RNA or proteins, on the one hand, and diseases, on the other hand. These projects may make it possible to do tests on RNA or proteins that can be used for presymptomatic and predictive purposes, even if the damage to the RNA or the protein has a highly complex multifactorial genetic background. To what extent this possibility will be realised is hard to foresee. Testing may not be feasible until the individual already has the symptoms of the disease tested for, that is, the change in the RNA or the protein and symptoms may emerge at the same time. In that case, the tests will not be useful for predicting disease or

---

[40] These positive expectations may rest on an underestimation of the complexity of inheritance. In support of this there is the claim that the genes for only a few polygenetic diseases have been identified, in spite of massive use of biochips.

[41] For instance, phenylketonuria (I.4.1) is tested this way.

determining the risk of disease before onset. However, it is also likely that, at least for some conditions, tests of this type will be able to reveal (the risk of) some diseases before onset.

Tests on RNA or protein are not genetic in a strict sense of the word, since they do not detect any property of a person's DNA. In cases where they can be used for presymptomatic and predictive purposes, however, they will not differ in any relevant way from strict genetic testing. They will still be tests for *diseases for which the malfunction of some gene(s) are an integral part of the explanation.* And this is the definition of genetic testing relevant to this book. The one-sided focus on examinations of the DNA in ethically oriented literature and various legislations on genetic testing is therefore misguided and should be exchanged for a more inclusive definition, which includes both biochemical tests on genes and the products of genes.[42]

In the light of all these uncertainties regarding the future of genetics, it seems prudent to experiment with different scenarios. For simplicity, I will consider two contrasting scenarios regarding the expected development of genetic testing during the coming 10-15 years. One of these scenarios is more cautious and in line with the opinions of many geneticists today (Göring *et al*, 2001; Kristoffersson, 2000; Wahlström, 2002a). This *cautious scenario* conjectures that we will identify more single gene disorders (each one rare), for which reliable presymptomatic genetic testing will probably be developed, but we will not be able to develop reliable predictive testing for most multifactorial diseases. In rare cases, tests on RNA and protein will be possible before the onset of the disease, but will mainly be used for diagnostic purposes. The reason for this is the above mentioned hypothesis that in most cases damage to the RNA or protein and the disease will emerge at the same time.

The *bold scenario* agrees with the cautious one that more single gene disorders will be detectable before onset through presymptomatic genetic testing. However, the bold scenario expresses a greater faith in the possibility of developing reliable predictive genetic testing for multifactorial diseases. It also implies higher hopes concerning the possibility of using RNA or protein tests for presymptomatic and predictive purposes. The most plausible version

---

[42] For regulatory purposes, methods of finding out genetic information about persons that does not include testing at all (e.g. by access to blood relatives' medical journals) may have to be considered too, which would require an even wider definition of what should be regulated.

of the bold scenario emphasises the latter rather than the former possibility. However, the end result of both these technical solutions is more or less the same: radically expanded opportunities of assessing risks of multifactorial diseases.

For the purpose of the ensuing deliberations, the practical difference between the scenarios is that in the cautious one only a small proportion of the population can be demonstrated to suffer from genetic defects, while in the bold one, genetic testing can reveal differences in genetic risks for a much larger group of people. Which scenario that will be realized is thus most important to consider when discussing wider societal questions regarding proper policies and regulations with regard to genetic testing and information. Questions such as these primarily arise in connection to third parties interest in genetic information, such as insurance companies and employers (see chapter VII).

Will the cautious or the bold scenario be realised? The answer to this question is a matter of speculation. The cautious scenario perhaps has a stronger foundation, given the opinions of geneticists today. The bold scenario is deliberately cast in vague terms, in order to allow different degrees of deviation from the cautious scenario. It is legitimate to ask why one should experiment with scenarios that appear less likely to occur given the well-founded beliefs of today's geneticists. We have already hinted at the answer to that question: scientific development is hard to predict, even in the short term. Scientific achievement often surpasses the most fanciful prognoses for the future. Even if the bold scenario at present seems less likely, we should consider the societal consequences of that scenario too, so we will not be taken by surprise if it should be realised after all. The realization of some version of the bold scenario will be a severe test for politicians and shapers of public opinion, and bearing in mind the inertia of political institutions there is good reason already now to formulate a strategy that enables us to handle the consequences of that scenario, should it come about.

One or two further possibilities of genetics are worth mentioning in this context. First, many genetic diseases cannot be treated today (e.g. Huntington's disease). However, one of the primary motives behind the HUGO project was to develop effective therapies for such diseases, or at least medicines that delay or lessen the severity of the symptoms. If this endeavour is successful for more diseases, presymptomatic genetic testing – on DNA, RNA or protein –

will be useful in order to offer treatment before the onset of these diseases. This will strengthen the moral reason to perform these tests (see II.2.1).

Second, the developments in genetics and biotechnology underlying the development of presymptomatic genetic testing also opens up for a special variant of these tests, namely commercial home tests. These are presymptomatic genetic tests that are sold on the open market directly to the user of the test. These tests thus enable individuals to find out about their genetic propensity for various conditions, without ever coming into contact with public health care or having the result noted in the medical record. Such tests already exist, which demonstrates the pace at which developments are progressing. In the USA, genetic home tests that reveal the risk of developing a certain form of breast cancer (see I.4.1) can be ordered by mail, and in London, genetic tests that reveal if you are sensitive to certain diets can be bought directly in stores.[43] The consequences might be that even more people will have access to genetic information with great relevance to the estimation of health and life expectancy, while at the same time being more able to keep this information private.[44]

4.3 The moral (ir)relevance of genetic information

Why have genetics received so much attention in recent moral discussions? This question may well be asked in the light of the exponential growth of genethics. I think part of the answer is that the development of contemporary genetics gives rise to practical problems that need to be tackled; problems like the ones addressed this book. These cannot always be directly answered with reference to norms of classical biomedical ethics. For instance, the question of why and when one should perform presymptomatic genetic testing can not always be cast in terms of the health of patients, since, sometimes no gains in terms of health can be made (see I.4.1 and II.2.1). Then the question arises: when, if ever, should these tests be performed? This is a practical question that certainly should be pondered.

However, the enormous interest in genethics may give rise to the impression that one is presuming that there is something unique or special with genetic information that makes it especially worthy of our interest. In

---

[43] In the US, the tests are provided by Myriard Genetics in Salt Lake City (Capron, 2000) and in the UK by Sconia (www.genewatch.org).

[44] I will discuss the defensibility of these tests later (see section IV.2).

order to avoid any future misunderstandings regarding my own view on this, I will state why I believe this presumption to be false. This has been successfully argued elsewhere (Holm, 1999; Launis, 2000; Sandberg, 1995, p 1550-1553; Takala, 2000, 95-96), and I will just provide a brief recapitulation of these arguments.

Four main characteristics have been proposed in favour of the claim that genetic information is morally relevant in a way that other (medical) information is not. Genetic information is: (i) predictive about disease before onset; (ii) transmittable to offspring; (iii) revealing about other persons than the one tested (namely the persons relatives); and (iv) especially personal and intimate or sensitive.

However, none of these characteristics single out genetic information as deserving special treatment compared to other medical information, not even taken together. This is so, since there are other kinds of non-genetic information that are relevantly similar. The point that other information is relevantly similar to genetic information is easily made concerning characteristic (i)-(iii). A lot of non-genetic (medical) information is predictive about disease before onset, e.g. information about HIV-carrier status, smoking and cholesterol. A lot of risk factors besides genes are transmitted to offspring, e.g. HIV-virus, the environment in the womb and social position.[45] Some non-genetic diseases reveal information about other persons than the one tested, e.g. sexually transmittable diseases. For instance information about HIV-carrier status, then, shares all these characteristics with genetic information.

The most debated characteristic concerns the personal and intimate nature of genetic information. The argument should not rely on the very controversial idea that there is something uniquely personal about genetic information as such, since this claim would draw on a form of genetic essentialism already refuted (I.4.1). Of course, one can claim that genetic information is considered very personal and intimate in our culture, but so are information about sexual preference, private relations and so on. So the claim that genetic information has any *special* properties that are morally relevant seems unfounded.

---

[45] All people evidently do not have the same social position as their parents, but people have increased probability of occupying the same social position (the social heritage). This is true about genetic heritage too, however.

I will argue further against the claim that genes and genetic information has direct moral relevance. For instance, I will argue that the alleged sensitive nature of genetic information cannot be used to found rights, even if one grants that genetic information is very sensitive (see IV.2.1). I will also argue that no one has special obligations towards others only due to being genetically related to them (see VI.3.2.1).[46] Moreover, I will argue that the fact that genetic information is not special in the sense just described calls for founding legislation on other concerns than the special nature of genetic information (see VII.4.1).

Of course, none of this means that there are no interesting moral questions regarding genetic information. There are indeed, and I would not think it worthwhile to write this book if I thought there were no such questions myself. As already mentioned, I find the practical problems that contemporary genetics gives rise to, some of which are discussed in this book, highly interesting. I also think that moral philosophy in general stands to gain from scrutinizing important practical questions, like the question of the right to and value of genetic information. And genetic information can be directly relevant to decision-making. However, the interest in these questions should not rest on any notions of genetic information being unique in a morally relevant way. This interest should rather be in the practical problems contemporary genetics give rise to.

If one accepts that there is nothing uniquely morally relevant with genetic information, it becomes more natural to resist any urge to formulate a new morality for questions regarding genetic information. Instead it becomes tempting to use the ideas of already existing moral theory to tackle the problems contemporary genetics gives rise to. Even if classical bioethics is insufficient to tackle all these problems, I think that we can come a long way, and perhaps all the way, in the moral discussion of issues that arise from contemporary genetics using concepts well known in moral philosophy, such as autonomy, well-being, rights, obligations and justice.

5. The plan of the book

As already mentioned, I hope that this book can provide valuable reading for both moral philosophers interested in health care and health care professionals

---

[46] Some additional moral premise is needed, which does not refer to genetic relatedness.

interested in moral issues (I.2). However, the same point that applies to this chapter applies to the whole book: some passages will be directed more to one of these groups than others. Most clearly, chapter II is directed more to those involved in the health care practice (for instance, I there discuss genetic counsellor's professional norm of non-directiveness) and chapter III more to moral philosophers (since I discuss more theoretical issues on the nature and value of autonomy in this chapter). Having said this, many arguments in this book hinges on arguments more fully explicated in other parts of the book, so a full appreciation of some arguments may require reading both the more practical and more theoretical parts. Nonetheless, I will now present an overview of the content of the book, so that the reader can concentrate on the parts of the book she or he finds most interesting.

The book is organised in accordance with the question of the value of and the right to genetic information from presymptomatic genetic testing for first, second and third parties. Most emphasis will be on first parties', i.e. individuals', value of and right to genetic information, since the findings here will prove useful for discussing the values and rights of other parties as well. Chapter II discusses the question of the value for the individual of presymptomatic genetic testing and the counselling often accompanying such testing. I argue that there are basically two values of both presymptomatic genetic testing and genetic counselling, namely well-being and autonomy. This provides us with a coherent account of more specific values in these practices, as well as a standard of evaluation for the practices based on these basic values. For instance, the norm of non-directiveness and the requirement of pre-counselling are thus evaluated. However, the idea of autonomy as a value to promote often presupposed in this context is somewhat of a novelty in biomedical ethics, in which autonomy is usually considered to be a right that should be respected. This calls for a closer analysis of autonomy, which is the subject of chapter III. This analysis consists of developing a conception of autonomy, useful for formulating ideas of autonomy conceived of as a value, as well as a right, and a discussion of the theoretical problems that arise in relation to the conceptions and moral ideals of autonomy. Some of these problems, for instance the problem of comparing and measuring autonomy, are found to have practical relevance as well.

Chapter IV and V deals with the individuals' right regarding genetic information from presymptomatic genetic testing. While chapter IV presents some basics on rights and deals with the question of the right to have such

information, or, as it is sometimes put, the right to know, chapter V deals with the question of the right not to have such information or, as it is sometimes put, the right to ignorance. In chapter IV, I argue that the proper basis of rights in the context of presymptomatic genetic testing is the values the recognition of such rights can promote. This warrants some more specific conclusions, such as somewhat limiting the scope of negative rights to purchase genetic testing, while granting positive rights to be tested in some circumstances. In chapter V, I address the question of the right to ignorance and argue that such a right, at least in one sense, should be recognized. I further defend a right to ignorance from charges to the effect that grounds of Kantian ethics or autonomy implies a duty to know, allegedly incompatible with a right to ignorance.

Chapter VI deals with second parties', and then primarily blood relatives', rights to genetic information. Although the value-question is tackled too, it is found to concern the same values as first parties, whereby the focus lies on the right-question. I argue that there may be a moral obligation to inform relatives that vary in strength with the value for the relatives of being informed, but that practical considerations make it plausible to leave the decision of whether or not to inform relatives to the tested person, except perhaps in very rare cases. I also argue that the consent of relatives should not be a requirement for testing.

Chapter VII deals with third parties' right to genetic information, and then almost exclusively insurance companies' rights. I argue that regulation is insufficient to protect the interest of those in need of being insured against the financial burdens of genetic risk and disease, but that, at least very stern, regulation may be counterproductive to this effect. Instead I argue that considerations of consequence and justice speak in favour of the protection or resurrection of social insurance, a key component in the welfare state. I use the findings in this discussion to very briefly address the question of employers' right to genetic information, where a more restrictive stance seems plausible. I finally add some remarks on researchers right to genetic information, which brings the plausibility of different versions of consequentialism to the stand.

Chapter II
Values in Presymptomatic Genetic Testing and Genetic Counselling

1. Introduction

We are all mortal. Although we may only grasp this truth at some abstract level or, like Tolstoy's Ivan Ilich, are unwilling to recognize that this is true also about ourselves, we all know that we are going to die at some point in the future. However, very few of us have any well-founded beliefs about when this will in fact occur. And if some omniscient archangel asked: "Do you want to know when you are going to die?" I guess many would feel reluctant to answer "yes!" Even if one knows that one is going to die, one might be hesitant to find out when this will actually happen.

It is also very likely that most people who live long enough will be affected by, more or less serious, disease. Very few are completely healthy all the time. And most of us do not know when and how they are going to be affected by disease, although the rapid development of medicine makes it more and more a truth with modification.

Genetics has provided an instrument to give more precise answers to these questions: presymptomatic genetic testing. Now, as should be clear from the previous chapter, one must take heed not to overvalue the predictive force of such testing. Nevertheless, for at least some of us, presymptomatic genetic testing is an instrument that can reveal information about possible future disease and death that is more well-founded and precise than the unfounded and imprecise beliefs most of us have.

Of course, genetics has to some extent also given us an instrument to live longer and healthier lives and will hopefully do so to a greater extent in the future. An obvious reason for performing presymptomatic genetic testing is to improve one's health and longevity. However, tests can, and in fact are, made for diseases where little or nothing can be done to prevent or ameliorate the

possible future disease. This gives rise to the question of the justification of presymptomatic genetic testing.

So, why perform presymptomatic genetic testing at all? If one asks for the reason to implement such a procedure, or any procedure for that sake, an answer that seems natural is to point to the (alleged) fact that this procedure makes at least someone better, or less worse, off. That is, one often justifies the implementation of a procedure, or the choice to act in a particular way, with reference to the value for someone that the procedure or act will, or may, produce. This chapter examines this kind of justification for presymptomatic genetic testing. Furthermore, it examines the values of genetic counselling, since it is commonplace to think that presymptomatic genetic testing should be performed within the framework of this practice.[1]

I will argue that the fundamental values in presymptomatic testing and genetic counselling are (subjective) well-being and autonomy. How well-being and autonomy should be understood is a matter of controversy in moral philosophy. These concepts will therefore receive some attention in the following. Subjective well-being is a relatively established concept and will thus be developed only to a minor extent in the end of this chapter (section 4). However, the concept of autonomy has received less attention in this context and will thus require some more elaboration (chapter III). For now, a very rough characterisation will do. Well-being is then to feel good and/or having it one's own way, while autonomy is to live one's life according to one's own plans.

To claim that well-being and autonomy is the fundamental values in presymptomatic genetic testing and genetic counselling is not only consistent with the most common claims about the value of these practices, but also provides a coherent framework of these practices that explains more particular statements and allows for an evaluation of the practices. However, conflicts within and between these values may arise. This gives rise to normative issues of how the practices should be designed. Some such questions will be addressed later in this chapter (II.3.4). They will also recur in chapters to follow (see e.g. VI.3.1.2).

---

[1] See e.g. WHO, 1998, p 7, that in their "Proposed Ethical Guidelines for Genetic Screening and Testing" claims: "Test result should be followed by genetic counselling".

2. The value of presymptomatic genetic testing

Why should, or should not, the individual know of genetic information concerning her own genetic constitution? Since I am dealing with genetic information that is the result of presymptomatic genetic testing the question becomes: from the point of view of the individual receiving information from presymptomatic genetic testing, why should such genetic testing be, or not be, performed? This is most naturally seen as a question of the balance of reasons in favour or disfavour of presymptomatic testing of the index-person(s) (or patient or client) for this person, i.e., what advantages and disadvantages presymptomatic genetic testing has for the person tested. Another way to put this is in terms of what good (or avoidance of bad) or *value* that a presymptomatic genetic test would realize for the index-person. The question I am interested in thus becomes: what reasons in terms of the effects on the individual are there for this individual to perform or not perform such a test? Or: what values *for the person*, or *personal*, or *prudential* values, may be realized by such testing?

Since the days of Hippocrates, it is a traditional assumption in biomedical ethics that the point of health care in general is to benefit the patient.[2] The same, then, goes for genetic testing as a health care practice. If this assumption is accepted, the ultimate *rationale* for genetic testing should be sought in the personal value that testing could realize for the index-person. The idea that the value for the patient provides the justification of medical practices in general and genetic testing in particular is widespread (Marteau & Richards, 1996, p 3; Munthe, 2002, p 78). If there are any such values then these values provide a legitimate *goal* (or aim or point) of presymptomatic genetic testing.

What is the goal of presymptomatic genetic testing? If we take the traditional doctrines of personal value or well-being for granted,[3] two of these doctrines are predominant in the justification of presymptomatic genetic testing, namely *subjective well-being* (from now on: well-being, see II.4.1.4) and *autonomy*.

> [T]he advantages [of genetic testing] are crudely of three types: 1. Positive effects on the physical health of the individual (correct

---

[2] The Hippocratic oath says the physician should "come for the benefit of the sick". See e.g. Beauchamp & Childress, 2001, p 173.

[3] They will be developed in closer detail in II.4.

> diagnosis of symptoms, preventive measures for e.g. demonstrated substantial risk of cancer). 2. Reduced anxiety/uncertainty (given initial suspicion of substantial risk, e.g. in families burdened with hereditary disease). 3. Better opportunities for the individual to plan her life. To simplify, related to basic values commonly referred to within medical ethics, one may say that point 1 and 2 focuses on aspects of the goal of promoting *well-being*. The goal of point 3 is rather to strengthen *autonomy*... (Munthe, 2002, p 78. My translation)

The view that well-being and autonomy are the two most important values of presymptomatic genetic testing seems to be widespread among clinicians, as well as those people who undergo these tests, i.e., the index-persons:

> Two main classes of reasons were given by subjects asked about their decision to take the predictive test for Huntington's disease: reduction of anxiety and uncertainty associated with being at risk, and enhanced planning and decision-making about one's future (Shiloh, 1996, p 90)

The first reason is obviously about well-being, and the second about autonomy (see II.2.3). That well-being is considered to be a rationale of presymptomatic genetic testing should not be a surprise, since it is a classic goal of health-care (see II.4). However, autonomy as a goal of health care can come through as more of a novelty. However, not only index-persons but also health care professionals seems to have some idea of autonomy in mind when providing a rationale for genetic testing: [4]

> An international survey of geneticists reported that virtually all respondents believed that an absolutely essential goal of genetic screening was to 'help patients understand their options so they can make decisions'. (Chadwick et al, 1997, p 3)

Of course, there are other (alleged) values that genetic testing may realize, such as knowledge conceived of as an intrinsic value or perfectionist values, but

---

[4] Empirical support for this can also be found in an ongoing study of the ideology and organisation of Swedish presymptomatic testing programmes for cancer (personal information from Christian Munthe).

they are more peripheral in the debate, and I will ignore them partly for this reason.[5] As we will see, often more specific goals are often mentioned, but as I will argue, I think most of these goals are ultimately derivative from or can be cast in terms of well-being and/or autonomy. Anyway, it is hard to see why the more specific suggested goals should be considered as *legitimate* goals if they do not promote well-being and/or autonomy.

We can call the type of well-being addressed in point 1 in Munthe's list above *health-related well-being*, since they are about therapeutic and/or preventive measures to avoid, ameliorate or delay the onset of symptoms of genetic disease.[6] Other positive effects on well-being of presymptomatic genetic testing are more related to Munthe's second point. In this context, I define health-related well-being somewhat narrowly and negatively, as well-being that is the direct result of avoidance of or amelioration of symptoms of disease or bodily harm. Even if one defines health more broadly, partly in terms of well-being, which perhaps is reasonable (Brülde & Tengland, 2003, p 237-245), there seems to be general consensus on the view that not all well-being is health-related: a person may change with regard to well-being, for instance for the better when her favourite soccer team is winning or for the worse when she has lost her new pair of gloves, without changing with regard to health (or disease). Given this, it seems obvious that there may be reasons of well-being for presymptomatic testing that is not of Munthe's type 1. Let us, somewhat coarsely, call this type of well-being *psychological well-being*. This is somewhat misleading, since ultimately all well-being is to some extent psychological.[7] But the term is designed to pinpoint the kind of well-being that is not directly tied to the avoidance or amelioration of symptoms of disease, and which is thus not the subject of straightforward genetic explanation.[8] Rather, with the term psychological well-being I intend to capture the kind of well-being that is the result of having certain attitudes to genetic information about oneself, e.g.

---

[5] I will elaborate on the reasons for this limitation further (see II.4.1.4).

[6] As we have seen, the term "genetic disease" or genetic disorder" is not an unequivocal one, but I take it to mean a disease the explanation of which contains as a significant part the malfunctioning of some gene. For instance, this makes common cold non-genetic, but Huntington's disease genetic.

[7] This is so regarding subjective well-being, which is the kind of well-being thought of in this context. See the section on well-being later on in this chapter to see why all subjective well-being is psychological.

[8] Of course, testing or lack of testing may lead to conditions that could be labelled as pathological, e.g. severe depression, but this is not part of the genetic disease itself.

anxiety as a result of receiving some genetic information about one's susceptibility for disease.

To sum up, then, the reasons that have been suggested to speak in favour of acquiring information about one's own genetic constitution are that such acquisition may promote the health-related well-being, the psychological well-being, or the autonomy of the person in question.

Just as the predominant *positive* values brought to stand regarding presymptomatic genetic testing are well-being and autonomy, the disadvantages or *negative* values of presymptomatic genetic testing that have been suggested are predominantly about the reduction of well-being and/or autonomy that such testing may result in. Of course, when there is no preventive life-style or medical measures to initiate (as is the case with e.g. Huntington's), there is a lack of positive contribution to health-related well-being. However, this is not so much a negative value as absence of a positive value. But it has been claimed that presymptomatic genetic testing may produce negative values or *harm* and primarily then psychological "ill-being" or reduction of autonomy. Several examples of such possible harms will be presented below.

Since it seems possible that values can be both promoted and reduced by presymptomatic genetic testing, conflicts may arise. For instance, a genetic test can lead to the promotion of someone's health, but the reduction of her overall psychological well-being. And promoting the well-being of someone in the short term may lead to the reduction of her well-being in the long term. Furthermore, promoting the well-being of one person may lead to the reduction of well-being of another. In addition, conflicts may arise both within and between persons regarding autonomy. And we cannot assume that there is no conflict between promoting well-being and autonomy. So the goals of presymptomatic genetic testing may come into conflict. I will return to this below (see e.g. section II.3.4).

Before that, I will now look at some claims about the possibility for presymptomatic genetic testing to promote, but also to damage, the values of well-being and autonomy. Since the literature on this subject is vast and expanding, a complete overview is not feasible. Rather, I will present some examples that I find to be representative. When doing this I will substantiate the point that more specific goals that are mentioned are ultimately derivative from or can be cast in terms of well-being and/or autonomy. The presentation of the values will allow us to make a list over the reasons for and against testing

or, to put it another way, the positive and negative values of genetic testing. Moreover, the presentation will allow us to draw some general conclusions on the value of different types of testing. For instance, I will argue that in general, reasons for the testing of multifactorial diseases are weaker than for monogenetic ones. Furthermore, some reasons are irrelevant regarding some testing, e.g. health-related values for testing of diseases for which there are no medical or life-style measures. However, even more importantly for the context of philosophical reflection, this analysis will provide the point of departure for more in depth inquiries regarding the more exact nature of these values, so it becomes clearer what ethical conclusions regarding the practice of presymptomatic genetic testing they support. These inquiries will occupy section II.4 and chapter III below.

2.1 Health-related well-being

As I said, in this context health-related well-being is understood as well-being that is about the avoidance, amelioration or delaying of the onset of symptoms of genetic disease. This kind of reason to obtain information of one's own genetic constitution has been stated by leading participants in the ethical debate on genetic testing:

> Let us suppose...that the [genetic] disorder is...curable or preventable at an early stage. Assuming that individuals want to live long and healthy lives, it would seem prudential for them to know about such a dormant condition. (Takala, 2000, p 59-60)

> For some genetic disorders there may be preventive measures that could be taken. For example a woman who has inherited the BRCA1 gene is likely to develop breast cancer. Some such women choose to undergo prophylactic bilateral mastectomy. Alternatively, regular follow-up could be offered to identify breast cancer at an early stage. (Chadwick et al, 1997, p 2)

> When the prevalence of the actual illness depends on these other [non-genetic] factors, it could be argued that people should know about their genetic weakness because the knowledge enables them to adjust their life-styles accordingly. (Takala, 2000, p 60)

> The knowledge [of genetic susceptibility for disease] may enable the individual to seek appropriate therapy or to take preventive of ameliorative action. (Chadwick, 1997, p 14)[9]

The realization of health-related well-being is accomplished through therapeutic and/or preventive measures. Strictly speaking, only diseases for which there are *preventive* measures can justify *presymptomatic* testing from a health-related perspective. If treatment or ameliorative measures are effective only when symptoms emerge, there is no health-related (in the sense above) reason to know about the susceptibility to develop the disease before the symptoms, i.e., presymptomatically. Then the argument only shows that there is a health-related reason to perform *diagnostic* testing. For instance, if there is an effective drug therapy to ameliorate the symptoms of Huntington's disease once they occur, but that does not work before the symptoms emerge, this in itself can only tell in favour of making a correct diagnosis, and not in favour of presymptomatic testing.

However, there is a possible exception to this. In order to recognize certain changes in the person as symptoms of disease, it is useful to know beforehand that this person has an increased risk of that disease. This may facilitate earlier therapeutic measures than if this risk were unknown, which can be a health-related advantage. However, once again, this is only a reason for presymptomatic testing if there are such measures to take. Furthermore, it is only a reason if symptoms can be conflated for normal changes and if early measures really are an advantage.

Regarding preventive measures, we can roughly distinguish between *medical measures*, such as the administration of prophylactic drug, surgery, and medical investigations to secure early diagnosis, and *life-style changes*, such as changes of behaviour or environment. Life-style changes are most interesting when it comes to multifactorial genetic diseases, where life-style factors can affect the probability and seriousness of the disease. Given the plausible assumption that, at least in most cases, the symptoms of a disease will affect the well-being of the person negatively and given that testing is necessary in order to determine whether preventive measures should be taken, the person has a good reason indeed to take the test. Presumably, the reason is stronger the better the test

---

[9] See also Wood-Harper & Harris, 1996, p 287, for similar statements on the value of using genetic testing in order to determining genetic susceptibility of disease.

predicts the onset of disease, the more efficient the measure is, the less hardship (e.g. side-effects) it imposes on the person,[10] and the graver the symptoms are.

However, an obvious prerequisite for this kind of reason is that there really are measures to take. For many genetic disorders there are no effective therapies or preventive measures at all (at least not yet), e.g. Huntington's disease, hereditary Alzheimer's, or FXTAS. For the time being, this kind of health-related argument cannot provide the rationale for those tests, then. Another prerequisite for the value to be realized is that the test is positive, i.e., shows that the index-person is a carrier of the disorder in question. Otherwise preventive measures are not needed.

A similar point applies to therapies that are independent of knowing the genetic background of the disease. Then it is not important per se to perform *genetic* testing in order to initiate effective treatment. For instance, the need to initiate some of the therapies to ameliorate some of the symptoms of fragile X, such as training to compensate for intellectual disability, can be determined without knowing about the genetic explanation of the symptoms that the therapies are designed to ameliorate. In such cases, the health-related argument of well-being for genetic testing is irrelevant, even though there may be other good reasons to test, as we will see.

However, in cases where genetic risk of disease is suspected and the test is capable of clarifying the risk, even a *negative* test result may be of positive value in terms of health. This since it may provide reasons for the avoidance of burdensome preventive measures and health controls for the disease in question that would otherwise have been undertaken. A good example of this is provided by the case when there is initial suspicion of breast cancer due to family history. Prophylactic mastectomy may be recommended and performed on this basis. A genetic test of BRCA1 with a negative result can provide grounds for thinking such a drastic measure unnecessary.

However, this example highlights the possible negative values in terms of health of presymptomatic genetic testing. Not only may the measures lead to preventive measures that may turn out to be more harmful than the genetic

[10] E.g. the hardships of prophylactic mastectomy, see below.

risk of disease,[11] moreover, the risk of depression, to be mentioned below, may in extreme cases lead to health-related consequences, such as physiological deterioration.

2.2 Psychological well-being

2.2.1 Positive values

In this context, psychological well-being refers to the kind of well-being that is not directly tied to the avoidance, amelioration, or delaying of symptoms of disease and bodily harm. One such mentioned advantage of presymptomatic genetic testing in terms of well-being is the removal of suffering due to the anxiety of uncertainty:

> An asymptomatic young person with a parent affected by Huntington's... may prefer to have uncertainty about their fate removed. (Chadwick et al, 1997, p 2)

> Some people may experience the knowledge [of genetic susceptibility for disease] as a liberation from the agony of uncertainty. (Chadwick, 1997, p 18)

There are testimonies of people feeling bad about not knowing whether or not they are carriers and people feeling good about receiving a definite test result, even when the test reveals genetic susceptibility to disease for which there are no cure or preventive measures and, thus, no health-related gains to be made.[12] This indicates that there may indeed be well-being to be gained by removing uncertainty. In addition, there are testimonies of people strongly desiring genetic testing on grounds of removing uncertainty,[13] which further strengthens the case for this claim.[14]

---

11 See Laurie, 1999, p 122, for further references to literature about the inherent risks of prophylactic mastectomy.

12 See Sue Wright's story about her presymptomatic test for Huntington's disease: "We [she and her partner] both felt more at peace now we knew I had the gene" (Marteau & Richards, 1996, p 7).

13 See Julia Madigan's story about her presymptomatic test for Huntington's disease: "I wanted the answer more than life itself." (Marteau & Richards, 1996, p 7)

14 "Feeling good about receiving the information" is primarily about well-being in hedonistic terms, and "getting information that you strongly want" is primarily about well-being in preferentialistic terms. These accounts of well-being will be developed (see II.4.2).

However, reduction of anxiety of uncertainty can most plausibly be expected only when test results are certain enough themselves. This, in turn, depends on the disease tested for and what testing possibilities are available. For instance, the less reliable the test is in the sense of likelihood to produce false positives and negatives, the less likely it is to remove uncertainty. Moreover, due to the nature of some genetic diseases, even the most reliable tests will only inform about a risk in form of a percentage figure. This is the case for all multifactorial diseases (since they are not solely caused by genetic factors) and some monogenetic diseases (like breast cancer caused by BRCA1). However, for the former, this figure will also be unspecific, that is, provide a range of possible risk-figures rather than one such figure. That is, the test will be less predictive. For instance, if the result of a genetic test is that the index-person has a combination of genes that increases his risk of having a certain disease with between 20 to 40% this will probably not be perceived as reducing uncertainty of what will happen for most people. Of course, "uncertainty" is a matter of degree and some may prefer even a very small reduction of uncertainty. However, generally speaking, the less reliable and the less predictive the test is, the weaker is the argument of reduction of anxiety of uncertainty in favour of testing.

Furthermore, it has to be emphasised that the anxiety of uncertainty is present only if the index-person has some prior suspicion that she has an increased risk of genetic disease. Such suspicion is usually evoked by a family history of disease or by knowing of relatives' positive test result.[15] The reduction of anxiety rationale for testing is thus mostly relevant in these kinds of cases. However, this is not to say that prior suspicion is always well-founded. There may be cases when persons have irrationally founded fears of genetic disease, for instance when test results of relatives have been misunderstood, or when the person is a hypochondriac. If it is not possible for health care professional to convince the person in question that she has no reason to be suspicious, and testing thus is the only way to remove the uncertainty of anxiety, this kind of rationale for testing also favours those persons being tested.[16]

---

[15] This gives rise to questions about whether family members should be informed about the result of genetic testing, a question that will be discussed in chapter VI.

[16] Compare with the argument for providing prenatal diagnosis to women who have unsubstantiated worries about the health of their future child in Munthe, 1996, chapter 2.

Other possible values for the index-person are the result of the test either being positive or negative. A potential benefit of a *positive* presymptomatic test result is the time it gives for psychological adjustment to cope with the (more or less probable) disease (Wood-Harper & Harris, 1996, p 284). The distress of having a disease might be ameliorated if one is previously acquainted with its effects. However, most presymptomatic genetic tests are for diseases that the persons sometimes are familiar with already, due to a family history of disease. These persons already have had the time for getting acquainted with and coping with the potential onset of the disease, in which case this value is not applicable.[17] However, when the family history has been repressed, as is sometimes the case, testing might force the person in question to deal with the consequences, which may be beneficial in the long run.

Another potential benefit in terms of psychological well-being is improved relations with family members and relatives. This effect seems to be most noted in cases when the index-person has tested positive in a family with formerly identified carriers (Brandberg, 2003, p 93; Sobel & Cowan, 2003, p 53-54). Presumably, feelings of belonging and having someone to share one's experiences and expectations with plays a role for the result of the test being welcomed as well as being conducive to feelings of well-being.

However, to be sure, the most obvious effect on psychological well-being of presymptomatic genetic testing is the relief of finding out that the result is *negative*.[18] For a negative result, the sources of relief may vary. It may be due to the simple fact of not having increased risk of the disease in question, not having to endure burdensome preventive measures (if there are any), the avoidance of stigmatisation, knowing that one will not pass the genetic disorder in question on to one's children, and so on.

2.2.2 Negative values

One possible factor that may affect the well-being of the individual for the worse is that the result of the test, whether positive or negative, may evoke an unwelcome change in (false) self-image (Chadwick, 1997, p 19; Laurie, 1999, p

[17] Of course, if testing is made within a setting designed to help the person to better cope with the psychological effects of the disease, e.g. genetic counselling, then the reason for testing within this setting will be stronger (see section II.3).

[18] See Julia Madigan's story about her presymptomatic test for Huntington's disease for a strong personal statement about this, Marteau & Richards, 1996, p 16-18.

124; Widmer, 1994, p 184).[19] As we will see below, some people seem to build an important part of their self-image on being predisposed to some hereditary disease. They may therefore regard a negative result as unwelcome and distressing. A similar point may be made of positive test results: "A woman who has genetic predisposition to develop breast cancer in later life may have a self-image that is incompatible with this as a possible future." (Chadwick, 1997, p 19) To present this woman with a positive result could be distressing to her, not only due to the fear of contracting a serious disease, but also partly due to her having plans for the future where breast cancer was never a considered possibility.

Of course, this is to claim that information that destroys the possibility for the individual to uphold a *false* self-image may have adverse consequences in terms of well-being. However, one could claim that a *true* self-image must be conducive to well-being in the long run. Closer inspection, however, reveals this possible response as not very plausible. Take Chadwick's example of the "woman who has genetic predisposition to develop breast cancer in later life" (Ibid.). She may receive information about her increased risk without ever developing breast cancer (despite not taking preventive measures). It is not unlikely that this information will make her life worse in terms of well-being than it would have been had she never received it: not only has she received undesired and distressing information, she may also have changed her plans against the background of this information without the risk for breast cancer ever being realized and thereby unnecessarily sacrificed what she would most have liked to have.[20] Thus, she may very well have been better off in terms of well-being if she had not received the information.

Moreover, the same may hold even if she in fact developed breast cancer. To be sure, she would then have to revise her self-image anyway, at the point when the cancer developed. But the gain in well-being effected by being able to keep a false self-image up till that point may still override the value of knowing beforehand. That this may be so seems plausible to hold against the fact that exaggerating the positive outlook of one's future seems to help us to

---

[19] Widmer and Laurie speak of a right not to receive information that can evoke an unwanted change in self-image, and Chadwick connects this with "notions of integrity and privacy." (Ibid.) I will ignore these ramifications, since, in this context, I am interested only in the (negative) value of such a change for the individual.

[20] Besides being distressing it is also negative in terms of autonomy, in a sense. So surprisingly, a false self-image may be conducive to autonomy. I will return to this (see II.2.3.2 and V.3.1.1).

cope with the minor problems of every day life. Deep down, we all know that the rosy picture of our future many of us have may be false, but it helps us to lead a good life until the day some misfortune actually occurs.

Of course, the examples are hypothetical. But they are not inconceivable or even unbelievable. Of course, many persons will perhaps benefit in terms of well-being from being forced to revise their self-image due to genetic testing. The point is that they do not have to. These are *possible* negative values of genetic testing in terms of well-being. As we will see, some such possibilities are not just theoretical examples, but have empirical support.

The possible realization of negative psychological well-being that typically could be the effect of the result of the test being *positive* are often mentioned and are in many way a reflection of the beneficial effects of negative testing: anxiety for having increased risk of the disease in question, the inconvenience of having to endure burdensome preventive measures (if there are any), the hardships of stigmatisation, and worries about passing the genetic disorder in question on to one's children.[21]

Even though many empirical investigations stress the long-term psychological benefits of knowing, data are conflicting (Sobel & Cowan, 2003, p 50). There are reports of people becoming distressed when learning that they are carriers of genetic disease (Marteau & Anionwu, 1996, p 127). There are also reports of severe depression and suicidal tendencies (even suicide) seemingly resulting from learning that one is a carrier of genes for serious disease for which the testing is highly predictive, like testing for BRCA1, Huntington's and Alzheimer's (Harper, 2001, p 16; Lannfelt et al, 1995, p 333-334). Probably, such information will be especially damaging if it is disclosed without the patient asking for it (Adelswärd & Sachs, 2002, p 74-75), if the patient has no known family history (Marteau & Anionwu, 1996, p 127-128), if the family has been denying the disease, if the patient is emotionally stressed (Shiloh, 1996, p 92-93), or if the information is disclosed without ensuring the patient's proper understanding of it or without proper professional support. This indicates that the way in which the information is disclosed is of great importance for what positive and negative values will be realized, a point to which I will return.

---

[21] See e.g. Brandberg, 2003, p 93; Chadwick et al, 1997, p 3; Takala, 2000, p 60; Wood-Harper & Harris, 1996, p 288-289.

A positive test result may also result in "feelings of isolation and self-stigmatism" (Wood-Harper & Harris, 1996, p 288). Presumably, feelings of isolation and self-stigmatism will affect any person's self-respect, that is the feeling a person has of her own worth and the confidence she has in her ability to realize her intentions. Not only is low self-respect unpleasant and something one wants to avoid, it will probably adversely affect the person's ability to live the life she wants and thus her autonomy, a point to which I will return.[22]

Not only may the index-person's knowledge of a positive test result lead to *feelings* of isolation and self-stigmatisation. It may also result in actual isolation and stigmatisation[23] from both family and society at large, which in turn affects the well-being of the person negatively. For instance, there may be permanent disconnections with other family members. There are examples of cancelled marriage plans and divorces as a result of positive presymptomatic test results of Huntington's disease (Sobel & Cowan, 2003, p 52). One woman, who's husband left her after her positive test result, said: "My ex-husband said he wanted healthy children. He said, 'I don't want to waste love and energy on a dead-end project.'" (Ibid.) There are also examples of disconnections and strained relationships with one's family of origin as a result of positive test result, since the family of origin does not want to acknowledge that there is a hereditary disease running in the family.[24]

One should be very careful when evaluating the effects on well-being of strained family relations. Often they are strained to start with (Sobel & Cowan, 2003, p 56), and one could argue that for instance the woman just quoted may lead a better life on the whole without a husband having such attitudes. However, when these things happen, they are likely to be distressing and perhaps even traumatising.

---

[22] Rawls claimed that self-respect in this sense is one of the primary social goods, since it is a prerequisite in order to live an autonomous life (1972, p 440).

[23] Stigmatisation has a psychological aspect: the shame and self-contempt one may feel due to having a (risk of) disease, as well as an aspect relating to the reactions of others: the stigmatised person may be misunderstood, ignored, isolated, or despised by others, as well as excluded from societal opportunities (Brülde & Tengland, 2003, p 26-27).

[24] See e.g. Sobel & Cowan, p 53, and Marteau & Richards, p 7-13 about this happening in families with Huntington's.

Another stigmatising effect of a positive presymptomatic genetic test may be that one conceives oneself or is conceived of by others as sick before any symptoms appear, which, of course, can be experienced as frustrating.[25] One may also be treated as if one is sicker than one actually is, or be expected to die at any time. Merry France-Dawson, affected by sickle cell anaemia, writes about the attitudes of her surroundings in her twenties: "listening to 'learned' people talking about my dying, having family and friends treat me like I was no longer valid (though still loved) affected me more than I realised. This was manifested by my loss of interest in academic work. After all, why bother if you are going to die?" (Marteau & Richards, 1996, p 48) When she wrote this she was in her forties. So obviously, the stigmatisation that may result from being labelled "sick" (even though presymptomatic testing only shows risk of becoming sick) may have detrimental consequences on an individual's well-being.

Moreover, third parties, like insurance companies and employers, may discriminate (in the non-evaluative sense) against individuals for having a positive presymptomatic genetic test result. Employers will be reluctant to employ someone who runs high risk of falling sick, especially if monetary compensation for sick leave and/or health-care costs is included in the terms of employment. This may of course affect a persons well-being, since it may stop her from taking the job she prefers and this will probably create frustration. Of course, insurance companies will want to charge higher premiums for life- and health insurance or deny insurance altogether to such individuals in order to safeguard against the higher risk of paying compensation. The extent to which this will be done is dependant on factors such as legislation. The extent to which this will have negative consequences on well-being for the individual depends on the extent to which private insurances are required in order to get goods necessary for well-being, e.g. health care and income compensation in case of working disability due to disease. I will discuss this issue later (chapter VII), so I will ignore it for now, except by pointing out that the well-being of positively tested persons could be negatively affected by society's reaction towards them.

Perhaps more surprisingly, also *negative* results of genetic testing may have adverse effects in terms of well-being for the individual. There are well-

---

[25] One can also experience oneself as sick, even though there are no pathological changes or symptoms. See Adelswärd & Sachs, 2002, p 76.

documented feelings of "survivor's guilt", i.e., feelings of guilt towards one's relatives with genetic susceptibility for disease for being "the one who got away": "The joy that should have been there disappeared in guilt towards the others who were affected." (Öberg's testimony in Öberg, 2002, p 59. My translation.)[26] This is sometimes due to a misconception of the nature of biological heredity, believing that you could have been the one of a group of siblings taking on the disease (Sobel & Cowan, 2003, p 56). There may also be feelings of distress for not being a carrier if one has expected that one might be before testing. For instance, a negative testing result may take away one's identity as "sick", which might mean for instance being robbed of having something to blame when failing and thus creating a feeling of a demanding obligation "to do something with one's life".[27]

Moreover, isolation from family is not an uncommon result of receiving a negative test result (Brandberg, 2003, p 93; Sobel & Cowan, 2000, p 53). This may be the case when there is previous knowledge of the history of disease in the family, which can create a family identity. A negative test result for those who receive it may then give rise to the feeling that they have "lost their commonality with the family", leading to disconnection with the other family members (Sobel & Cowan, 2000, p 53).[28]

2.3 Autonomy

"What is the point of predictive testing if there is no cure for the disease?"[29] This pithy question, asked by a person considering whether or not to test for Huntington's disease, for which there are no cures or other preventive measures, asks for the value of testing in the absence of traditional health-

---

[26] See also Brandberg, 2003, p 93; Chadwick et al, 1997, p 3; Julia Madigan's testimony in Marteau & Richard, 1996, p 18.

[27] Once again, I want to refer to the personal story of Julia Madigan (Marteau & Richards, 1996), who writes: "In a funny, ironic way the second option [a positive test result] seems more appealing. Enjoy yourself and go out with a bang!" (p 15) "It has been a crutch half my life... It's easy to blame HC." (p 18)

[28] Sobel & Cowan has specifically investigated the impact of genetic testing for Huntington's disease on the family system, but as they point out, there is no reason not to assume that their findings will not be "likely to be applicable to people at risk for other autosomal dominant, mid-life onset genetic diseases" (p 49). This is supported by the ongoing study of the ideology and organisation of Swedish presymptomatic testing programmes for cancer (personal information from Christian Munthe).

[29] From Julia Madigan's story in Marteau & Richards, 1996, p 7.

related reasons for medical testing. One answer, which was addressed in the previous section, is to refer to other possible gains in well-being, such as the reduction of anxiety. Another is to refer to possible gains of autonomy.

My vivid impression is that autonomy is becoming increasingly widespread as an answer to the question of what values presymptomatic genetic testing can promote.[30] Besides the examples of referral to this value we have already seen (II.2), consider the following statements:

> [K]nowledge [of genetic predisposition for cancer][31] would be beneficial, as it would enable individuals to draw up their life plans realistically. (Takala, 2000, p 59)

According to Chadwick, the reason to grant the individual access to her genetic information is the same as granting access individuals to any medical information, namely "principles of autonomy and self-determination", since "access to information will always be important in making plans and life choices" and genetic information is especially relevant for "*reproductive* choices." (Chadwick, 1997, p 14) And again:

> An international survey of geneticists reported that virtually all respondents believed that an absolutely essential goal of genetic screening was to 'help patients understand their options so they can make decisions'. (Chadwick et al, 1997, p 3)

The line of reasoning seems roughly to be the following: if individuals possess the knowledge that they (probably) will fall sick (or the knowledge that they will not if they have suspected that they might be), they are in a better position to plan their lives in accordance with their own conception of a good life, to live in accordance with their own values or basic wishes or to realize their own important projects (or something like that), against the background of this knowledge. To live such a life is roughly what is means to live an autonomous life or being an autonomous person, according to traditional general accounts of autonomy (III.2.1). The idea is, then, that leading an

---

30 The same point seem to apply as well to other areas of health care and health policy, such as prenatal diagnosis, assisted reproduction, and public health.

31 The example of genetic disorder used in this context is Li-Fraumeni Syndrome, a mutation that increases risk of "a spectrum of cancers" (Takala, 2000, p 60).

autonomous life, or at least increasing the possibility to do so, is something that presymptomatic genetic testing can promote. Indeed, since this is a reason to do the test, it is seen as a value that presymptomatic genetic testing *should* promote, according to this line of thought.

However, traditionally autonomy has not been considered primarily as a value to promote, but rather as something that gives rise to moral restrictions on how we are allowed to treat each other when trying to promote other things found valuable. If an individual is adult and competent to make decisions, other individuals should not prevent that individual from making decisions and act upon them, at least if she does not violate the rights of others (Locke, 1689; Nozick, 1974) or inflict harm in a wider sense on someone else (Mill, 1859; Glover, 1977). According to this line of reasoning, we thus have a duty (at least of a prima facie-kind) not to restrict the autonomy of others. This, however, does not imply any obligation to help others to be more autonomous or live more autonomous lives. In other words, we have a moral obligation to *respect* autonomy but not necessarily to *promote* it.

This way of thinking about autonomy is the predominant one in biomedical ethics (II.4, III.3). In biomedical ethics, the right to have one's decisions respected is often claimed (III.3). This has been taken as the ground for not being manipulated or coerced into medical treatments. Instead, the patient has a right to know what the treatment is about and a right to accept it or reject it, i.e. informed consent should be obtained from the patient. This is well in line with the idea of autonomy as something that is the foundation of rights or as something that ought to be respected.

However, as indicated, the quotations above express another idea of autonomy: it is conceived of as a value that ought to be promoted. The point is thus not only to respect the patient's wants when trying to promote her health and well-being, but also to enable her to become more autonomous. That is, autonomy is not only the foundation of restrictions of how health care are allowed to treat people, expressed in duties and rights, but a value the promotion of which may provide the very rationale of health care procedures, e.g. presymptomatic genetic testing. However, at the same time, the idea of autonomy founding duties and rights is not entirely cast away. On the contrary, notions of rights "to know" or "not to know" is a recurring theme in the ethical discussion of genetic testing. Such notions will be discussed in chapters to come (IV and V). So, apparently, the idea is that autonomy can both be seen as a value to promote *and* as a basis of restriction of this as well as

other values. This means that promoting and respecting autonomy can conflict in certain situations (see e.g. III.3.3). However, as we will see (e.g. in IV.3.2) some of the rights to genetic knowledge and/or ignorance might be based on autonomy conceived of as value, just as the value of well-being has sometimes been thought to be the basis of respecting autonomy (Mill, 1859; Tännsjö, 1999).

It is far from clear, however, how the notion of autonomy as a value to be promoted should be understood, if it can be made sense of and to what extent it may be combined with traditional ideas of respect for autonomy. We thus need an account of autonomy that allows us to formulate the idea that autonomy is a value that should be promoted, so as to make it intelligible and plausible. For this we need a conception of autonomy and a demonstration of moral ideals with regard autonomy cast in terms of the conception, which develops autonomy as a value to promote. To develop such a conception and try to demonstrate how autonomy conceived of as a value to promote, but also as a right that should be respected, can be formulated by this conception will be the task of the next chapter. I will now proceed with a very brief sketch of this conception and how it may be employed to make sense of the idea of promoting autonomy. Thereafter, I will investigate whether presymptomatic genetic testing does promote autonomy in this sense.

Autonomy, generally characterised, says that to be autonomous is to govern oneself or to decide one's own way. To live autonomously is then to live in accordance with one's own basic desires or values. There are three ways to be less than fully autonomous according to this general characterisation: if one does not or cannot live the life one has chosen to live or if one does not or cannot chose the life one wants to live, or if one's wants are not really one's own.

As will be developed in the next chapter, this means that autonomy is a matter of degrees: a person can more or less lead the life he has chosen and more or less choose how to live according to her own wants. This can be seen on the basis of the following minimal definition of autonomy: a person is autonomous (in a situation) to the extent that she does what she has decided to do, because she has decided to it and decides to do what she wants, because she wants it. Thus, the degree of a person's autonomy is dependent on the want causing the decision and the decision causing the action. Here three components are discernable: will (desire, value), decision, and action. All these

three components determine how autonomous a person is and they can all vary in degree.

First, the desire from which one acts can be more or less one's own, or more or less *authentic*. Generally speaking, an authentic desire is a self-determined desire. How this should be taken more precisely is far from self-evident, but will in the next chapter be identified with the ability to identify with a desire in light of knowledge about oneself and the desire. More specifically, there is nothing about the knowledge of why the person has the desire that would make her inclined to disapprove of having it. The agent can identify herself with the desire, willingly acknowledge that she has it and will not be inclined to abandon it just because she learns new things about herself. Inauthentic desires are desires that one would be inclined to disapprove of having if one were to find out why one has them. The following empirical hypothesis seems to be plausible. Desires that are a result of indoctrination, brainwashing, hypnosis, self-deception, fear, phobias and other psychological pathologies are typically such that we would be inclined to disapprove of, if we were convinced that some of these events were the explanation to why we have the desire. Thus, such desires are less to be counted as "one's own".

Another factor that influences the autonomy of an individual is the capacity to make decisions from one's desires, or *decision competence*. In order to reach a decision, it is not enough to want something. One also has to have beliefs on how to act in order to achieve what one wants. This component of autonomy is thus essentially about beliefs and the ability to choose on the basis of these beliefs and one's wants. That is, what is required is the ability to judge the alternatives one considers in a way conducive to the satisfaction of one's desires, i.e. the capacity of rational deliberation. Decision competence is also a matter of degrees, since one may possess a more or less clear picture of what one wants, how this may be achieved, which options are open in a situation, how these rate in terms of desire-fulfilment, and, on top of this, one may be more or less able to process this information into a decision.

This takes us to the last component in the conception of autonomy: *efficiency*. Efficiency is about acting so that one carries out what one has decided. A number of factors affect the efficiency of a person. One of these is how well founded the beliefs underlying one's choice are. If one has incomplete or erroneous information, one is more likely to take a course of action that is inefficient for the realization of one's decision. Another factor is inner obstacles, for instance in the form of obsessions, that stand in the way of

effectuating one's decisions. Also external obstacles, for instance coercive measures from others, can affect the efficiency component. Other people can also help a person to become *more* efficient by helping to develop the capacities required to effectuate the person's decisions.

As will be elaborated to a greater extent in chapter III, this conception can be used to formulate different, and sometimes competing, ideals of autonomy. Regarding ideals of autonomy that conceives of autonomy as a value that should be promoted, I will present two basic ideals: the ideal of self-realization and the ideal of capacity.

The ideal of self-realization claims that the value of autonomy consists in actually living one's life in accordance with one's basic authentic desires, through one's own decisions and actions. Crudely put, the more a person in fact succeeds in achieving or realizing her basic authentic desires, the more autonomous she is. And the more autonomous the person is (in this regard) the better it is for that person, ceteris paribus. A person's degree of autonomy is then a function of the realized basic desire's authenticity (the more authentic they are, the more autonomous the person becomes given their realization), number and strength in comparison with the non-realized basic desire's authenticity, number and strength. In other words, the more "important" (strong) and "self-governed" (authentic) desires that the person succeed in achieving of the desires she has, the more autonomous she is and, in virtue of this, the better off she is. This ideal captures the idea that the good thing about autonomy is to actually succeed in living the life one wants to live. The decision competence and efficiency of the person will causally influence the extent to which the person is autonomous in this sense. However, decision competence and efficiency does not have to be ascribed a value of their own, according to this ideal.

The ideal of capacity says that the value of autonomy consists in being an *autonomous person*. This is a person with authentic desires, and enough decision competence and efficiency to implement these desires. The autonomous person, then, has the capacity required to independently consider her own basic projects and values, make decisions on the basis of them and realize them through her own action. This ideal is thus to a great extent an ideal of character. An autonomous person is one who is not weak of will, self-deceiving, confused, phobic, irrational, and so on, since all these things tend to destroy autonomy in the capacity sense. This ideal also emphasises not being

manipulated, coerced or in other ways prevented by others to realize one's plans of life. Also this ideal makes autonomy a matter of degree. The more authentic, decision competent and efficient I am, the better for me. The value, then, is to be such a person that *can* be self-realized, i.e. a person possessing such capacities required for self-realization (but not necessarily one who makes use of them).

On the basis of this, we may now pose the question about the extent to which autonomy may be promoted by presymptomatic genetic testing in a more precise way. The issue to address is to what extent such testing would promote self-realization or those capacities of a person that make her capable of self-realization.

2.3.1 Positive values

We have already seen claims to the effect that promotion of autonomy in fact is a possible advantage of presymptomatic genetic testing (II.2.3). The conception and the ideals of autonomy as a value presented here put us in a position to formulate and evaluate these claims more precisely. As will be seen, in terms of self-realization and the capacity for this, these claims actually do seem warranted.

First, presymptomatic genetic testing may result in the index-person realizing her basic desires to a greater extent. Perhaps most obviously, this can be the result of improving the person's efficiency, i.e. the person's ability to implement, through her own action, what she has decided. This is so since presymptomatic genetic testing results in information, the knowledge of which may be relevant to decision-making. And knowledge relevant to a decision can increase the ability to live in accordance with one's basic desires and thus promote self-realization.

In order to further corroborate this, consider the following example. Jill is in her thirties and is facing an important crossroad in her life. She is considering embarking on a new carrier as a doctor and possibly a researcher in medicine. This would require her to complete a very long and arduous education. Up till this time, she has been working as a clerk in a store, an occupation she has been satisfied with and that has left her with considerable spare time to engage in her time consuming hobby, leading an amateur theatre group. She, let us assume, realistically thinks that this hobby would be

incompatible with the career plans and has therefore decided to give one of her cherished projects up. Now, a few years back, her mother was diagnosed with Huntington's disease and the mother's condition is rapidly deteriorating. Jill therefore knows that she may be a carrier, possibly facing the same destiny in a perhaps not too distant future. She is considering going through with presymptomatic genetic testing, since she thinks that the information provided by the test is relevant to her decision of whether or not to embark on the new career. If the test is positive, she suspects that she will not have enough time to complete her education, and certainly not enough time to reap the benefits of it, before symptoms become grave enough.

Let us assume that Jill's assessment of her own capabilities and time is correct: she will not have the time to complete her education if she is a carrier of the gene for Huntington's disease. Let us furthermore assume that both of her projects, the career and the hobby, are basic and authentic, so their achievement would boost her self-realization. Let us furthermore assume that if she does not go through with testing, she will take a chance and start her education. We also assume that, alas, she is a carrier of the gene and that a test thus would be positive. It now seems obvious that the test will help her to realize her basic plans, projects and desires to a greater extent. This is so, since the test will help her to avoid a project she cannot succeed in accomplishing. Faced with the test result, she will gain good reasons for continuing to engage herself in her hobby and stick with her "bread job", something she would have given up for no good without testing.

The general point of the example is the one made by Takala and Chadwick above: the knowledge that can be provided by presymptomatic genetic testing can increase one's ability to plan and live one's life in accordance with one's own basic desires. Now we can see why this is so more precisely in terms of autonomy: knowledge can increase one's possibility to choose a line of conduct that more efficiently realizes one's basic desires. One is more likely to fail in the realization of one's plans if one has false beliefs about one's future. So information can contribute to the efficiency of a person and thus, indirectly, to her self-realization. This is not only true of career planning in particular, but holds generally for all areas in which genetic information may be relevant, e.g. family planning.

In the example of Jill, genetic information from presymptomatic genetic testing helped a person fulfil the ideal of self-realization to a greater extent, i.e.,

helped her live a life that was more in accordance with her authentic and basic desires, than she would have, had she not had access to the information provided by the test. But presymptomatic genetic testing can also help the person to become a more *autonomous person*, in terms of the ideal of capacity. As Jill's example shows, a person may become more *efficient*, i.e. more capable of realizing her decisions, as a result of presymptomatic genetic testing, since the information made her more able to take an efficient route towards her ends.

She may also become more decision competent due to the information provided by the test, i.e. increase her capacity to make choices on the basis of her desires and beliefs. As we have seen, a person's capacity to choose an alternative from her desires and beliefs is displayed in the psychological process of deliberation. This process may be facilitated by more information. For instance, sometimes one knows what one values, but is unsure about how to realize this. More information on how to accomplish such a realization may then make it easier to make a decision on what to do in order to accomplish this realization. One example, similar to the one of Jill, is when one has two central life projects, but only wants to invest the time and effort needed to realize these projects if there is a reasonable chance of success. And, just like the case of Jill, the substantial risk of future (genetic) disease may be crucial to future chances of success for one of these projects. The information of this can then help one, not only making a choice that is more likely to succeed, but to make a choice at all. This is so, since it is sometimes psychologically easier to make a decision if one has enough information to form a more definite picture of what will happen given different decisions. That is, uncertainty may be paralysing and thus damaging to the capacity to make decisions.

Furthermore, genetic information from presymptomatic genetic testing can make a person more authentic, since knowledge in general may be helpful in "making up one's mind", i.e. in seeing and formulating what one really wants. An example that may be interpreted as an indication of this psychological mechanism is the often-cited reports of people asked if they would like to know about their genetic risks (Chadwick et al, 1997, p 2; Takala, 2000, p 58). Many say that they would, but when testing is offered, much fewer actually uses this possibility. One possible interpretation of this behaviour is that at least some of the people who chooses to reject testing once that they can really have it, have more carefully considered what they really wants in light of the knowledge of the possibility of testing. As will be seen in the next chapter,

some plausible views of authenticity would not require that one actually has such knowledge, but only that one would uphold the desire in question if one had it (III.2.2.2).[32] However, in that case, the information can be seen as contributing to decision competence.

Nevertheless, the information resulting from presymptomatic genetic testing can be helpful in exposing some desires as less authentic. Let us change the example of Jill slightly, assuming that once she receives the positive result, she feels a great relief because she now realises that the medical career was not something she really wanted after all. Rather, she begins to understand that this "desire" to have a career was a result of her family's pressure that she "should do something with her life". However, she resisted seeing this when the option of a career was still open. Furthermore, knowledge of genetic susceptibility to disease may also encourage an evaluation of one's basic aims and desires, which may be argued to promote authenticity (III.2.2.2), or at least, the ability of a person to discard inauthentic desires (which may promote efficiency).

So, genetic information from presymptomatic genetic testing can make a person realize her authentic and basic desires to a greater extent and can make her more efficient, decision competent and authentic and, thus, a more autonomous person.

2.3.2 Negative values

The claim that presymptomatic genetic tests can reduce or damage autonomy is less common than the claim they can promote it. However:

> If we understand autonomy... as empowerment ... it might be argued that that genetic knowledge is not empowering, at least not always... (Chadwick, 1997, p 19)

Other have similarly remarked that increased (genetic) knowledge does not necessarily increase autonomy:[33]

---

[32] Even if I myself am inclined to accept the view that actual knowledge would increase autonomy even more (III.2.2.2).

[33] See also Munthe, 2002, p 85.

> The fact that a person receives new and relevant information does not in itself justify a claim of enhancement of autonomy."(Husted, 1997, p 63)

Claims such as these also seem warranted. Perhaps most obviously, the autonomy of a person may be reduced, if she does not understand the information received properly. This is an important point. If the patient receives information without understanding, the information cannot be used to make better predictions about the future and cannot thus be helpful in order to realize her basic aims. In general, misinterpretation decreases the possibility of achieving aims, for the same reason as knowledge increases the possibility: knowledge of what will happen increases and ignorance of this decreases the possibility of taking an efficient route in the realization of one's aims.[34] For instance, interpreting a positive test BRCA1 as indicative of being sick already,[35] or as a certain result that one will be sick in the future, may make one give up plans that one could have realized. Misinterpretation of test results can also result in omission of much needed treatment, if the significance[36] of the test is underestimated, or in unnecessary anxiety and depression, if the significance of the test is overestimated. So, in general, it seems that the positive values of genetic testing are dependent on the proper understanding of them. Otherwise it seems as though they are likely to produce negative values of well-being (anxiety or depression) and autonomy, since, as will be argued shortly, such emotional states may be detrimental to autonomy as well.

Attaining proper understanding is often especially problematic regarding genetic information. This is partly due to the information often being emotionally charged, being as it is about future disease of a, sometimes, terminal nature. Information that is likely to produce powerful emotions of fear and anxiety or of strong relief and joy (should the test be negative) are less likely to be understood properly. Moreover, genetic information is often risk information. The literature on the difficulty of understanding and interpreting genetic risk information is vast.[37] This is not only due to patient's problems understanding risk-information. There is also reason to be cautious of the risk-

---

[34] This point is even more obvious regarding false test results.

[35] Which sometimes happens. See Adelswärd & Sachs, 2002, p 76.

[36] With significance in this context I mean the severity of the disease and the probability for it that the test reveals.

[37] See Adelswärd & Sachs, 2002, for an overview.

estimations in genetics, since there is reason to believe that they often are overestimated (I.4.3).[38]

But even if they are not, and the risk-estimations given are adequate, there are many problems of understanding risk and relating it to one's own decision-making. First, it can be difficult to see the relevance of a numerical risk-figure that is based on genetics and statistical population-studies to one's own situation. But being able to make the connection between a general risk-figure and one's own situation is crucial in order to determine what one should do oneself on the basis of the information. Second, several studies show that people often try to simplify numerical measures to rough estimations, interpreting risks as 'fifty-fifty' when they are not, and translating recurrence rates "into 'binary' views – it either will or will not happen" (Shiloh, 1996, p 88). Third, there is the well-known and often-cited example of people's attitude towards risk being affected only by presenting risk differently: the formulation of risk in "positive" ('X percent chance of survival') or "negative" ('100-X percent risk of dying') terms can affect the estimation of the seriousness of risk, making people more inclined to take the risk if it is formulated positively (Beauchamp & Childress, 2001, p 90). Because of all this, to ensure understanding when it comes to genetic information seems crucial for its prospect of promoting the autonomy of people. I will return to this when discussing genetic counselling (II.3). From this we can also conclude that information as such is insufficient for the promotion of autonomy. It is also necessary that the information have been properly understood. Otherwise, information rather increases the risk of reduction of autonomy.

However, even if properly understood and not confusing in itself, genetic information may still reduce autonomy. In fact, there are at least two ways in which genetic information relevant to a person's decision-making can decrease that person's autonomy. First, avoiding genetic information can be a basic desire. If one receives genetic information while having an authentic and basic desire not to, this is clearly a reduction of one's autonomy. To be true, having one's autonomy promoted in other respects may counterbalance this reduction. However, it is an open question to what extent this should be seen

---

[38] This is so, since the risk-numbers are based on the correlation between a gene and disorder in a population and the selection of the persons that has been investigated are very likely to be biased in favour of a positive correlation, since those are detected first. This is probably true of BRCA1 and BRCA2 (see Adelswärd & Sachs, 2002, p 66 for further references).

as morally justified, since different normative ideas may assess the relative importance of respecting and promoting autonomy differently. This issue will be further clarified in chapter III, and developed in the chapters on rights (chapters IV and V). Second, genetic information can get in the way of realizing one's other basic desires and/or being an autonomous person. Since this other possibility seems less obvious, I will develop it.

There are two ways genetic information can get in the way of realizing one's other basic desires and/or being an autonomous person. First, it may harm one's psychological well-being in a way that has negative effects on the autonomy of a person. Second, it may give rise to "faulty choices".

To begin with the first point, we have seen that presymptomatic genetic testing may have adverse psychological consequences. For instance, it may result in depression. A typical reaction of depression is that it becomes difficult to realize one's plans, since both one's capacity to make decisions and one's capacity to act on these decisions can be seriously impaired.[39] We have also seen that genetic information may result in confusion, which may make it difficult to evaluate one's alternatives, and thus damaging one's decision competence. So, both in terms of the ideal of self-realization and capacity, genetic information may be harmful. To see this, consider the case of Jolene.[40]

Jolene is a writer. Several of her female relatives on her mother's side, including her mother, have contracted breast cancer in their adult years. Therefore Jolene's sister took part in a genetic study, which established that she is a carrier of the mutation BRCA1 (I.4.2). When the study was done, Jolene was asked to test herself. Jolene declined, however. She knows that she has a predisposition for depression. She underwent periods of deep depression in her adolescence, when her mother contracted breast cancer. She then became unable to live an active life for several years. She therefore considers herself to have good grounds for believing that a test that would show her to be a carrier of the gene would make her equally, if not more, depressed. She is on the verge of finishing her great novel. This project she considers to be her most important aim in life. She therefore declines the test in order to be able to realize one of her basic aims of life (which, we may take for granted, is an authentic one too).

---

[39] "Weakness of will" in the sense of lacking the "motivation" (e.g. energy and self-esteem) required to realize one's plans is a part of being depressed. See Smith, 1994, p 120-121.

[40] I will return to this example (see V.3.1.1).

Let us assume that Jolene is not mistaken about her own reaction that a positive result would make her too depressed to finish the book. Assume that a test would be positive, but that if she were to contract cancer eventually without being tested, she would have finished the book before that. In addition, assuming that she has no life plans that would be promoted by testing, she will really realize her basic plans to a greater extent without testing.[41] This means that genetic testing will make her life worse in terms of the ideal of self-realization. Furthermore, since her capacity to act on her decisions and her decision competence would diminish as a result of her depression, she would become a less autonomous person, leading a life worse in terms of the ideal of capacity.

Moreover, even without the negative consequences of well-being that can damage autonomy, information may lead persons to make "faulty" choices in terms of realizing their own authentic and basic goals, thus leading a life that is worse according to the ideal of self-realization. Consider once again the example of Jill, who abandoned the option of education and career in light of a positive test result of Huntington's disease. However, let us change the example slightly, now supposing she had made incorrect estimations of time: in fact, if she embarks on the career option, she will have in fact have time to complete her education and engage in a successful career for some time before symptoms become too grave. If we assume her career plan to be more important to her than her hobby and continue to assume that she will abandon her career plan because of the test result, she will in fact lead a life where she realizes her authentic and basic goals to a lesser degree than she would have without testing.

The example will have the same implications if we instead assume that she has underestimated her capabilities: in fact she is capable of realizing both plans. It is not unlikely that an exaggerated perception of one's future as bleak, manifesting itself in e.g. underestimation of time and capacity, is a result of receiving the "death sentence" a positive test can be perceived as. And the risk of this may increase the earlier before onset one gets the result.

Furthermore, especially positive results may damage one's authenticity, by "forcing" or "tricking" one, psychologically, into seeing some options as more attractive than what is actually reflected by the strength of one's desires. Think

---

[41] This could be true even if she had a negative test result, if we assume that she were paralysed by such a result, due to feelings "survivor's guilt" towards her sister.

about a woman planning to start a family and having children, receiving the result that she is a carrier of BRCA1. This may give rise to a felt obligation not to bring "sick" children into the world.[42] If this feeling is a result of social pressure and fear, rather than considered judgement on what life one wants to lead, acting on this is (probably) to act on an inauthentic desire (III.2.2.1 and III.2.2.3).

2.4 Concluding remarks on the value of presymptomatic genetic testing

We have now seen various positive and negative values presymptomatic genetic testing can realize for the tested person. The positive values are reasons for the person in favour of testing and the negative values are reasons against testing. If one grants the traditional view that the ultimate rationale for providing testing to start with is the value for the tested persons, the possible positive and negative values are also arguments for and against offering testing in the first place.

I have argued that the positive and negative values that I have taken from the existing literature are about well-being and autonomy. However, some of the values that I have discussed are rarely mentioned: perhaps most obviously, the general remarks about genetic information not necessarily being conducive to autonomy (II.2.3.2). The analysis of the conception and different moral ideals of autonomy I briefly presented showed why these general remarks are plausible. I will elaborate further on this analysis in the next chapter, which will further underpin this claim. This, in turn, shows that declining genetic information is not necessarily in conflict with moral ideals emphasising the importance of autonomy, contrary to what some authors have claimed (Harris & Keywood, 2001; Rhodes, 1998). I will return to this in chapters to come (see V.3.1.1).

The discussed values and negative values of presymptomatic genetic testing can be summarized in the following list.

---

[42] This reaction does not seem to be uncommon. See Adelswärd & Sachs, 2002, p 108.

Table II. Positive and negative values that may result from presymptomatic genetic testing (for the index-person that receives the information that results from the test)

Positive values of presymptomatic genetic testing

General (regardless of whether the test is negative or positive)

- Psychological well-being
  - The index-person does not have to suffer the anxiety of uncertainty.

- Autonomy
  - Possibility to plan life in accordance with one's own basic desires (e.g. plans about carrier, family formation, reproduction).
  - Becoming more authentic, competent, and efficient.

Of positive results

- Health-related well-being
  - Preventive measures to avoid, ameliorate or delay the onset of symptoms of genetic disease.

- Psychological well-being
  - The index-person strengthens emotional bonds with other carriers in family.
  - Time for psychological adjustment to cope with the (more or less probable) disease.

Of negative results

- Health-related well-being
  - Avoidance of unnecessary medical procedures that may be harmful.

- Psychological well-being
  - Avoidance of burdensome preventive measures and health controls for the disease in question.
  - Feeling of relief for not being a carrier if one has suspected that one might be before testing.
  - Reduction of anxiety (e.g. for the disease in question, for burdensome preventive measures (if there are any), for stigmatisation, for knowledge of possibility to pass genetic disorder on to children).

Negative values of presymptomatic genetic testing

General (regardless of whether the test is negative or positive)

- Psychological negative well-being
  - Unwelcome change in self-image.
  - Strained family relations.
  - Distressing confusion over content of result.

- Reduction of autonomy
  - Reduced possibility to plan life in accordance with one's own basic desires (e.g. plans about carrier, family formation, reproduction), due to e.g. confusion and depression caused by test result.
  - Autonomy reduction as a direct result of unwanted test result.
  - "Faulty choices" as a result of knowledge of test results.
  - Becoming less authentic, competent, and efficient, due to e.g. confusion and depression caused by test result.

Of positive results

- Psychological negative well-being
  - Anxiety (e.g. for the disease in question, for burdensome preventive measures (if there are any), for stigmatisation, for knowledge of possibility to pass genetic disorder on to children).
  - Depression.
  - Feelings of isolation and self-stigmatism.
  - Loss of well-being due to being stigmatised and discriminated by family or society at large (e.g. insurance companies and employers).

Of negative results

- Psychological negative well-being
  - Feelings of distress for not being a carrier if one has expected that one might be before testing (e.g. feeling not being the proper subject of the care of others, feeling of demanding obligation "to do something with one's life").
  - Survivor's guilt.
  - Feelings of isolation from other family members.

I do not have an ambition to exhaust all possible positive and negative values of presymptomatic genetic testing with this list. Moreover, as the discussion above showed, the specific items on the list are of rather different kinds. For instance, the first item under the heading of general psychological negative well-being mentions "unwelcome change in self-image", which is by conceptual necessity directly detrimental to well-being.[43] On the other hand,

[43] At least according to preferentialism, which will be presented later in this chapter (see II.4.1.2).

the "strained family relations"-item is something that is presumed to cause a reduction of well-being in most cases, while not being a reduction *per se*.

However, despite thus being both heterogeneously organized and incomplete, the list does contain such items that have in fact been mentioned in the debate. Moreover, it should be taken to serve as a rough classification that can be used as a starting point for a fuller and more systematised account of the possible advantages and disadvantages of testing for the index-person. Another important point of the foregoing discussion, which has also governed the organization of the list, is that all the specific positive and negative values put forward in the debate really boils down to two basic and classic values of medical ethics, namely well-being and autonomy. If that argument and the analysis of the values presented here are accepted from a moral point of view, the heterogeneity just mentioned is in fact a chimera. What matters are these two basic values and because of this, we have an instrument to evaluate the practice of presymptomatic testing: it is acceptable to the extent that it is conducive to these values and should be designed to promote them and avoid their reduction.

Of course, it will be difficult in practice to determine whether a certain practice is conducive in this way, since there are methodological problems with predicting the effects of particular tests and to measure the presence of the respective values.[44] Furthermore, in order to determine how the values should be promoted, one has to settle normative questions, for instance about the importance of respecting and promoting autonomy respectively, autonomy as compared to well-being, and the issue of the just distribution of values among the affected parties. These kinds of questions will be repeatedly addressed in coming chapters.

However, the discussion above nevertheless does indicate a number of conclusions of direct relevance to the practice of presymptomatic genetic testing. One such conclusion is that the justificatory basis for some types of testing is weaker than for others. For instance, the basis for performing presymptomatic genetic testing for diseases for which there are no preventive measures whatsoever are weaker than testing for diseases for which there are

---

[44] The measurement of autonomy will be discussed in the next chapter (III.3.2.3). The measurement of well-being is a much debated question. See Resnik, 1987, p 81-100, for a discussion of measurement of preferentialistic well-being and Tännsjö, 1998b, p 67-77 for a discussion of measurement of hedonistic well-being.

such measures (II.2.1). This is so simply because there are no health-related reasons to perform these tests. Since the "therapeutic gap" (I.1), i.e. the gap between our ability to test for diseases and to treat them, is large especially regarding monogenetic diseases, this point applies to a great number of such diseases, for instance Huntington's disease, and some forms of hereditary Alzheimer's.[45]

It would thus be impossible to justify testing for such conditions if the only point of health care was to cure, ameliorate or prevent disease. All this evokes the intriguing but difficult question of what the goals of health care in fact should be, a question far too extensive to discuss here. Nevertheless, it is a question that ultimately must be tackled in order to finally answer if, and to what extent, health care should provide presymptomatic testing. Another result of the discussion is, then, to point out the questions that still need answers.

In addition, the discussion indicates that the justificatory basis for presymptomatic genetic testing becomes weaker the more uncertain the test in question is. This is true of uncertainty in two senses: risk of false positives and negatives, i.e. reliability, and the likelihood of the disease, i.e. predictability. This is so, since the more uncertain a certain test is in any of these senses, the less likely it is to be advantageous and the more likely it is to be disadvantageous in terms of autonomy and well-being. This is so since the more uncertain a test is, the less likely it is to remove possible anxiety of uncertainty and the less useful it will be in making predictions about the future that may be useful for the planning of one's life in accordance with one's own basic desires and the implementation of medical preventive measures conducive to health. And despite the uncertainty of the test, it may still lead to anxiety, depression, feelings of isolation and self-stigmatism, discrimination and stigmatisation. This makes the prospect of defending testing for many multifactorial diseases very bleak indeed, since the predictability of these diseases will be low. This factor might be counterbalanced by the presence of effective preventive measures to take in order to reduce the possibility of onset of the disease in question (if there are any). However, if these measures are burdensome and risky in themselves, it may be argued that either it would be indefensible to apply them on the basis of very uncertain predictions, or they may be applied to people without the need for prior testing.

---

[45] See Harper, 2001, Part II, for further examples.

Another general conclusion that the discussion indicates is that the way and the context in which the test result is disclosed is of the utmost importance for what positive and negative values will be realized. I draw here on empirical research to which I have referred earlier (II.2.2-II.2.3). But it should come as no surprise that e.g. stress can distort decision-making and thus autonomy, and that stress can be evoked by shortage of time or lack of understanding. This emphasises the relevance of the way information is disclosed and the need to have a setting in which genetic information is disclosed in a manner conducive to the values that testing can realize. I will return to this when discussing genetic counselling below. Also, wider concerns of the context of disclosure arise. Societal attitudes will determine the level of stigmatisation that can result from a positive test and societal institutions the level of discrimination. This underlines the point that the context of disclosure will affect to what extent positive and negative values will be realized. I will return to the question of the impact of societal institutions on the value for the individual already in the next section (see II.3.3.1 and II.3.3.2).

Furthermore, a general conclusion is that proper understanding of information seems to be a particularly important prerequisite for promoting the positive values and avoiding the negative values (see II.2.3.2). This is important to notice, since it underlines that the value of presymptomatic genetic testing will not so much be a result of disclosure of information as such. Rather, it is the individual's possibilities to use the information that in various ways can be conducive to her well-being and autonomy and that thus determines the prospect of presymptomatic genetic testing for being a reasonable health care practice at all.

Finally, the discussion reveals that the goals of presymptomatic genetic testing may come into conflict, both within and between persons. First, health-related well-being may be both promoted and reduced by the very same measure taken as a result of testing. For instance, a person may be both damaged and saved as a result of prophylactic mastectomy. Second, there is a potential conflict between health-related and psychological well-being, since a person may be benefited medically but at the same time depressed as a result of presymptomatic genetic testing. Third, there is a potential conflict between well-being and autonomy, to which we will return (see II.3.4.1). Fourth, there are various conflicts of autonomy, for instance since not respecting someone's autonomy at one time may promote her autonomy in the long run, and

respecting her autonomy at one time may reduce her autonomy in the long run. I will return to this possibility as well. Furthermore, all these conflicts may arise interpersonally. Due to all these potential conflicts, there is reason indeed to try to ponder how they should be solved, i.e. to ponder the morality of presymptomatic genetic testing. To start with, we will consider the ethical issues of the practice surrounding much presymptomatic genetic testing: genetic counselling.

3. The value of genetic counselling

As we have seen, the way in which genetic information retrieved through presymptomatic genetic testing is presented can affect the decision-making of the recipient of that information (II.2.3.2). This means that whether or not the positive values of presymptomatic genetic testing are in fact realized, and whether or not the negative values are avoided, depends not only on the content of the information, but also on the manner in which it is disclosed. To be more precise, three factors besides the content of the information seems to be relevant to the perception of genetic information and hence the way it will be subsequently used: the sender, the formulation of the information (the message), and the receiver. The values, beliefs, attitudes, and behaviour of the sender can affect how the receiver perceives the information. For instance, the identity of the sender may be of importance, e.g. if she is regarded as an authority according to the social standards applicable in a particular case. In addition, the values, beliefs, and attitudes of the sender will probably affect what she emphasises and how she presents the information.[46] This regards not only the linguistic form in which the information is presented, but also aspects such as body language. And, as we have seen, the presentation of the information (which, in turn, is affected partly by the sender) can affect the perception of it. For instance, the formulation of risk in "positive" or "negative" terms can affect the estimation of the seriousness of risk (II.2.3.2). Furthermore, the values, beliefs, and attitudes of the receiver will affect her perception of the information, e.g. risk perception is often affected by perception of seriousness of outcome, and not just its likelihood (Michie &

---

[46] The finding of an investigation of the directiveness of genetic counselling indicates this: the explanation to the fact that counsellors tend to be more directive towards those with low socio-economic status indicates that the beliefs and attitudes of the counsellors affects the way they present information (Michie et al, 1997).

Marteau, 1996, p 107). Furthermore, the recently mentioned factor of the sender's identity is, of course, also dependent on the receiver's perception.

Let us call the three factors of sender, message, and receiver the *situation of disclosure*. *Genetic counselling* is a practice that aims at designing the situation of disclosure so that it is conducive to promoting the positive and reducing the negative values of (presymptomatic) genetic testing. It then works under the assumption that *how* information is disclosed and processed is crucial for the realization of this aim. As we will see, studies of the practice of genetic counselling seem to have rendered some empirical support for this assumption.

Much has been said on what genetic counselling is and what the ultimate goals of the practice should be, and not all of these accounts coincide.[47] However, there seems to be considerable consensual overlapping on the nature and goal of the practice.[48] For instance, the following characterisation of genetic counselling is, I think, fairly uncontroversial: "Broadly speaking, genetic counselling is a communication process aimed at helping people with problems associated with genetic disorders or the risk of these in their family."[49] (Michie & Marteau, 1996, p 104)

In the following, after a very brief historical account of the practice of genetic counselling, which hopefully will provide some clarification of why the goals or values of genetic counselling are embraced, I will give a more precise description of what genetic counselling involves, and what the goals of genetic counselling are usually taken to be. I will then consider the ethos of genetic counselling, which I think is most naturally seen as more specific

---

[47] For instance, see Michie & Marteau, 1996, p 104-105 for different definitions of genetic counselling, either in terms of the objectives or the process of the practice. Compare also Munthe, 1999, p 82-85, who emphasises autonomy as the goal of genetic counselling and Brandberg, 2003, who emphasises psychological well-being as the goal of genetic counselling. Further accounts that emphasises different aspects of the practice can be found in Clarke, 1994.

[48] In order to keep within the "received wisdom" on what genetic counselling is and should be, I will draw heavily on Platt Walker, 1998. The fact that her text is a textbook account of genetic counselling should suffice to ensure that the account of genetic counselling is a reasonably "standard" one.

[49] Michie & Marteau, 1996, p 104, thus presupposes that it is the family as a collective entity that genetic counselling aims at helping. I will for now remain neutral on the issues of whether, and what parts of, the family that should be included in genetic counselling and thus assume that the index-person can be alone. The question of whether the family should be included cannot be settled by definition.

norms and rules of thumb, the compliance to which allegedly will tend to promote the goals and values of genetic counselling. As we will see, some of these norms are really about society at large, giving rise to questions about what characterises the good and just society, questions that cannot be tackled within the discussion of the value of genetic counselling.[50] The focus of my treatment will instead be the much-debated idea of *non-directive* genetic counselling. While doing that, I will elaborate some of the possible conflicts of values in general and autonomy in particular. These conflicts will also give rise to larger questions, like what the aims of health care in general should be. I will in this section also say something of how the ethos of genetic counselling should be evaluated. On the basis of this, I will, to some extent, argue that genetic counselling, at least if some requirements on the practice are assumed to be met, can be an efficient way to realize the positive and avoid the negative values of presymptomatic genetic testing.

3.1 The history of genetic counselling

The history of genetic counselling runs parallel to the history of genetics.[51] The rapidly growing possibilities to predict and diagnose genetic disorders have created a need for a practice that can explain and give support to patients who are faced with the suspicion of hereditary disease. Genetic counselling has developed to answer to these growing needs. During the last decades, genetic counselling has developed from an activity normally performed by clinical geneticists to a profession of its own, providing a service that combines elements of the professions of geneticist, social worker, psychologist and administrator (Platt Walker, 1998, p 2).

It is customary to claim that Sheldon Reed introduced the term "genetic counselling" in 1947.[52] He considered it to be vital to provide genetic information while withholding advice, leaving the ultimate decision on what to do to the patient. Another root of today's genetic counselling is psychoanalyst Carl Roger's client-centred psychotherapy, which gave the patient (or client) the role of controlling "the agenda, pacing and direction of therapy" (Oduncu, 2002, p 56) These ideas are clearly connected to the idea of protecting and promoting autonomy being a primary task for genetic

---

[50] However, these kinds of questions will receive some attention in chapter VII.

[51] For an overview of the history of genetics, see Connor & Ferguson-Smith, 1997, p 3-8.

[52] See e.g. Oduncu, 2002, p 54; Platt Walker, 1998, p 2; Resta, 1997, p 255.

counselling: the patient's values and wants should dictate counselling and decisions.

It is a widespread opinion that this emphasis on autonomy and the client taking centre stage is largely due to the eugenics movement and the massive abuses that this movement was responsible for.[53] Eugenics was socially implemented studies and programs, which aimed at improving the "genetic quality" of the population by trying to eliminate undesired traits from the gene-pool. These programs, which flourished throughout the developed world during a large part of the 20th century, were regularly based on ignorance of genetic mechanisms together with the adoption of political agendas of racial or population hygiene. The gross atrocities that were made in the name of eugenics are well documented,[54] ranging from "advising" mentally retarded and social misfits not to reproduce, prohibition of marriage, compulsory sterilisation, all the way to the Holocaust, where 70.000 people with hereditary disorders were murdered, besides Jews and others (Platt Walker, 1998, p 3).

The urge to avoid eugenics has been a strong motivating force in the genetic counselling of today. This explains the strong emphasis on "genetic counselling as a service aimed at meeting the needs of individuals rather than society, the nation, the population, the race, the gene-pool or some other abstract entity." (Munthe, 1999, p 82) This also explains the emphasis on autonomy, leaving it entirely up to the individual what decisions, including reproductive one's, to make in the light of genetic information.

3.2 The nature and goals of genetic counselling

If there ever were a standard account of what genetic counselling is, it must be the following often-cited one[55] from Fraser, 1974, that was adopted by the American Society of Human Genetics in 1975:

---

53 Resta, 1997, p 257, seems to deny this. He argues this by showing that Reed and other clinical geneticists responsible for the practice of today still had "eugenic" opinions. However, this seems to me to be compatible with wanting to avoid eugenics by focusing on patient's autonomy. I rather think that they favoured what Platt Walker, 1998, p 3, calls the medical/preventive model of genetic counselling, which has some paternalistic features.

54 The objective here is not to present or discuss the massive literature on eugenics or its effects on today's genetic counselling, but only to provide a brief background on why autonomy and individual well-being is at the heart of genetic counselling. For further reading and references, see Buchanan et al, 2000, p 30-40.

55 See e.g. Michie & Marteau, 1996, p 104-105; Oduncu, 2002, p 54; Platt Walker, 1998, p 5.

> Genetic counseling is a communication process which deals with the human problems associated with the occurrence or risk of occurrence of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family to: (1) comprehend the medical facts including the diagnosis, probable course of the disorder, and the available treatment, (2) appreciate the way heredity contributes to the disorder and the recurrence in specified relatives, (3) understand the alternatives for dealing with the risk of recurrence, (4) choose a course of action which seems to them appropriate in the view of their risk, their family goals, and their ethical and religious standards and act in accordance with that decision, and (5) to make the best possible adjustment to the disorder in an affected family member and/or to the risk of recurrence of that disorder. (Fraser, 1974, p 637)

This account has sometimes been described as a "definition" of genetic counselling (Michie & Marteau, 1996, p 104; Platt Walker, 1998, p 5). I will not enter a debate on whether it is a definition in the rigid traditional sense of strictly necessary and sufficient conditions for the proper application of a notion in every possible situation. It could for instance be questioned if the emphasis of the family as the receiver of the counselling ought to be considered necessary in order for it to be genetic counselling. I will for now remain neutral on the issues of whether, and what parts of, the family that should be included in genetic counselling and thus assume that the index-person can and, perhaps, sometimes *should*, be alone. The question of whether the family should be included, even if they often are from the start, is a difficult moral problem that cannot be settled by definition. It could also be questioned whether "to make the *best possible* adjustment to the disorder" is a necessary condition, since it seems to imply a too narrow scope of the definition; presumably, rather few instances of what is commonly viewed as genetic counselling lead to the *best possible* (whatever that means) adjustment.

However, engaging in the enterprise of finding a traditional definition will most likely not be fruitful. This is so partly since genetic counselling is a practice that changes over time, and there is probably no way to encode the necessary and sufficient conditions of (changing) practices in an uncontroversial way. More importantly, such an enterprise would be beside

the point, since the focus here is on the goals and ethics of the practice. The above-mentioned standard account of genetic counselling is perhaps not flawless in the sense of providing a crystal clear traditional definition, but it is clear enough as to give an account of what is being discussed so as to enable us to evaluate the practice.

Having said this, the reason why this general *characterisation* of genetic counselling has become so popular as to be "subsequently adopted by the society" (Platt Walker, 1998, p 5) is that it contains the most commonly held *components* and *goals* (or values) of genetic counselling in its contemporary form, i.e., an account of how, according to currently accepted standards, genetic counselling is to be performed and what it should accomplish.

Regarding the *goals* or values of genetic counselling, they are most commonly interpreted as being the same as those for presymptomatic genetic testing, namely autonomy and well-being. This is perhaps most clear in point 4 of the characterisation: "choose a course of action which seems to *them* appropriate in view of *their* risk, *their* family goals, and *their* ethical and religious standard and act in accordance with that decision." (My italics) This is naturally seen as an "emphasis on the client's autonomy in decision making" (Platt Walker, 1998, p 5), since such decisions are considered to be "*appropriately*... different depending on the personal, family, and cultural contexts in which they are made." (Ibid.) That is, it is as it should be when the values and standards of the person(s) tested are directing the counselling: "Today... the main objective of genetic counselling is to help individuals to make decisions in accordance with their own basic aims and desires – i.e., to promote and protect the patient's personal *autonomy*." (Munthe, 1999, p 82)

However, even if autonomy then certainly is one main objective of genetic counselling, the characterisation of genetic counselling indicates that there are others too. Point 5 makes the goal of making "the best possible adjustment to the disorder" explicit, which is naturally interpreted as helping the index-person(s) coping with the consequences of the disorder and knowledge of it. This interpretation is widely acknowledged: "there should be a *psychotherapeutic* component of genetic counseling" (Platt Walker, 1998, p 5. My italics) "The goal [of genetic counselling] is to give the ability to use genetic information in a way meaningful to the person that *reduces psychic stress* and increases personal control." (Brandberg, 2003, p 89. My translation and italics) "Its [genetic counselling's] most uncontroversial goal is to improve the quality of life of the

families that seek such help" (Michie & Marteau, 1996, p 104. My italics). All this is well in line with the value of psychological well-being presented earlier (II.2.2).

The *components* of genetic counselling become intelligible in light of these values. Firstly, the characterisation says that genetic counselling is a "communication process". The communication-part indicates that it is a question of interaction between the counsellor and counselee, rather than the doctor telling the patient what the medical condition is and what she should do about it. This is also how genetic counselling is seen (Platt Walker, 1998, p 5). And it is well in line with the autonomy-inspired idea that it is the values and concerns of the person that should govern genetic counselling. The process-part indicates that genetic counselling "ideally takes place over a period of time so that the client can gradually assimilate complex and potentially distressing information." (Ibid.) This is well in line with the psychotherapeutic idea of promoting well-being, as well as autonomy, since, as we have seen, psychological "ill-being" can damage autonomy (II.2.3.2).

Secondly, according to Fraser's characterisation, the counsellor should be "one or more appropriately trained person". The idea is that the complex information that is communicated and the sensitivity of the process of doing so requires not only knowledge of genetics, but also pedagogic skills to ensure comprehension or *understanding* (which is mentioned rather than just *disclosing* information), caring skills of helping the patient to cope with psychological and social consequences in order to accomplish the goals, and so on. Acquiring such a blend of skills will presumably require some training.

Fraser also mentions a number of more concrete components of genetic counselling, stating what stages the process involves. The process can roughly be divided into two parts: pre-testing and post-testing.[56] Pre-testing refers both to the process before the decision whether or not to take the test and the actual testing situation. Pre-testing involves *information gathering* (Platt Walker, 1998, p 9), both information of a "medical" kind and information of more "psychological" and "social" kind. Usually, in order to determine the medical

[56] There are genetic analyses made without molecular or other biochemical testing, most notably by making a pedigree of a family history of disease. For those cases, it is more appropriate to talk about pre- and post-analysis. However, these kinds of genetic investigations are not discussed in this context, and neither is testing for other purposes than predicting onset or risk thereof, e.g. diagnostic testing.

indication supporting the suspicion of risk for genetic disorder, the medical history of the patient and often also the family members[57] need to be gathered.[58] This normally results in a pedigree (Harper, 2001, p 5-9), i.e. a family tree containing the relevant genetic information about the relatives. Furthermore, in order to help the patient with achieving her aims and coping with result of the test, the counsellor needs to investigate the aim of the patient, what she expects to learn from testing, how she is likely to respond to different test results, what her fears and hopes are, and so on. The patient must be informed about possible outcomes, not merely in terms of risk for disease for herself and involved family, including potential children, and available preventive measures and treatments, if there are any (point 1-3 in Fraser's characterisation), but also in terms of psychological reactions and social and economic consequences (important to achieve point 4 in the characterisation). She must also be informed of means of support to cope with such consequences (point 3 and 5 in Fraser's characterisation).

If the patient decides in favour of testing and testing is subsequently done, then enters the stage of post-testing. Post-testing involves *information giving* (Platt Walker, 1998, p 10) of risk for disease. But post-testing may also include psychological counselling and other means of support from the counsellor (Platt Walker, 1998, p 10) in order to handle the possible psychological effects of learning the result, such as distress, anxiety, guilt and strained family relations (II.2.2.2).

3.3 The ethos of genetic counselling

Genetic counselling has developed its own norms or principles, what could be called the "ethos" of genetic counselling (Platt Walker, 1998, p 7). The most natural way to think of these norms, I believe, are as more specific action-guiding norms the compliance of which allegedly will tend to promote the overall values of genetic counselling, namely autonomy and well-being. There are several reasons to think of the ethos of genetic counselling in this way. As we will see, one reason is that the norms of the ethos often are justified in this

---

[57] I will return to the question of whether this should mean that the consent of the relative has to be obtained in chapter VI.

[58] This is not to say that it is obvious that testing should be denied if there is no medical indication whatsoever. If psychological well-being is a major rationale for testing and testing is the only way of improving the psychological well-being of the index-person, there is at least a good reason for testing (even if there may be reasons against testing as well).

way, primarily with reference to autonomy. Another is that these justifications often seem reasonable, especially if one refers to the conception and ideals of autonomy adumbrated earlier in this chapter (II.2.3) and further elaborated in the next one. Moreover, if one conceives of the ethos in the way, one will have a critical tool for assessing the norms, seeing more clearly how they should be interpreted and when and how they should be complied to.

What, then, is the ethos of genetic counselling? Well, there probably are several ways to carve up the moral territory. I will use one way that I find to be relatively clear and exhaustive, namely Platt Walker's, 1998, p 6-9, textbook account used in the training of genetic counsellors. This account distinguishes between seven norms of genetic counselling, making up its ethos: voluntariness, equal access, client education, complete disclosure of information, non-directiveness, attention to psychosocial and affective dimensions, and confidentiality/privacy. I will discuss "client education" and "complete disclosure" under the same heading.[59] In addition, complete disclosure will be discussed under the heading of non-directiveness, since it should be viewed as a part of that norm. Voluntariness and equal access will be argued to be about society at large, leaving us with additional questions about the good and just society, questions that are left open. However, the norm that has received most attention is the one about non-directiveness, "perhaps the most defining feature of genetic counseling." (Platt Walker, 1998, p 8) Therefore, I will focus on that norm, treating the others more schematically.

3.3.1 Voluntariness

The core idea of voluntariness in this context is that the decision to use genetic services, including presymptomatic genetic testing, should be voluntary, i.e. entirely up to the individual herself. However, how this idea should be understood is far from evident. Voluntariness could be construed in libertarian terms (see IV.2.2.1 and VII.5.2.2), claiming that decisions are voluntary if they are made without coercion, i.e. threats of sanctions or outright force, and without deception. However, a more extensive idea of

---

[59] "Client education" would have deserved its own heading if it explicated the idea that only disclosing information is insufficient: one also has to ensure proper understanding of it. But in Platt Walker's account "client education" just contains an enumeration of various types of information that should be explained, and may therefore be seen as a part of the requirement of complete disclosure. The requirement of understanding might then just as well be discussed under the heading of "complete disclosure" as in Platt Walkers account, p 7-8.

voluntariness seems to be at work here, requiring that decisions about genetic testing should be "unencumbered by pressure or any intimation that a particular course of action is fiscally or socially irresponsible." (Platt Walker, 1998, p 6)

Consider a destitute single woman who is aware of having a substantial genetic risk of giving birth to a disabled child,[60] who cannot expect financial or other support from society or otherwise, and who thus would have very grave difficulties in meeting the needs of this child. Given the extensive idea of voluntariness, her decision to take the test (assume that this is free of charge) and terminate her pregnancy if genetic risk is detected is probably not voluntary, since there is serious "fiscal" pressure on her to take the test and to terminate the pregnancy should the result of the test turn out positive. The same goes for someone who has to take a test in order to get a private health insurance in a society where private health insurance is necessary to get health care at all. Another kind of pressure incompatible with the extensive idea of voluntariness is a society where everyone finds it morally irresponsible not to take various genetic tests when pregnant and therefore express strong dislike of those who elect not to take such tests.

Obviously then, the norm of voluntariness is not so much about genetic counselling as an isolated practice, but about society as a whole. This is so, since whether the practice can fulfil the norm depends on society as a whole, as these examples demonstrates. Of course, the cherishing of voluntariness is a result of the insight that decisions to take or abstain from taking a genetic test is sometimes made for other reasons than personal goals and well-being, e.g. out of (at least perceived) economic necessity (see VII.2.3). If the norm of voluntariness were confined to genetic counselling in isolation from the surrounding circumstances, requiring that the counsellor should abstain from coercion, manipulation, bias, and other kinds of pressure to affect the decision-making of the patient, it would collapse into some norm of non-directiveness (see II.3.3.5).

However, in light of the idea of autonomy as a value to promote, it becomes intelligible why the extensive norm of voluntariness is favoured as a part of the ethos of genetic counselling. If a crucial goal of genetic counselling is to make people live their lives more in accordance with their basic aims, or

---

[60] For instance, imagine that she knows that she is the asymptomatic carrier of the mutation for Fragile-X (see I.4.1).

at least to enable them to do so, this goal will be compromised if there is a strong societal pressure to make certain kinds of decisions over others, since these decisions may not be in accordance with these aims. Take the example of someone who desires to find out whether she carries the mutation for Huntington's, but refrains from finding this out due to risk of not being able to purchase health insurance.[61] At least one of her aims will thus be compromised as a result of the design of society. The important point here is that whether the goals of genetic counselling can be accomplished is not only determined by genetic counselling, but also by the structure of society at large. So, rather than being a norm for the practice of genetic counselling as such, e.g. saying something about how genetic counsellors should behave, voluntariness expresses a norm for society at large that most likely has to be fulfilled in order for the values of presymptomatic genetic testing to be realized for all those tested.

3.3.2 Equal access

Roughly, the norm of equal access says that genetic testing and counselling should be equally available to all those who want it. Like the norm of voluntariness, the norm of equal access is not really about the internal design of genetic counselling, but rather addresses the design of societal institutions. What kind of access to genetic services that society should implement is a question of justice, since it is one about the distribution of the goods of genetic testing and genetic counselling. I will say more about the question of justice in later chapters, which at least has indirect bearing on the question of the distribution of genetic testing and counselling. I will thus leave it for now, just making a few remarks.

First, the norm of equal access is not taken in a politically neutral way. Platt Walker, 1998, p 7, claims, for instance, that "genetic services... should be available to all who need and choose to use them" and "they are to be available to *all* who might benefit". What is claimed is a positive rather than a negative right to genetic services. That is, equal access is not only taken to mean that no person should be prevented from using genetic testing and counselling, but that everyone who wants and needs it should have access to it, regardless of e.g. ability to pay (Platt Walker, 1998, p 7). As will be seen in later chapters, this

[61] I will return to this (see VII.2.3).

idea is not compatible with some influential ideals of the just society – in particular libertarian ideas (see VII.5.2.2).

Second, the norm of equal access is ambiguous. For one thing, it is unclear whose access it is that should be equal. Is it enough to want and ask for the test in order to have a legitimate claim to equal access or should access be granted only to persons fulfilling additional conditions, like e.g. severity of condition, medical indication, and other parameters of "need"? Furthermore, it is unclear what equal access implies. For instance, is there equal access if not everyone knows that the services exist? In one sense there is, since everyone will get the service if they ask for it (at least given some other conditions, e.g. medical indication). In another sense there is not, since you will not ask for the services if you do not know that they exist. In fact, this would mean that only informed people, presumable mostly well-educated urban people, would use the service. This could be claimed to be incompatible with equal access in the normatively interesting sense.[62]

Third, since the number of possible tests is growing rapidly, more and more persons most likely will use them. This will make it more and more expensive to ensure equal access, giving rise to questions of distribution between genetic and other health care services. So, numerous questions of justice are actualised by the norm of equal access: should the wealthier individuals be obliged to support the poorer in order to reach the ideal? Should resources be invested in letting everyone know about the services? How should we distribute resources between genetic and other services? I will not try to answer any of these questions, but rest content with pointing out that some norms of genetic counselling gives rise to them and that they merit further investigation. Furthermore, trying to arrive at an answer by applying the values (of genetic counselling) of well-being and autonomy will only take us so far, since they need to be supplemented with normative principles: should the values be maximised or distributed equally or what (see III.3.2)? Finally, even if one has resolved such issues, it will be hard to know what to do. If one finally opts for, say, maximisation as an answer to the normative question, there remains the difficult question of how genetic services should be distributed in order to maximise the net sum of autonomy and well-being.

---

62 Since Platt Walker, 1998, p 7, points to e.g. the factor of education as a problem for equal access, she would probably claim this.

The question of the value of genetic counselling thus gives rise to broader issues of the good and just society. This connection calls for further investigation in the relation between the ethics of genetic counselling, and other health care services, and society at large. This task seems to me too huge to tackle in this context and I will therefore leave it for now.

3.3.3 Attention to psychosocial and affective dimensions

This norm does not only say that patients should be informed about possible psychological and social consequences of genetic testing but also that genetic counsellors should help them in coping with these consequences, which may require "long-term therapy" (Platt Walker, 1998, p 4). This emphasis on psychosocial and affective dimensions is a more recent development in genetic counselling and a response to a previous emphasis on providing genetic information and abstaining from advice (Platt Walker, 1998, p 3-4).[63] The reason for this shift in emphasis is that the disclosure of genetic information from genetic testing can and sometimes does have the negative effects on autonomy and psychological well-being discussed earlier (see II.2.2.2 and II.2.3.2).[64]

By attending to psychosocial and affective dimensions, possibilities to promote patient's autonomy and well-being can then be improved in several ways. First, by learning about possible detrimental consequences due to societal institutions, e.g. lack of private insurance, patients have more information relevant to their decision and can avoid testing options that are considered to be too detrimental. Second, by considering the patient's psychological and social, e.g. family, state pre-test, patient and counsellor can communicate in order to enable the patient to make decisions that is not too distressing or damaging to important relations. Third, pre-test, therapy with the counsellor, or with someone referred to by the counsellor, can be helpful in order for the patient to be become more clear about what she really wants, which can be conducive to autonomy (II.2.3.1). Fourth, post-test, the counsellor

---

[63] Michie & Marteau, 1997, points to investigations showing that "patients presents emotional and social agendas to a greater extent than do doctors" (p 113).

[64] See also the story of the anonymous woman in Marteau & Richards, 1997, who considers testing for BRCA1: "I feel that the doctors and consultants I have met as a result of my cancer story do not appreciate the inner feelings I have; they have all been very matter of fact" (p 38). This indicates an overestimation with medical facts and underestimation of attention to psychosocial and effective dimensions in some counselling.

can support the patient and his family emotionally, for instance through therapy, or by referral to therapy. Fifth, the patient's social, cultural, educational, economic, emotional, and experiential background influences the way in which she understands and copes with test results, and awareness of this in counselling is necessary in order to help the patient with understanding and coping. And, as we have seen, proper understanding is important both to realize patient's well-being and autonomy (II.2.3.2).

3.3.4 Confidentiality and protection of privacy

Privacy regarding genetic information is respected when the individual controls who has access to this information. This idea relates to confidentiality, since breach of confidentiality consists in further disclosure of information without the consent of the patient. Since issues of privacy and confidentiality are actualised only when there is a reason to breach confidentiality to protect some vital interest of relatives or third parties, I will discuss the question of privacy and confidentiality in these contexts (see VI.2.2). We will then see that the scope and content of this norm is far from evident. However, it is common to assume that the basis of respecting privacy and confidentiality is patient's autonomy and the consequentialistic concerns of upholding trust in the doctor-patient relationship (Husted, 1997, p 56; McGleenan, 1997, p 44). The norm is thus well in line with the idea of autonomy and well-being being the basic values of genetic counselling.

3.3.5 Non-directiveness

There are controversies about the meaning of non-directiveness (Oduncu, 2002) and doubts have been expressed whether it is a plausible, or even feasible, norm for genetic counselling at all (Clarke, 1991; Lippman, 1991). However, there seems to be consensus on the view that the point of non-directiveness is related to concerns about the patient's autonomy. The idea is not only that the decision of the patient should be respected, i.e. the traditional one in biomedical ethics, but also that "ND [non-directiveness] describes procedures aimed at promoting the autonomy and self-directedness of the client." (Kessler, 1997, p 166)[65] This calls for developing a conception of

[65] See also Munthe, 1999, p 82, describing the objective of genetic counselling and non-directiveness as being "to promote and protect the patient's personal autonomy", and Oduncu, 2002, p 61, discussing non-directiveness in genetic counselling: "the duty of the counselor is, primarily, to empower the patient/client to make autonomous decisions."

autonomy as a value that, besides calling for respect, is to be actively promoted, a task that, as mentioned earlier, will be undertaken in greater detail in the next chapter. Although the promotion of well-being is another goal of genetic counselling, it is not as salient as autonomy in the discussion of non-directiveness. Since non-directiveness is often held to be the primary norm of this practice, this seems to indicate some favouring of autonomy over well-being as the overarching goal of genetic counselling.

Despite the above mentioned doubts about the plausibility of the norm of non-directiveness, it seems to be widely acknowledged among practitioners of genetic counselling.[66] However, this may be due to the fact that the concept of non-directiveness has not been very precisely defined - the wide acknowledgement thus perhaps revealing a verbal rather than a substantial agreement on the plausibility of the norm. But even if there are differences as to how non-directiveness is conceived of, some components of non-directiveness are recurrent. In order to get things off the ground, I will use a characterisation of non-directiveness put forward by Henk ten Have, which I think captures these components:

> Accurate information should be provided to the person concerned regarding the nature of potential genetic conditions, the prognosis, possible treatments and preventive strategies. The experts providing such information should not, in any respect, try to influence decisions made by persons who are counseled or screened. The moral ideal underlying this practice is value-neutrality. The genetic expert is withholding any normative judgement regarding the obtaining and application of genetic information; his aim is merely to provide information and to help the patients or clients to work through possible options.[67]

Three components, of which the third can be seen as a part of or a clarification of the second, can be discerned in this characterisation of non-directiveness. First, there is the provision or disclosure of information. In ten Have's characterisation of non-directiveness, the emphasis is on genetic and

---

[66] Extensive surveys of genetic counsellors reveal this: 90% in one study considers non-directiveness as appropriate in genetic counselling in one study, and 96% considers it as very important in another (Oduncu, 2002, p 56-57).

[67] ten Have quoted from Oduncu, 2002, p 56.

other kinds of medical information, but additional kinds of information may be relevant to the patient's decision-making in the context of genetic counselling, e.g. psychological and social information. The traditional lack of recognizing the relevance of such kinds of information has led to an increased focus on these other kinds of information, i.e. attention on the psychosocial and affective dimensions (III.3.3.3). So the aim of non-directive counselling should be "to see to it that the decision they [the patients] make are based on as full, correct, precise, relevant and comprehensible information as possible". (Munthe, 1999, p 82) This could then be called the idea of complete disclosure of information. That idea merits a discussion of its own, and therefore I will return to it below.

Second, there is the emphasis on abstaining from (attempts to) influence the decision of the patient. Third, in abiding by the norm of non-directiveness, the counsellor (or other "expert") "is withholding any normative judgement regarding the obtaining and application of genetic information" (Ibid.) or, rather, *should* withhold such judgement. It is unclear whether withholding normative judgement is sufficient for avoiding illegitimate influence or if it is only a part of such avoidance. The addition of "in any respect" when talking about influence indicates that abstaining from normative judgement is not sufficient, since there are other ways to (try to) influence the decisions of others.

However, avoiding any influence over the patient seems to be (almost) impossible, a fact that is widely acknowledged.[68] Just by presenting some information, a patient's decision can be affected. For instance, revealing some piece of information about preventive measures, previously unknown to the patient is not unlikely to influence her decision, e.g. to use that measure. There are other more subtle ways of influencing, e.g. by the way information is presented (through choice of words, body language, etc). So non-directiveness in the sense of avoiding *any* influences *whatsoever* on the patient's decision is neither a feasible, nor a plausible (see below), ideal for genetic counselling.

There are two ways of reacting to this criticism: either by denying the importance of the norm of non-directiveness (Clarke, 1991; Lippman, 1991) or by trying to reformulate it in a way that makes it feasible and plausible. Kessler adopts the second route, defining non-directiveness directly in terms of its

[68] See Oduncu, 2002, for a discussion and further references regarding this.

goal, namely the promotion of autonomy: "ND [non-directiveness] describes procedures aimed at promoting the autonomy and self-directedness of the client." (Kessler, 1997, p 166)[69] I think the route of trying to reformulate such a widely cherished ideal is to be preferred to the discarding of it, at least if it can be justified with reference to the basic values of the practice and if it is helpful for guiding practical action. Kessler's definition has the first property, but in order to be action-guiding, it must be supplemented with regard to what autonomy is and how to act in order to achieve the aim. Without a more precise idea of autonomy, we will not have a way of determining whether some type of behaviour is promoting autonomy, and without a more precise idea of how to act in order to realize autonomy, the definition is not so much a norm as a repetition of the idea that the aim of genetic counselling is autonomy. As mentioned, in the next chapter, I will specify a fuller conception of autonomy and above, I have said some things about how genetic testing and counselling can promote autonomy in this sense (II.2.3.1). This leaves us with the second task of describing in what way one should act in order to be non-directive. That is, the task is to take a stand on the various ways in which genetic counselling is supposed to be non-directive and see if it indeed should be non-directive in these ways. I will now enumerate various ways in which genetic counselling can be claimed to be non-directive and evaluate these in light of the value of genetic counselling that is supposed to be promoted by non-directiveness, i.e. autonomy.

First, non-directiveness should not mean that information that is not asked for by the patient and which is not part of the prior reason for testing should not be disclosed. This will be demonstrated when discussing complete disclosure of information below. For now it is enough to say that such information may help the patient to realise that she has options she had not previously considered. For instance, the recognition of the option to use PGD in order to avoid a child with Tay-Sachs may help a couple in realizing their plans of starting a family.

Second, non-directiveness should not mean that counsellors should abstain from giving other information than genetic, since we have seen that psychological, social, economic and other kinds of information can be crucial

---

[69] Kessler defines directiveness as deliberate deception, threat or coercion (Kessler, 1997 p 165-166), which makes much communicative behaviour neither directive or non-directive, since it neither contains deception, threat or coercion or promotes autonomy.

for the formulation of realistic and efficient plans. Neither should non-directiveness mean that counsellors should behave in an emotionally detached manner, withholding support from the patient in her decisions. Actually, persons with experience of counselling emphasises the need of "support to families whatever their decisions may be." (Harper, 2001, p 15)[70] This should come as no surprise, since such support is important in order to cope with possibly paralysing psychological reactions, as we have seen.

Third, traditionally, a common interpretation of non-directiveness has been counselling without *advising* or *recommending* the patient what to decide (Munthe, 1999, p 82; Oduncu, 2002, p 54). However, giving advice can in fact promote the patient's autonomy, and in various ways. For instance, the counsellor's giving advice can be conducive to the authenticity of the patient's desire. Consider the following statements: "[S]erving the patient's autonomy may even include recommending her to see a psychologist in order to *get a better grasp of what she actually is trying to achieve*, so that the counsellor can act in her own best interests." (Munthe, 1999, p 85. My italics) "[T]he doctor's role is to help clarify the *values*, *possibilities* and consequences and, so far as possible, *create valuable options* suited to the individual's unique situation." (Husted, 1997, p 63. My italics)

It is obvious that these authors are not solely concerned with autonomy in the sense of respecting decisions or improving the possibility to achieve already formulated aims. Rather, they are concerned with the process of *formulating* desires, aims, and values. This process is best cast in terms of authenticity, since authenticity is precisely about the "self-determination" of the desires, aims and values of the person. This is why genetic counselling needs an idea of authenticity, and for this reason, I will formulate and defend one in the next chapter (II.2.2). One idea that will be proposed in that context is that the process of critically evaluating one's basic desires makes them more authentic. This can be done, for instance, with the aid of a genetic counsellor or a psychologist referred to by a genetic counsellor. Thus, the advice to go through with such a process can increase the authenticity of the person. Another way in which such advice from a counsellor can promote autonomy is by securing that the patient actually acts on desires that are truly *hers*,

---

[70] This does not mean that counsellors should explicitly say the words "I will support any decision you make", since this can come through as a reminder of the professional's greater power, creating an emotional distance (Kessler, 1997, p 170). Rather, support should be expressed, also by helping the patient go through alternatives she maybe has not thought of.

something that will make acting more efficient in autonomy terms (see II.2.3 and III.2.4).

Advice can also help the individual's capacity for autonomy, thus making her a more autonomous person according to the ideal of capacity (see II.2.3 and III.3.1.2). For instance, advice to see a psychologist leading to therapy can help people in coping with paralysing emotional distress, helping them to become more decision competent and capable of efficient action. Since a more autonomous person is more likely to actually succeed in leading a more autonomous life, advice may thereby also help the person in realizing her aims in accordance with the ideal of self-realization (see II.2.3 and III.3.1.1).

So abstaining from advice should not be an integral part of non-directiveness.[71] Rather, it is a certain *kind* of "advice" that one should have in mind when being critical against advice-giving from the counsellor, namely advice aimed at making the patient decide in one direction *regardless of the desires, aims, and values of that patient.* But the promotion of the patient's autonomy consists in successfully assisting the patient in realizing her desires, aims, and values, or at least enabling her to do so. If the counsellor disregards these desires, aims, and values, she will not succeed in this assistance, other than perhaps by pure luck. But then the problem is not advising, or in other ways influencing the decision-making of the patient, but disregarding the basic aims of the patient. Information and advice given should then be given in the light of the aim to promote the patient's deciding and acting on her own basic aims.

Problems thus arise when the counsellor brings her own normative agenda to counselling sessions. When this happens all kinds of influence, not just advice, becomes problematic. Overemphasising the risk of certain alternatives while playing down risks of others, failure to bring out certain information about possible consequences (including psychosocial), manner of behaviour, like expressing, however subtle, discontent when patients want to develop certain aspects, are all examples of ways of illegitimately influencing the decision of the patient. These ways of acting are even more problematic in terms of autonomy than open advice and even open condemnation, since they are more manipulative by being less overt and thus more difficult to detect and react against. They are also damaging to authenticity, since an open communication without prior ideas of what is desirable for the patient from

---

[71] This is also increasingly recognized in the discussion about genetic counselling. See Shiloh, 1996.

the counsellor is important in order for the patient to be able to make up her own mind about what she really wants.

The conclusion of all this is that the sound core of non-directiveness is abstaining from certain kinds of influence, but embracing other kinds. Roughly, all influence should be exercised only in order to assist the person in becoming more autonomous, letting the desires, aims, and values of the patient guide the counselling.[72] I will not take a stand on whether it is the ability to realize one's aims (the ideal of capacity) or actually succeeding in doing so (the ideal of self-realization) that is to be the aim of genetic counselling.[73] This will depend on which of these ideals (if any) are plausible in the end.

When it comes to the practical question of how to achieve this kind of non-directiveness, training in counselling skills and practical experience of counselling is essential. Since I have no expertise in either, I will not say anything about the more practical sides of this. Experienced counsellors have done that with much more accuracy than I could ever hope to achieve (Kessler, 1997; Harper, 2001). The aim in this context is restricted to provide a standard of evaluation for genetic counselling practices, and indicate in a very general way how it may be used to evaluate, and make more precise, norms like non-directiveness.

Before moving on, one note must be added about the limits of non-directiveness. There may be actual limits on non-directiveness, due to pressure from society at large to decide on one alternative rather than another. This was discussed under the heading of voluntariness earlier in this section. However, there may be actual normative limits of non-directiveness, due to alleged duties of disclosure primarily to relatives. This possibility will be discussed in chapter VI.

---

72 Kessler makes the same point, Kessler, 1997, p 169-170.

73 Different authors seem to have different intuitions. When discussing genetic counselling, Munthe says "The essential thing is that such activities have the effect of promoting and protecting the patient's autonomy, i.e. her *ability* to attain and fulfil her own basic aims and desires." (Munthe, 1999, p 85. My italics.) This points to the ideal of capacity. Compare to Husted, 1997, p 62, who, when discussing disclosure of genetic information, says: "what primarily has value is the autonomous life, the value of autonomy in the capacity sense being only contributional to this", pointing to the ideal of self-realization.

Complete disclosure of information

There is still the question of the first component of non-directiveness: disclosure of information. It is commonly assumed that "all relevant information should be disclosed" (Platt Walker, 1998, p 7) to the patient in genetic counselling. This assumption leads to two related questions: Why should all relevant questions be disclosed? What information is relevant? Not surprisingly, the answer to the first question is in terms of "individual's autonomy" (Ibid). This also provides an important clue to the answer of the second question. Since autonomy is an overarching goal of disclosure, it becomes natural to say that "any information *relevant to decision making* in ways that the client can interpret and act on" (Platt Walker, 1998, p 8) should be disclosed. The underlying line of reasoning to this interpretation of "relevant information" should be familiar by now: if a person has information relevant to decision-making she is more likely to decide on a course of action that is efficient in realizing her basic aims. To abstain from disclosing this information is then to decrease the possibility of accomplishing autonomy for the individual.[74]

We have seen that this line of reasoning can be questioned, since there is no guarantee that more information leads to increased efficiency and autonomy. For instance, psychological distress, confusion and "faulty choices" can be consequences of more information, resulting in a reduction of autonomy (II.2.3.2). However, to the extent that genetic counselling can counteract such consequences, e.g. by attending to psychosocial and affective dimensions, the line of reasoning seems sound: (genetic) information is likely to improve the patient's ability to choose a line of conduct conducive to her basic aims. Let us, at least, assume that this is so in order to be able to focus on the question of disclosure of information.

In order to disclose information relevant to decision-making, it seems to be an obvious advantage if the counsellor finds out the reason(s) why the patient is considering genetic testing in the first place. This may be straightforward enough when the patient has some background knowledge and a clear purpose of testing. For instance, a couple from a population where a certain genetic

---

[74] Another criticism in terms of autonomy to deliberately withhold certain information is that this withholding seems to express the paternalistic view that the patient is unable to handle it, thus showing disrespect for her autonomy in a sense. I will return to this in short.

disorder is more common, e.g. Tay-Sachs disease among the Ashkenazi Jewish population, may come to see a genetic counsellor in order to do genetic carrier detection for making reproductive decisions. Or someone, like Jill (II.2.3.1), may consider presymptomatic genetic testing in order to make career plans. In these cases, the purpose of considering genetic testing reveals what kind of information is relevant for decision-making.

This, however, does not mean that the norm of complete disclosure implies that genetic counsellors can abstain from disclosing information that falls outside the patient's explicit purpose of testing. There may be information that *would* be relevant to the patient's decision-making if she had only had the opportunity of considering it. It would then affect the patient's decision-making, but not through being related to the purpose of testing. For instance, a woman with recurrent breast cancer among her relatives may consider genetic testing in order to decide on issues of family planning, without knowing that there are some preventive measures, like regular check-ups or prophylactic mastectomy. It is not unlikely that this kind of information would affect her decision-making if she received it. (In fact, it would be considered to be gross negligence if the counsellor failed to inform her of this.)

This means that the norm of complete disclosure, in order to be practically usable, has to be supplemented with some idea of what information that presumably will be considered relevant by patients in general. The following list, which draws on Fraser's generally adopted characterisation of genetic counselling (II.3.2), contains the items considered to be important to educate about in genetic counselling:

> (1) [T]he features, natural history, and range of variability of the condition in question, (2) its genetic (or non-genetic) basis, (3) how it can be diagnosed and managed, (4) the chances that it will occur or recur in various family members, (5) the economic, social, and psychological impacts - positive as well as negative - it may have, (6) resources that are available to help families deal with the challenges the disorder presents, and (7) strategies for amelioration or prevention the family wish to consider. (Platt Walker, 1998, p 7)

Let us suppose that this list of items presents a plausible account of what most people would consider relevant for decision-making. However, there are cases

when following the list seems to exclude too much and when it seems to include too much information.

For instance, consider the occasional cases of genetic testing revealing unexpected facts about paternity, i.e., the test reveals a man who is believed (by himself and his family) to be the biological father of a child not to be so. Let us assume that this information has no implication for risk of disease, the risk being on the mother's side of the family. It is thus not part of the list of information considered important to educate about, that is, information that normally can be considered to be relevant. Should this information be disclosed to the patient, even if the patient has not asked for this kind of information?

It is not obvious that this piece of information should be disclosed on grounds of autonomy. First, it may be deeply disturbing, leading to various types of paralysing distress. Second, even though it may affect decision-making, it does not have to. The patient may not redefine any family relations or in other ways act on the information. So the information may be irrelevant to decision-making, just being a disturbing piece of perhaps unwanted knowledge.

Still, it seems questionable for the counsellor to withhold the information of non-paternity. First, withholding the information seems disrespectful to the person's autonomy, according to the idea that we should be treated as if we are autonomous. Withholding the information from the individual seems to be to make a decision on behalf of the individual that one really is not entitled to make, treating her as a person that cannot handle the information. This is a kind of paternalism, treating someone as a minor rather than a competent adult.[75]

Second, maybe the patient would have wanted the information of non-paternity if she had known that the counsellor had it. Even if one is sceptical of attributing the satisfaction of such hypothetical desires any value, this relates to a third point: the patient may find this information out in other ways, realising that the counsellor kept it a secret. This would not only (probably) be upsetting to the patient, reducing her well-being for at least some time. What is worse, it might undermine the trust and confidence in genetic counselling in

[75] See III.3.3 for an elaboration of this rather neglected idea of autonomy.

particular and health care institutions in general, perhaps leading to a wider public distrust in the long run, if it becomes routine.[76]

This reason of trust to disclose information is a general one, holding regardless of whether the information will be relevant to decision-making or not. This is so, since this basis of reason for disclosure relates to the consequences of norms of health care in terms of well-being (see VI.2.2). So the interpretation of "relevant" as "relevant for decision-making" seems misconstrued, or at least insufficient, since information may be irrelevant to decision-making, but withholding it would undermine patient-doctor trust. So just revealing information that is relevant to decision-making, even if we include information from the list that normally would be considered relevant, seems to exclude too much information.

However, revealing all information relevant to decision-making may be to include too much information too. This is so since such information may be damaging to both the autonomy and well-being of the person. I have argued this point (II.2.4) and I will further corroborate this argument (see V.3.1.1), so I will not repeat that argument here. The general point of those arguments is that if autonomy (and well-being) is the rationale of disclosure, there can be no reason to disclose when disclosing damages the autonomy and well-being of the patient.

However, there is one point in relation to this that I will elaborate on. If some piece of information is not asked for by the patient, nor relevant for the patient's risk of disease, it is not self-evident that the patient would want this information. Take once again the example of a genetic test revealing non-paternity. Just as some patients would resent not being told about this, other may resent being told about it. The following would not be strange reaction: "I did not come to find this out. I would have preferred if you had never told me."

The problem posed by this possible reaction seems to be the following. It would seem desirable if one could disclose information to those who want it or would want it, partly since this seem to be a reason in itself for disclosure and partly because they would be upset and mistrusting if they were to find out the information in other ways. Furthermore, we would like to avoid

---

[76] In fact, according to anecdotal "evidence" from several health care professionals, withholding this information is quite common. However, to substantiate this claim would require more thorough investigations.

disclosure of unwanted information, much for the same reasons. But the only way to find out if a person wants to know a certain piece of information seems to be to bring that information to the person. So only by finding out whether someone would like to know, one would frustrate the wants of those who would like to remain ignorant. "Would you or would you not like to know whether or not the man you think is your biological father is not really so?" is a question that in practice excludes the second alternative.

A possible way to sidestep this problem is to find out before testing what of the possible information a genetic test may reveal that the patient would like to remain ignorant about. One could ask something like the following: "If we were to find out things that is not related to your risk for disease or reason for testing, would you like to know this?" However, the patient is likely to wonder what kind of information that might be. If one then answers something like "Well, things like non-paternity" it may be difficult for the patient to answer no to a question like this, even though she is not sure of the answer. She may feel that it is disturbing that someone else has information of such an intimate nature about her life, without knowing it herself. This is not to say that a counsellor should hesitate to inform that a possible result of genetic testing is that it may reveal non-paternity. Not doing so seems disrespectful to the autonomy of the individual, since it seems obvious that this possible result can be relevant for the decision of the index-person to take the test.

However, and more importantly, there may be unexpected information that not even the counsellor has thought about beforehand. Then the question of whether the person would like to have this information arise again. And there is still no way to be certain about what information the patient would like without at the same time revealing the information in question.

I think that the problem demonstrates that there is no neat answer to the question of what information that should be disclosed. Of course, there is a very general answer, relating to the values of genetic counselling. "Disclose the amount and kind of information that is most conducive to the autonomy and well-being of the patient." However, we have seen that it is difficult to say what information that will be for practical purposes. It does not obviously coincide with the information asked for in relation to the purpose of testing, the information relevant to decision-making, or the information that normally would be relevant to decision-making (i.e. information from the list above).

And it seems as if the only way to find out whether some information is wanted is to disclose it, at least once testing is done.

However, the default position seems to be to disclose "everything" since there are traditional reasons of autonomy (non-paternalism) and well-being (doctor-patient trust) against withholding information. So, as a rule of thumb, the counsellor should not know anything about the test result that the patient does not also get to know. Such a rule of thumb would, however, require measures to ensure that the values of genetic counselling are promoted also by potentially disturbing knowledge. As our discussion of voluntariness showed, this does not only include setting up the internal structure of genetic counselling in a way conducive to these values, but also that society as a whole is structured in certain ways. Finally, it must once again be underlined that disclosure of information is not the most important objective, but rather ensuring understanding of it (see e.g. II.2.3.2).

3.4 Two practical problems of autonomy in genetic counselling

As was seen at the end of the section on the value of presymptomatic genetic testing (II.2.4), the alleged values of such testing may conflict in various ways. Expectedly, these conflicts reappear in the context of genetic counselling. Some of these have been briefly touched upon above. However, before closing this section, I will further elaborate on two of these possible types of value conflicts that seem to be of practical importance for the practice of genetic counselling.

3.4.1 Autonomy versus well-being

I have claimed that there basically are two values that constitute the goal of presymptomatic genetic testing in general and genetic counselling in which information from such testing is disclosed in particular, namely autonomy and well-being.[77] Different authors emphasise one value over the other to different degrees (III.3). However, those authors who discuss non-directiveness seem to favour, or at least put emphasis, on autonomy as the overarching goal of genetic counselling (III.3.3.5). Since non-directiveness is considered to be perhaps the most important part of the ethos of genetic counselling (III.3.3.5), there seems to be a tendency to favour autonomy over well-being.

---

[77] I will further elaborate why these values really are different one's, at least if well-being is understood as subjective well-being, below in this subsection and in section 4 of this chapter.

But obviously, the actual favouring of autonomy does not in itself provide any justification for autonomy being more important. Since health-related well-being in particular is a traditional goal of health care, health care professionals can be inclined to "direct" patients towards alternatives that are considered to be favourable from a medical point of view: "Genetic professionals are almost always directive about behaviours that are considered therapeutically beneficial to their counselees". (Oduncu, 2002, p 57)

So there seems to be a tension between the goal of autonomy and well-being in genetic counselling. Is this a problem in practice?

In order to answer this question, one can start out by noticing that autonomy and well-being consists of different states of affairs and can therefore part ways. For someone, leading a life that is autonomous to a high degree may mean leading a life that consists of less well-being than a less autonomous life would have consisted of. This is not so hard to see when well-being is understood in terms of "feeling good" (see II.4.1.1). Striving to become more in control of one's decisions and the actions and circumstances that guarantees the efficient realization of them can be quite arduous. And the accompanying feelings of responsibility and anguish of striving for self-determination is a well-known theme in the tradition of existentialism. Even if inner feelings of satisfaction are the natural result of accomplishing a self-determined and arduous task, a less ambitious life or life of *mauvais fois* may very well be a happier one.

Less obvious perhaps, is that a more autonomous life may be less fulfilling in terms of actual satisfaction of one's desires than a less autonomous life. As will be more fully explained in the next chapter, autonomy is not just about getting what you want but about being able to realize and/or realizing what you want yourself, through your own decisions and actions. Even though it may seem unlikely, it is not inconceivable that a person who never does anything much, just "hanging around" gets more preferences satisfied than she would have if she had tried to accomplish her ends on her own. (For instance, such person may evoke the (perhaps misplaced) pity of others, so they give her what she wants.)

However, regarding genetic counselling, in many cases, promoting well-being is to promote autonomy as well. For instance, as I argued, affective states such as depression, anxiety and hopelessness will be detrimental to both autonomy

and well-being (II.2.3.2). Genetic counselling is, or should be, helpful in dealing with such psychological reactions. If this is accomplished, both well-being and autonomy are likely to be improved.

Of course, there may be cases when some course of action promotes one of the values and reduces the other. Someone may realize her plans to a greater extent from getting to know that she will have Huntington's disease because she draws her plans more realistically in light of this knowledge, but at the same time becoming worse off in terms of well-being from knowing about the Damocles' sword hanging over her head (but at the same time not so bad off that it affects her capacity to realize her plans). However, even if there are such cases, it seems difficult to point them out before and during genetic counselling, since it would depend on the long-term effects on the index-person. If these cases cannot be identified beforehand, we will not need to take a stand on which value is more important for practical purposes. This is so, since only when one can have good reasons to believe that counselling will promote one of the values at the expense of the other, the conflict between autonomy and well-being is important to sort out for practical purposes.

Nevertheless, autonomy and well-being *can* part ways, and there may be examples of cases when a counsellor can hold that she has good reason to believe that they will. Perhaps this is so in some cases where there is a preventive measure that is likely to be efficient and, thus, is likely to improve quality of life, but has some risks and the patient is risk-aversive. For instance, consider the case of surgery to prevent hereditary colon-cancer. Let us assume that the counsellor has good grounds for believing that the patient in question would "play it safe" by avoiding surgery if she knew about the slight but existing risks to die as a consequence of the procedure. In this case, the counsellor can either honour non-directiveness by telling about the risk, whereby the patient probably would refuse the surgery, and thus probably would lead a worse life in terms of well-being (or this is what the counsellor is convinced of is the case). Or the counsellor can try to affect the choice of the patient in various ways, e.g. by not talking about the risks, by presenting the surgery as the "only" or "obvious" choice, and so on, in which case the counsellor probably is reducing the autonomy of the patient.[78]

---

[78] Of course, being directive in cases like this may have negative side-effects in terms of well-being that make honouring of autonomy justified in cases like this too (Tännsjö, 1999). In that case, the practical conflict between autonomy and well-being is lessened.

Besides situations similar to this, there is a practical conflict between well-being and autonomy when deciding what to prioritise when it comes to comparing genetic counselling with other health care practices in a system where health care is funded through taxes. This conflict becomes most obvious when it comes to presymptomatic genetic testing for disorders for which there are no health-related gains to be made, e.g. Huntington's disease. Is the autonomy-promotion that such testing can lead to important enough to be financed, maybe even at the expense of health-promotion in other areas?

These situations of practical conflict gives rise to the question of whether autonomy should be considered to be a value of health care in general at all: should promotion of autonomy be a goal of health care? In order for the question of priority to arise at all, that question must be answered affirmatively. So concerns about the potential conflict between autonomy and well-being in genetic counselling gives rise to two major questions that have to be further investigated: What are the ultimate goals of health care? And: Given that autonomy is such an ultimate goal, how much weight should it be given in comparison to other values, like the well-being of the patient? Questions of such magnitude cannot be meaningfully dealt with here. I merely want to point out what work that lies ahead.

3.4.2 Autonomy versus autonomy

As we have already briefly touched upon (II.2.3), the idea of autonomy being a right that should be respected and a value that should be promoted are different ideas (this claim will also be further elaborated, III.3.3). For instance, autonomy as a right to respect gives rise to negative duties towards others, i.e. duties to abstain from certain things like manipulation and coercion, while autonomy as a value to promote can give rise to positive duties towards others, i.e. duties to do certain things towards others, like helping others becoming more autonomous persons or leading more autonomous lives.

However, this must be qualified. First, the distinction between positive and negative duties is far from crystal clear, due to the fact that the underlying distinction between acts ("to do") and omission ("to abstain from doing") is unclear (IV.1.1.1). For instance, the duty to abstain from manipulation in health care is often taken to imply a duty to inform the patient of medical procedures (III.3.3), and informing someone about something is intuitively an action rather than an omission. Second, even if one grants that the idea of respecting autonomy is different from the idea of promoting autonomy, the ideas are not

mutually exclusive and can even be argued to be mutually reinforcing. This is so, since disrespecting someone's autonomy probably will make the person less autonomous, by making her realize her aims to a lesser degree.[79] Because of this, a case for respecting the autonomy of individuals in general can be built on the basis of autonomy being a value that should be promoted, just like it may be argued that a defence of respecting the autonomy of individuals can be built on well-being as a value to promote.[80]

Nevertheless, these are different ideas (III.3.3) and they may come into conflict: it may be possible to make someone more autonomous in the long run in terms of any ideal of autonomy as a value, by not respecting that person's autonomy at one point in time. It then follows that not respecting autonomy can be permissible even if one grants that people have a basic right to have their autonomy respected or if one grants that negative value is realized just by not respecting someone's autonomy, given that one grants that the right is only prima facie and that the negative value is not infinite. This is so, since it then becomes permissible to not respect the right to autonomy if the value in terms of the autonomy promoted is great enough to override the right to respect or negative value of failure to respect autonomy.

This possibility opens for justifiable paternalism in the name of autonomy. Roughly speaking, X is exercising paternalism when X prevents someone else, Y, from deciding and/or doing something, and X justifies this prevention by the goal of benefiting or avoiding harm to Y. Traditionally, discussions of paternalism has revolved around the conflict between the right to autonomy (or liberty) and the promotion of well-being (or avoidance of ill-being): is it ever justified to disregard the will of someone in order to make that person better off? However, if autonomy is considered to be a good of persons in the same manner as well-being, i.e. as something that can be promoted or reduced and is valuable in proportion to degree, the same question can be asked with regard to autonomy. Since the answer to this seems to be yes, at least in principle, it is conceivable that it sometimes may be permissible, and perhaps even obligatory, to disrespect the autonomy of someone in order to make that

---

[79] However, it is not equally self-evident that disrespecting the autonomy of someone will make her a less autonomous person according to the ideal of capacity. However, being manipulated probably will decrease one's capacity to realize one's basic aims, i.e. one's capacity for being efficient. For more about this, see chapter III.

[80] Like in Tännsjö, 1999.

person more autonomous.[81] In an incisive wording, this can be called the *paradox of autonomy.*

In the following, I will only consider this paradox intrapersonally. That is, I will only consider cases where it may be argued that it is permissible to disrespect the autonomy of someone in order to make that very same person more autonomous. In principle, however, the conflict between autonomy as a right and as a value can also arise interpersonally: it may be permissible to disrespect the autonomy of someone in order to make someone else more autonomous. I will return to this in chapters III and VI.

There may also be interpersonal and intrapersonal conflicts of autonomy as a value. That is, one may increase the autonomy realized by first decreasing it, and the value of the increase may well weigh in favour of it. Let us once again focus on intrapersonal conflicts. It may then be true that the most efficient way of increasing someone's autonomy overall is to decrease it first. Take for instance a disabled person who is reluctant to engage in physical exercise in order to improve her physical agility. It may then be the case that this person becomes more autonomous in the long run if she is coerced into getting started with the exercise.

Since autonomy is increasingly being considered as a value to promote besides a right to respect in genetic counselling, the conflicts of autonomy will arise in that practice. I will now argue that this theoretical possibility is in fact also a part of the practical reality of genetic counselling by using two examples and say something about how they could be tackled. I will then pose some general questions that will have to be answered in order for the conflict to be resolved.

The first example of the conflict is when genetic counsellors refuse to be directive against the explicit wishes of their patients. Experienced counsellors report that they frequently get the question 'What would you do in my place?' (Harper, 2001, p 14; Shiloh, 1996, p 86) Often, questions like these should not be taken literally as a request to be directed, but maybe, for instance, as a way of making the counsellor less detached. In fact, there may be several ways to answer this question in a non-directive way (Kessler, 1997, p 168-169). As we

---

[81] One could even claim that this is to show proper respect for someone's autonomy. See Lindley, 1986, chapter 6.

have seen, *giving advice* as such is not contrary to non-directiveness and promotion of autonomy (III.3.3.5). The question becomes problematic only when the patient wants the doctor to *decide* for the patient in important issues as family planning, treatment and testing or the like. In the name of non-directiveness and, thus, ultimately in the name of autonomy, counsellors may refuse to do so (Harper, 2001, p 14).

But should not respect for autonomy entail the possibility of deciding not to decide oneself? This certainly has been held: "We defend a principle of respect for autonomy with a correlative *right* to choose (not a mandatory *duty* to choose)." (Beauchamp & Childress, 2001, p 61) And moreover: "There is a fundamental obligation to ensure that patients have the right to choose... Forced information, *forced choice* and evasive disclosure are inconsistent with this obligation." (Beauchamp & Childress, 2001, p 63. My italics) So, influential biomedical ethicists hold that the right to respect for autonomy entails that not making the decision for the patient if she wants it is disrespectful of the autonomy of the patient. In line with this, one could argue that if the patient makes an autonomous choice to *delegate* her decisional authority to the counsellor, for the latter to act on that delegation would be proper from the point of view of autonomy.

If that is so, deciding on behalf of the patient in such circumstances would seem to be compatible with the *ideal* of respecting the autonomy of the patient. However, it is highly doubtful whether *refusing* to direct or decide for the patient in such a situation is to *fail to respect* the right to autonomy of the patient. The right to autonomy does not entail that patients have rights to get certain things from health care, like directions on what to do. It only entails that services performed by health care should be performed in certain ways, i.e. without coercion, manipulation or treating the patient as a minor (III.3.3). To abstain from directing or deciding on behalf of the patient in questions of great importance to the patient's life is neither coercion, nor manipulation, and certainly not to treat the patient as a minor (rather, demanding that the patient should make up her own mind is to treat her like a competent adult). Of course, as we have just seen, one could argue that patients should have a right to decide whether or not to decide. However, this right does not imply a duty of anyone else to make the decision in the patients place. For such a duty to follow, we need to transcend the ideal of *respecting* autonomy and claim that it would *promote* the autonomy of the patient if the counsellor complies with her

wish of deciding in her place. However, this move nonetheless makes the refusal to decide on behalf of the patient a conflict of autonomy.

Since non-directiveness can be defended with reference to the promotion of autonomy and the right to delegate decisions maybe also can be defended in such a manner, it is hard to settle the question of whether counsellors should abstain from direction when asked for just with reference to autonomy. What other kinds of arguments are there? Well, there are arguments that refer to the well-being of patients. But they are also inconclusive. In relation to discussing the question of what to do as a counsellor when asked: 'What would you do in my place?' on the one hand the following has been claimed: "Denying counsellees' request for advice may impede the counselling relationship, be interpreted as lack of care, and even become a bitter struggle" (Shiloh, 1996, p 86). On the other hand, the following claim seems equally plausible: "It is very tempting to give a clear direction in these circumstances, but frequently these are the very couples where this may be most inadvisable. Such a plea often indicates an unwillingness to face up the consequences of a serious situation, or a serious disagreement between marriage partners, and for the physician to take on the responsibility that can only really be taken by the couple themselves may have serious long-term consequences." (Harper, 2001, p 14)

This only goes to show that it is difficult to give a *general* answer to the question of whether direction in important issues, such as whether or not to undertake a genetic test, should be given when asked for by the patient. However, when there is effective treatment or preventive measures, there seems to be more reason to decide for patient when asked to than if there is not. When there are no such measures, as in the case of Huntington's disease, the very point of testing is often to decide about what to do regarding such central and personal issues of one's own life as forming a family or planning a career. To leave decisions like these to someone else expresses a desire to leave responsibility of consequences one has to live with oneself to someone else. To grant such a desire is for the doctor to take on a role she should not have, "leading the life of others" and furthermore probably will be detrimental to trust in the profession in the long run. However, when there are effective preventive measures, and thus apparent health-related reasons for the individual to test herself, there is some reason to answer the inherently directive question of what one would do oneself. This is so, since in these cases there is an additional reason for testing: health-related well-being, in

which the professional has some expertise (as opposed to the question of what life the patient should live). But the health-related reasons must then really be apparent. For instance, in the case of BRCA1, the most radical measure is prophylactic mastectomy. Besides not being failsafe prevention and bringing some risks of physical harm, this surgical procedure can be experienced as almost as grave a consequence as the disease itself. Being a case where the "cure" is very painful in itself, to take on responsibility to make a decision for the patient that she later can resent seems less wise.

The second example of the conflict is displayed by the common requirement of pre-test counselling. That is, in order to be tested at all, the patient has to go through with a rather lengthy counselling procedure (Marteau & Richards, 1996, p 6). The reason for this requirement should be obvious by now: genetic counselling aims to help the patient to consider what she wants and make a decision that is as informed and well-considered as possible, so that she decides in accordance with this want. In short, the aim of genetic counselling is to promote the autonomy of the patient.[82] One straightforward way in which genetic counselling tries to accomplish this is by giving the patient more time to ponder her decision whether or not to go through with testing (Harper, 2001, p 17).

However, this requirement of pre-test counselling, at least seemingly, is at conflict with the right to respect the autonomy of the patient, since, pre-test counselling being a requirement, the patient cannot go through with testing without this counselling even if she wants to. Is refusal to give the test to the patient without genetic counselling to disrespect her autonomy?

The answer may be argued to be no, along similar lines that refusal to make decisions for the patient is not obviously to disrespect her autonomy. Respect for autonomy does not imply that patients should be given any service they demand. Health care does offer some services (like genetic testing), but not others (like homeopathic treatment). Furthermore, health care makes access to most services conditional. For instance, you will not get certain treatments or tests unless there are medical indications. Not to provide all services people ask for unconditionally is not to disrespect their autonomy. Respect for autonomy only limits the way in which services offered should be given. For instance, it implies that patients should not be coerced or manipulated into

[82] I ignore the well-being part in this context.

testing or treatment. Rather, they have the right to be informed what the procedure in question is about, and should be allowed to decline it if they so want. That is, respect for autonomy implies informed consent, at least for persons autonomous enough. Therefore, health care has the right to choose what services to offer and what conditions should be fulfilled in order for people to access these services and patients have the right to accept and reject this offer.

However, this line of reasoning may be questioned when it comes to requiring pre-test counselling. Health care is offering certain services of genetic testing. Generally, if health care is offering a service and there is medical indication that the service is needed and informed consent is obtained, the patient has a right to get that service. Why should genetic testing be any different? The point of genetic counselling is to promote autonomy. But what if the person is uninterested in this? Should we force the patient to become more autonomous? Besides looking almost paradoxical, it seems paternalistic to demand her to go through counselling for her own good with the threat of sanctions if she does not (then she will not get testing) and thus disrespectful of the patient's autonomy.

One could of course argue that the point of genetic counselling is to ensure informed consent and nothing more. Since genetic information is often complicated it just requires more time than most other medical interventions, which make the procedure of pre-test counselling necessary. But this is not credible. First, it is not in line with how the aim of genetic counselling is conceived of. Genetic counselling aims at and does more than just ensure informed consent. Second, to require pre-test counselling in order for consent to be counted as informed would set the standard of informed consent higher when it comes to genetic testing than in health care in general. Normally, when a normal adult is given information, says that she understands it and consents to the procedure, this is taken as enough evidence that one has obtained informed consent. This is so, since trusting the patient to be competent enough to understand the information and not to lie when she says she does is part of treating her like an autonomous person and, in this sense, respecting her autonomy. Why should standards be stricter when it comes to genetic testing? Is that not to treat the patient as a minor, assuming that assurance that the information about testing is understood is insufficient?

It then seems to be a case in favour of claiming that requiring genetic counselling in order to get genetic testing can be disrespectful to the patient's

autonomy. At least this is so if the patient has prior indications of being a carrier of the gene in question, that is, there is medical indication, and if the patient shows understanding of what the test tests for and wants testing, that is, she has given informed consent to testing. Does this mean that the requirement should be abandoned?

This is a tricky question indeed. But a general answer should go along the following lines. The very *point* of providing much presymptomatic genetic testing to start with is to promote the psychological well-being and autonomy of the individual. This is especially obvious regarding those genetic diseases for which there are no cures, palliations, or preventive measures whatsoever, like Huntington's disease. Genetic testing of these kinds of diseases has no health-related advantages at all. The point of genetic counselling is to see to it that the values of autonomy and psychological well-being are realized. As we have seen, there are good reasons to believe that the realization of these values are dependent on how the decision is made and the information disclosed. Genetic counselling provides a setting aimed at ensuring that decisions are made and information disclosed in a manner conducive to the values.

Since the point or reason to provide these tests is psychological well-being and autonomy and genetic counselling is an institution that tries to accomplish these values, there is no reason to offer these tests without genetic counselling. That is, the health care system has no reason to offer this particular service if it were not for the promotion of autonomy and psychological well-being that the service can lead to. Since genetic counselling seems to be a prerequisite for the values to be realized, they have no reason to offer presymptomatic genetic testing without it. And it seems unreasonable to claim that patients have a right to demand a service from health care that it has no or little reason to offer.

However, for some presymptomatic genetic testing, health-related values can be realized. This is the case when there is preventive measures or other kinds of therapeutic advantages with knowing beforehand that disease is probable. Health-related values can be realized without genetic counselling. So for these diseases, there seems to be less reason to require genetic counselling. However, it should be observed that the force of this line of reasoning resides on a sliding scale. As was pointed out above, in some cases where preventive measures are available, there may still be doubts as to whether these would really benefit the patient or not.

So the conclusion seem to be that it is harder to justify a requirement of pre-test counselling for diseases for which there are (sufficiently safe and

efficient) medical or other health-related measures to take, but not for those where there are no such measures. This is so, since the very point of offering these tests are undermined if they are not preceded by genetic counselling. However, the conclusion that genetic counselling should not be required for genetic diseases for which there are health-related measures to take must be further modified. Since genetic information is about one's blood relatives, the patient's understanding of the possible implications of this must be ensured, which can require a more lengthy procedure of informed consent than usual. I will return to the question of relatives in the chapter IV.

3.5 Concluding remarks on the value of genetic counselling

We have seen that the ultimate goals of genetic counselling is the same as the ultimate goals of presymptomatic genetic testing, namely the promotion of the autonomy and well-being of the patient. An important part of the explanation of the allegiance to these values is the grim history of eugenics. Even though a traditional crystal clear definition of what genetic counselling is cannot be obtained, a standard characterisation of the practice contains a number of components: that genetic counselling is a professionally lead process of communication that contains pre-test information gathering and post-test information giving, as well as support to cope with the psychosocial consequences of testing.

In order to ensure that the goals of genetic counselling are obtained, genetic counselling has developed an ethos, containing particular norms or principles. The goals of genetic counselling provide an instrument to evaluate these norms. The norms of voluntariness and equal access are about the societal institutions surrounding the practice of genetic counselling. The norm of voluntariness leads to questions about how society should be organized in order to ensure that the decision of whether or not to have genetic testing should be entirely up to the individual herself, ultimately questions about justice. The norm of equal access leads to questions of who should finance genetic testing and counselling and who should receive it, which are also ultimately questions of justice. These questions need further investigation. The norms of attention to psychosocial and effective dimensions, as well as, confidentiality and protection of privacy, are most naturally justified with reference to the ultimate goals of genetic counselling.

Non-directiveness, being the most salient norm of the ethos of genetic counselling, can be usefully evaluated with reference to the ultimate goals of

genetic counselling. I have argued that non-directiveness should not be taken as equivalent to withholding advice, but rather as abstaining from influencing the patient without regarding the patient's own basic aims. Non-directiveness thus requires of the counsellor not to pursue a normative agenda independently of the patient's own values and wants. Furthermore, it is argued that, as a rule of thumb, the counsellor should not know anything about the test result that the patient does not get to know about. Sometimes such "complete disclosure" will be detrimental to the well-being and autonomy of the patient, but this cannot be found out beforehand. This means that sometimes genetic counselling will be acting contrary to its own goals.

Finally, I have argued that having autonomy-promotion as a goal may give rise to conflicts with well-being, as well as intrapersonal conflicts between autonomy as a value to promote and as a right to respect, and intrapersonal conflicts of autonomy as a value to promote. Two such practical problems of autonomy in genetic counselling have been presented: the first being about refusal to be directive and the second about requiring pre-test counselling as a condition of testing. It is proposed that the way to solve these conflicts is to treat different kinds of tests differently. Generally, when the value of testing is primarily about traditional health-related reasons rather than autonomy, refusal to be directive and requiring genetic counselling is more problematic. But when the very point of testing to a large extent is promotion of autonomy, "forcing" the patient to be autonomous by refusing to be directive and requiring genetic counselling seems more easy to justify. However, we are left with more questions: should promotion of autonomy really be a goal of health care practices and to what extent should they then be prioritised in relation to more traditional health care practices?

The analysis undertaken in this section on genetic counselling, as well as the one above on presymptomatic genetic testing, has left open a number of theoretical issues regarding the more exact nature of the goals of autonomy and well-being. In some cases, particular solutions to such issues have even been presupposed. In the next chapter, I will proceed to investigate such issues (and substantiate the presuppositions made with regard to them) as concerns autonomy. This will be a task of a chapter of its own since, as remarked, the idea of autonomy as a goal of health care practices is a rather novel one that has not been much analysed. Before that, however, I will close this chapter by making some notes with regard to the more traditionally embraced goal of

promoting well-being. Hopefully, some remarks on well-being that may have come through as unclear, controversial or questionable will become less so as a result.

4. Well-being

According to standard accounts of biomedical ethics, the *goal* of health care in general is to improve the quality of life, the welfare, or the well-being of the patient (Beauchamp & Childress, 2001, p 177).[83] Another way to put this is to say that well-being is the *rationale* or *value* of health care. This idea is often referred to as the principle of beneficence, "whereas respect for autonomy (along with nonmaleficence and justice) sets the moral limits on the professional's actions in pursuit of this goal." (Ibid.) As we have seen, another goal of presymptomatic genetic testing is autonomy, which then is a value to be promoted and not just something that provides "moral limits" on the pursuit of the goal of well-being (II.2.3). This idea will be elaborated in the next chapter.

In general, the goal of health care has been to promote *health-related* well-being, but regarding presymptomatic genetic testing, another goal is to promote psychological well-being, e.g. by reducing the anxiety of uncertainty (Platt Walker, 1998, p 12; Munthe, 2002, p 78). This kind of promotion of well-being[84] is not part of health-related well-being, at least not conceptually (II.2.1).[85] Therefore, the discussion of the value of presymptomatic genetic testing requires a broader grip on the concept of well-being.

What is well-being, then? The essential characteristic of well-being is that it is always about the good or (intrinsic) value for any being or person.[86] Theories of well-being are, then, theories of what makes someone's life go better, or what makes a person better off, or values *for* someone, or *personal*, or *prudential* values. Theories of well-being are thereby a subclass of theories of value, since there may be values that cannot be properly attributed to any person, but only

---

[83] I will use the term well-being from now on and consider the other two terms as synonymous.

[84] Or perhaps, rather, reduction of (health-related) "ill-being", e.g. sickness. I will not put emphasis on this distinction, unless needed.

[85] See Brülde & Tengland, 2003, p 165-270, for a discussion of the concept of health.

[86] In order to simplify, I will conform to the convention of using "person" as a label on the sort of beings that well-being can be attributed to, even if it is controversial whether non-persons can be well or bad off or not.

to outcomes or state of affairs (Temkin, 1993, p 277). One such example could be structural features of the distribution of well-being among persons, such as equality.[87]

Theories of well-being thus try to answer the question: what makes a person's life go well or bad, better or worse? Or (rather): what does the good and bad of persons consist of? This question should be carefully distinguished from other, related, questions. First, the question is not one about the meaning of linguistic expressions "personal value" or "well-being", i.e., it is not a meta-ethical question (I.3). Rather, it is a question of what constitutes the good life. Second, it is not a question of what actually affects the good of someone, i.e., what has causal impact on the value of a life. Rather, it is a question of what a good life consists of, regardless of how it comes about. Theories of well-being are thereby concerned with *final* or *intrinsic* values, i.e. what is of value in itself, rather than instrumental values, i.e. what factors that in fact affect value.[88] Third, the question is *evaluative* rather than *normative*, i.e., it is a question of what is good (and bad) for someone rather than a question of what someone ought to do. Certainly, evaluative and normative questions are intimately related. If something is good for someone, at least someone has a reason to promote it, ceteris paribus. However, what kinds of reasons of actions are provided by values is a tricky question, to which I will return (II.4.2, III.3.2).

4.1 Theories of well-being

Nowadays, it is customary to distinguish between three main theories of well-being:[89] *hedonism*,[90] the desire fulfilment theory or *preferentialism*, and the *objective list theory*. I will present the basic tenets of these theories. My primary purpose is to explicate the concept of well-being that I have used so far, so that it becomes clearer why I have made the claims regarding well-being that I have made and will make.

---

87 However, it may be possible to construe even equality as a personal value, if the intuition is that it is bad for someone to be worse off (in terms off other constituents of well-being) than someone else, through no fault of one's own. See Francén, Gren & Juth, 2003, p 31-33.

88 For a brief discussion of final and intrinsic values, see III.3.1. As we have seen, this makes most of the discussion of the practice of presymptomatic genetic testing one about the instrumental values of the practice.

89 At least since Parfit, 1984, p 493-502, even if vocabulary differs somewhat between writers. See e.g. Brülde, 1998; Kagan, 1998, p 29-41; Sandman, 2001, p 26-40; Temkin, 1993, p 258-280.

90 Strictly speaking, hedonism is just a subgroup of mental state theories, but the most important one.

4.1.1 Hedonism

Hedonism is the view that well-being consists of certain mental states, namely pleasure and the absence of displeasure. The basic tenet of hedonism is thus that feeling good is good and feeling bad is bad. The term hedonism is often used to designate the theory of *welfare hedonism*, which says that the pleasure and displeasure of a person is the only thing of relevance in order to determine the well-being of a person (Kagan, 1998, p 31).[91] This version of hedonism is, of course, much more controversial than the weaker form that only states that pleasure is a good thing (and displeasure a bad) without taking a stand on whether or not there are other components of well-being. Naturally, I will not assume the truth of welfare hedonism. However, from now on, I will use the term hedonism for welfare hedonism, unless otherwise explicitly stated.

Hedonism should be carefully distinguished from other related doctrines. For instance, hedonism does not state the normative doctrine that one should act as to maximise the net balance of pleasure over displeasure, i.e. *hedonistic utilitarianism*, or that pleasure is the only thing of intrinsic value, i.e. *value hedonism*, since hedonism as a theory of well-being is compatible with claiming that there are states of affairs of intrinsic value that are not personal.

But even carefully formulated so as to avoid conflations with other related doctrines, hedonism comes in many versions.[92] For instance, there are different versions due to different accounts of what it is that makes a pleasant experience pleasant (and unpleasant experiences unpleasant): there are *quality theories*, according to which (the valuable kind of) pleasure is a felt quality of our experiences (or a "hedonistic tone"),[93] and there are *preference theories*, according to which (the valuable kind of) pleasure is a matter of intrinsic preferences towards the experience.[94] Furthermore, there are different versions due to different opinions on whether only the intensity and duration

---

[91] I will to a large extent use the terminology of Kagan, 1998, for the theories of well-being and consequentialism.

[92] For a thorough exposition and discussion of different versions of hedonism, see Brülde, 1998, p 68-153.

[93] There are monistic and pluralistic versions of quality theories, the first saying that there is one kind of hedonistic tone that all pleasurable experiences have in common, and the other one saying that there are several such kinds. See Brülde, 1998, p 84-86.

[94] More specifically, the preference theory says that an experience is pleasant if, and only if (and because), the person wants to go on having it because of the experience it is (and is unpleasant if the person does not want to go having it because of the experience it is).

of a pleasure is relevant to the value of it (*pure hedonism*), or whether other things matter too, such as the quality of the pleasure or the fact that the cause or object of the experience is "proper" (different *modified hedonisms*). Indeed, there are numerous questions on which different versions of hedonism can take different stands, for instance the question of whether and where there is a zero-point between pleasure and displeasure, and whether and how pleasure is measurable.[95]

Needless to say, I will not take a stand on all these vexed questions. And for practical purposes of this book, I need not do so either. The reason for this is that all hedonistic theories will agree in practice regarding the questions of value discussed in this context. For instance, regardless of whether one is defending a quality theory or a preference theory of pleasure and displeasure, there will be almost total agreement on what *kinds* of experiences that are pleasant or unpleasant. Sensations, such as the taste of delicious food, emotions, such as the joy, hope, or love of something or someone, or moods, such as energy or peace of mind, can almost without exception be reasonably argued to be pleasant.[96] Similarly, pain, anxiety, worry, frustration, shame, guilt, sadness, despair, depression, and apathy are typical examples of unpleasant experiences (Brülde, 1998, p 73-78). And, as we have seen, it is the impact of genetic testing and information on feelings such as these that are the focus of the practical debate of well-being at issue in this book (II.2.1-II.2.2).

4.1.2 Preferentialism

Preferentialism is the view that the well-being of a person consists of that person having her preferences satisfied or, to put in more ordinary language, to have it the way she wants to. It is commonplace and intuitively appealing to assume that the more and the "more important", or stronger, the preferences satisfied, the better it is for the person. Furthermore, it seems intuitively appealing to say that only the satisfaction of intrinsic preferences, i.e. things one wants for their own sake, adds to well-being. This is the case since it seems strange to claim that it is good for a person to have instrumental desires satisfied. If you want to exercise only because you think it will be an effective means to stay in shape, which is your ultimate motivation for exercising, it

---

95 For a discussion of the mentioned questions, see Tännsjö, 1998b, p 67-77.

96 This should also hold regardless of the account of the relationship one thinks is holding between these feelings and pleasure, i.e., regardless of whether pleasurable experiences consist of, are supervenient on, or are caused by these feelings.

seems natural to say that it is your staying in shape that makes your life better, while exercise is only a contingent cause of this without any independent value.

Just like hedonism, preferentialism must be carefully distinguished from other related doctrines.[97] And just like hedonism, preferentialism comes in many different versions.[98] Although a popular doctrine, preferentialism is hardly ever defended without qualifications. Different proponents of the doctrine have different ideas on how it should be qualified, giving rise to different versions of it. The qualifications are united by the idea that the satisfaction of some kinds of preferences or desires that the person actually has is irrelevant to the well-being of the person. Basically, there are two kinds of such arguments (Tännsjö, 1998, p 82-89). First, we have arguments of idealisation, stating that only preferences that the person would have in certain circumstances are relevant to the well-being of the person. Commonly, the idea is that it is only preferences that the person would have were she more rational that is relevant. Different conditions of rationality have been proposed: that the person is rational in decision theoretical terms (i.e. that she has complete, non-contradictory, and transitive preferences),[99] that she has all relevant information and has deliberated carefully (Harsanyi, 1982, p 55), or that she has undergone cognitive psychotherapy (Brandt, 1979).[100] Second, we have arguments of elimination, stating that the satisfaction of some actual preferences of a person should be disregarded altogether for the purpose of determining the well-being of that person. Examples of preferences that has been claimed should be disregarded are preferences one wish one did not have (Tännsjö, 1998b, p 83), preferences one does no longer have when they can be satisfied (Hare, 1981, p 102), other-regarding preferences (Tännsjö, 1998b, p 85-86), and "anti-social" preferences (such as sadistic or envious ones) (Harsanyi, 1982, p 56).

---

97 For instance, preferentialism as a theory of well-being should be distinguished from preferentialistic utilitarianism and value preferentialism, which are the preferentialistic counterparts of the hedonistic doctrines (see II.4.1.1). It should also be distinguished from the doctrine of neo-classical welfare economics, which says that the rational agent acts to maximise the satisfaction of her preferences.

98 For a thorough exposition and discussion of different versions of preferentialism, see Brülde, 1998, p 154-285.

99 See Resnik, 1987, p 22-25.

100 For a fuller list of such conditions of rationality and a discussion of them, see Brülde, 1998, p 236-260.

Unlike hedonism, it is plausible to assume that the different versions of preferentialism will have very different practical consequences. At least, an idealised version of preferentialism, claiming that only the satisfaction of fully informed and carefully considered preferences increases well-being, will give any person different recommendations of what she should do in order to live a good life than a theory claiming that the satisfaction of the person's actual preferences are of value to her, given the highly plausible empirical supposition that everyone has at least some preferences that are not fully informed and carefully considered.

Thus I have to state if I am presupposing idealistic versions of preferentialism or not: I have not presupposed any kind of idealisation. I have two reasons for this. The first is that ideal preferentialism is not the one favoured in bioethics in general and in the discussion on genetic information and testing in particular (III.2.2.1). The second is that idealisations of the sort mentioned changes preferentialism so as to approximate objective list theories of well-being,[101] to which I will turn shortly. Moreover, I have not, and will not, specifically discuss any kind of preferences that anyone has argued should be eliminated, according to the arguments of elimination. So, I disregard this complication as well.[102]

4.1.3 Objective list theories

Objective list theories propose the view that the well-being of a person consists of the person having certain goods, whether or not the person herself likes these goods or not. This is not one theory of well-being but, of course, there is one separate theory for every list of goods. However, all objective list theories share some common characteristics, which make it appropriate to treat them under the same heading. First, all objective list theories are *objective*, in the sense that they claim that certain things (or states of affairs) are good for persons, regardless of whether they enjoy or want these things or not. Second, objective list theories (usually) are *pluralistic*, in the sense that they claim that there are different kinds of things that contributes to well-being.

---

101 For arguments to this effect, see Kagan, 1998, p 38-39; Tännsjö, 1998b, p 87-88.

102 However, I find the arguments to accept that now-for-now preferences and self-regarding preferences are the only kind of preferences that adds to the well-being of persons compelling, given that one accepts preferentialism. For an argument for just counting now-for-now preferences as relevant, see III.3.2.2. For arguments for just counting self-regarding preferences, see Brülde, 1998, p 205, 224-225, Kagan, 1998, p 37-38; Tännsjö, 1998b, p 85-86.

Different lists of objective goods will provide different versions of the theory or, rather, different theories of well-being.[103] However, there are some goods that tend to crop up regularly as objective goods of well-being: certain activities (such as artistic, intellectual, political activities, games, moral action), certain human relations (such as friendly, romantic, family, citizen), contact with reality, certain abilities (such as physical, intellectual, moral), autonomy, and freedom are typical examples (Brülde, 1998, 288-302). Mere enumeration is of course not enough to warrant an objective list. One has to provide some kind of justification of why the included goods on the list are included. Such justifications do almost without exception refer to some essential characteristic of human nature, like some ideal of human life, perfecting typical human abilities (i.e. *perfectionism*), or human needs (Kagan, 1998, p 40).

4.1.4 Subjective well-being

I take it for granted that these theories provide the major candidates for what may be the ultimate value (or point, goal, rationale) of presymptomatic genetic testing. It is perhaps unnecessary to point out that I will not try to investigate the implications of all these theories of well-being to presymptomatic genetic testing. As already mentioned, the reason for presenting the theories is to explicate the concept of well-being I presuppose when discussing the value of genetic testing.

I have to a large extent ignored objective list theories. The most important reason for this is that the discussion of presymptomatic genetic testing, of which this book is a part, shares this negligence, and on good grounds too. The reason for the negligence is that arguments for the value of presymptomatic genetic testing from most goods on objective list theories would be farfetched. For instance, it seems to require an advanced exercise in sophism in order to defend that the point of genetic testing is that it promotes patients' political engagement, creativity, intellectual capacity or something of the like.

However, there is one very important exception to the negligence of motivations for presymptomatic genetic testing of an objective list kind. Of course, I am primarily thinking of autonomy. As we have seen, autonomy is one of the most salient subjects of discussion in the moral debate of

[103] For a thorough exposition and discussion of different brands of objective list theories, see Brülde, 1998, p 286-366.

presymptomatic genetic testing and one of the most common values brought to stand in order to defend the practice. Therefore it has a salient place in this book. For now, I just want to make one point about autonomy that relates to the theories of well-being in general. Modern conceptions of autonomy occupy an interesting middle-ground between preferentialism and objective list theories. It is an objective theory in the sense that it is saying that one should be a certain way (autonomous) and/or live a certain kind of life (achieving one's goals); regardless of whether this is something that one wants to do or enjoys. But it is also related to preferentialism in the sense that it is saying that the goals one should achieve (and/or the goals that other should respect) are one's own goals – not some alleged goals that all should pursue.[104]

I will to some extent elaborate on the value of relations, when discussing relative's value of and right to genetic information (VI.3.2.2). However, my focus of attention will be on if the index-person has any duties to reveal such information and not if the value of relationships can be improved upon by presymptomatic genetic testing. Nonetheless, I will address questions of whether the alleged value of such relationships founds such duties.

A further value of an objective list kind that sometimes enters the context of presymptomatic genetic testing is "contact with reality" or, as it is usually phrased within this context, knowledge (Shickle, 1997, p 72).[105] Of course, presymptomatic genetic testing can provide knowledge. However, knowledge is a very controversial value and, to my knowledge, no one has claimed that the point of genetic testing is merely to give the patient knowledge about some genetic fact(s) regarding herself. Rather, the quest has been for a firmer and more uncontroversial basis of presymptomatic genetic testing, like avoidance of harm,[106] subjective well-being (see below) or autonomy. I will join this assumption and, therefore, to a large extent ignore the intrinsic value of

---

[104] Unlike (Aristotelian) perfectionism that says that some goals are desirable for all men, e.g. friendship.

[105] If someone knows something, she also by implication has true beliefs about it (according to the standard account of knowledge as true, well-founded beliefs) and thus is "in contact with reality" regarding his piece of knowledge. However, one may have contact with reality in the sense of being causally related to the external world in various ways, without having knowledge, and one may have knowledge while not being in much contact with reality in ways that can be considered valuable (e.g. being a brain in a vat knowing that one is that). So in theoretical discussions of intrinsic value, these ideas should be kept separate.

[106] With harm, I mean unpleasantness and/or frustration of preferences, i.e. what hedonism and preferentialism counts as negative values.

knowledge as a possible rationale for presymptomatic genetic testing.[107] This book cannot deal with all questions of relevance to the subject and the question of knowledge as an intrinsic personal value as a basis for the practice of presymptomatic genetic testing I leave for someone else to discuss.

I will also leave another possible personal objective value, but one that has not been attended to (as far as I know), namely the value of "realizing one's potential" in the sense of cultivating one's natural talents. This essay focuses on presymptomatic genetic testing that can be done today, testing that informs of (risk for) future disease. However, testing that reveals other kinds of information could perhaps be done in future. Genes that are advantageous to "positive traits" like athletic capacity, musicality, and mathematical ability may be discovered (if these traits are partly genetically explained) and one might be able to test for these genes. If we could realize this theoretical possibility, it might be argued that we should do so on perfectionist grounds. The argument, then, is that if one knows what genetic advantages or "natural talents" one has, one has more opportunity to cultivate skills in areas in which one is more likely to excel. There is some common ground between this question and the "science fiction" question of enhancements of traits through gene therapy. However, as remarked in chapter I, I will not discuss any of these questions.

Thus, when talking about well-being, I *exclude objective list theories.* I only presuppose *subjective* theories of well-being, i.e. hedonism and (the non-idealistic version of) preferentialism. So, whenever I speak of well-being in general, I will mean only pleasure and/or preference satisfaction and whenever I speak of ill-being, I will mean displeasure and/or preference frustration, unless I explicitly state otherwise.

But which of the theories of hedonism and preferentialism is presupposed? Well, for most practical purposes, this will not matter, since they will agree on almost all practical issues I address, at least in general. In general, the possible effects of improving people's health or reduce their anxiety that presymptomatic genetic testing may lead to (II.2.1-II.2.2), will be favoured both by hedonism (improved health and reduced anxiety tends to promote feeling

---

[107] An exception to this is discussions of the idea that knowledge is a prerequisite, or at least an advantage, for the promotion of autonomy. In this regard, knowledge receives much attention. See e.g. chapter III.

good for most people most of the time) and preferentialism (most people want to be healthy and avoid anxiety most of the time). And, for instance, the possible effect of leaving positively tested persons without insurance will probably be problematic according to both hedonism and preferentialism, for parallel reasons. Of course, there are complications to examples of this sort and sometimes the two theories *might* part ways. For instance, as mentioned in II.2.4, unwelcome changes in self-image are conceptually a loss in well-being. However, this holds only given preferentialism.[108] Nonetheless, it is very likely that such unwelcome changes will reduce well-being also in hedonistic terms, since it is likely to evoke emotional frustration. So unless there are good reasons to assume hedonism and preferentialism will part ways, I will not discuss them separately. This means that one may choose one's favourite theory of well-being, be it hedonism or preferentialism or some mixture between them. However, I will assume that there is something to at least one of these theories. This is not very controversial. Anyway, it seems unintuitive indeed to deny that both feeling good (and not feeling bad) and having it the way one wants are irrelevant to the well-being of persons. That at least one of these things (and maybe both) constitutes well-being is therefore assumed.

4.2 Norms of well-being

As previously pointed out, the theories of well-being presented are theories of value rather than normative theories (II.4). That is, they are theories about what constitutes the good (and bad) of persons rather than theories about what persons ought (and ought not) to do. However, theories of value are intimately related to theories of norms. An extreme version of such an intimate relation is *consequentialism*, which says that one ought to perform actions that produce better consequences than any alternative action, and only such actions. Consequentialism is traditionally conceived of as a theory of moral rightness, which claims that a particular action is right if, and only if, there was nothing the agent could have done instead in the situation, such that had the agent done this, the universe (on the whole) would have been better. A shorthand expression for the necessary and sufficient conditions for right actions is to say that an action is right if, and only if, there is no alternative with better consequences. Furthermore, the theory claims that if an action is right it is morally permissible to perform it and if it is wrong it is impermissible to

---

[108] At least if the aversion to changing self-image is intrinsic, self-regarding and now-for-now.

perform it. That is, only optimal acts are right and, thus, morally permissible to perform. In effect, the theory claims that only the consequences are relevant in order to determine the moral status of any action.

Consequentialism is, of course, void of content if it does not provide an account of what consequences that are good consequences. The theories of well-being presented provide such accounts. When combined with theories of well-being, consequentialistic theories are often called *utilitarianism*, a terminology I will use too. So there is hedonistic utilitarianism, claiming that an action is right if, and only if, there is no alternative action the agent could have performed instead that produces a greater balance of pleasure over displeasure, and preferentialistic utilitarianism, claiming the same thing regarding preferences. Of course, different accounts of well-being may be combined, e.g., ones that claim that both pleasure and satisfaction of preferences are valuable. Such theories have to say how these values should be compared in order to generate definite answers on what consequences that are better than others.

Consequentialism comes in many versions too. Firstly, one can favour some objective version, stating that the actual consequences of an action determines it rightness, or some subjective version, stating that the (reasonable) beliefs about the action's consequences (also) determine its rightness. Secondly, one can favour a total version, stating that it is the total value that should be maximised, or an average version, stating that the average level of value for all individuals should be maximised. Thirdly, one could favour rule utilitarianism or act utilitarianism.[109] I will only consider these different versions of consequentialism when I find that it will be important for the discussion at hand.

A common criticism of consequentialism and utilitarianism is that they demand too much of the agent, since nothing but "the best" is permissible. In light of this criticism, various "milder" forms of consequentialism have been formulated. The perhaps best known is Michael Slote's (1985) satisficing act-consequentialism, which claims that if an action produces consequences that are "good enough", this is sufficient in order for it to be right.[110] I will not discuss the plausibility of this idea. However, I will neither assume that the

---

[109] I will discuss these last two versions more closely later (see VII.6.2).

[110] What is counted as being good enough is deliberately left imprecise by Slote, leaving it up to judgement to decide.

traditional maximising version of consequentialism defined above, is the correct one. Instead, I will sometimes speak loosely of consequentialistic concerns and considerations and/or considerations or concerns of well-being. When I do so, I will only assume that subjective well-being (see above) is of some relevance in order to determine the moral status of actions and institutions and remain neutral on the issue of whether it ought to be maximised or just considered relevant in some other way. However, sometimes I will discuss maximising consequentialism. It should be clear from the context and terminology if this is so.

5. Conclusions

This chapter has dealt exclusively with the value-question regarding first parties or individuals, that is, what is the value of presymptomatic genetic testing for the individual? I have argued that there are basically two such values: subjective well-being and autonomy. I have argued that both these values may be both promoted or reduced, or even damaged, by receiving the result from presymptomatic genetic testing. I have also argued that, generally, these values show the basis for some types of testing weaker. For instance, this goes for testing for diseases for which there are no preventive measures, since these cannot lead to the realization of health-related values, and testing that is uncertain (testing with low reliability or predictability), since they are less likely to reduce anxiety and promote autonomy. I also argued that the situation of the test, for instance, the way in which the test result is disclosed, is crucial for the realization of the values of well-being and autonomy. Perhaps most notably, ensuring proper understanding of the test result, as well as of the possible psychological and societal consequences, and providing support, is of importance for promoting the values in question.

This renders some support for genetic counselling, a practice which aims at understanding and emotional support. We have seen that the ultimate goals of genetic counselling is the same as the ultimate goals of genetic presymptomatic genetic testing, namely the promotion of the autonomy and well-being of the patient. In order to ensure that the goals of genetic counselling are obtained, genetic counselling has developed an ethos, containing particular norms or principles. The goals of genetic counselling provide an instrument to evaluate these norms. Against this standard of assessment, I have argued that non-directiveness, being the most salient norm of the ethos of genetic counselling, should not be taken as equivalent to

withholding advice, but rather as abstaining from influencing the patient without regard for the patient's own basic aims. Furthermore, it is argued that, as a rule of thumb, the counsellor should not know anything about the test result that the patient does not get to know about. However, sometimes such "complete disclosure" will be detrimental to the well-being and autonomy of the patient, but this is difficult to find out beforehand. This means that sometimes genetic counselling will be acting against its own goals.

I have argued that having autonomy-promotion as a goal may give rise to conflicts with well-being, as well as intrapersonal conflicts between autonomy as a value to promote and as a right to respect, and intrapersonal conflicts of autonomy as a value to promote. This led to the discussion of some practical problems that arise as result of these conflicts. One important conclusion when discussing these practical problems was that when the very point of testing to a large extent is promotion of autonomy, as is the case with testing for serious diseases for which there are no preventive measures, "forcing" the patient to be autonomous by refusal to be directive and requiring genetic counselling seems more easy to justify.

The discussion of the practice of presymptomatic genetic testing and genetic counselling left some question marks on how well-being and autonomy, being the values of these practices, should be understood more precisely. In the end of this chapter, I explicated the concept of well-being that I used, primarily arguing, but in some regards just assuming, that objective list theories of well-being should be regarded irrelevant. I thus revealed that the concept of well-being presupposed was a concept of subjective well-being, stating that the good of an individual consists in feeling good (hedonism) or having it one's own way (preferentialism). I have briefly argued why I think that one can remain neutral on which of these theories that are the correct one when discussing the issue of the value of presymptomatic genetic testing. A more precise analysis of autonomy is the task of the next chapter.

However, the discussions of this chapter have left us with more questions. Two of the most important ones are: should promotion of autonomy really be a goal of health care practices? To what extent should the practices that primarily promote autonomy be prioritised in relation to more traditional health care practices? These are very interesting, but very difficult, questions, which leaves more work to be done for the future.

Chapter III
Autonomy

1. Introduction

As demonstrated in the previous chapter, autonomy is one of the values most usually referred to when arguing why presymptomatic genetic testing can be a good thing for the person tested. This is especially so in the cases of presymptomatic genetic testing for diseases for which there are no medical or other preventive measures. In the previous chapter, we also saw that autonomy is not only considered as a right to be respected in this context, but also as a value to be promoted. Furthermore, autonomy as a value, rather than the traditional right, provides (part of) the justification for the practice of presymptomatic testing, as well as the basis of its ethos. Although I briefly adumbrated the general features of a theory of autonomy that also can describe and defend autonomy conceived of as a value, a more thorough exposition of the notion of autonomy is needed, a notion fit to illuminate ethical discussions, and primarily biomedical ones.

The purpose of this chapter is, then, to elaborate an analysis of autonomy that is useful to analyse discussions in biomedical ethics in general, and the discussion of presymptomatic genetic testing in particular. In order to do that, a crucial distinction will be made between conception of autonomy and ideals of autonomy. Hopefully, the analysis will prove valuable for ethical theory in general.

In order for there to be different opinions about the value of autonomy, there has to be unanimity on what autonomy is. A conception of autonomy should therefore be useful for formulating different competing ideals of autonomy. As a general rule in moral philosophy, it is fruitful to avoid discussions about what something (e.g. autonomy) "really is" (that is, discussions on how the word (autonomy) "truly" should be understood) and instead discussing what is valuable and what ought to be done (regarding autonomy). One and the same conception of autonomy has in fact often been

used to defend different moral ideals (Tännsjö, 1998b, p 99-113). A useful conception of autonomy should therefore allow this plurality of ideals.

So this chapter will start of with the task of elaborating such a conception that is useful to formulate different ideals of autonomy, which are explicit or implicit in modern biomedical ethical discussions. In these discussions, the meaning of autonomy is seldom clarified. An elaborated conception should then be useful in making sense of these argumentations. A fruitful conception should suggest why autonomy is considered to be valuable and how it can be used to defend normative judgements. A fruitful conception should also be useful to explain normative disagreements between different proponents of autonomy, e.g. with reference to differences in the weight different proponents attach to different aspects of autonomy.

More specifically, the conception of autonomy presented in the following should primarily be useful for analysing the debate on the right to and value of genetic information, the subject matter of this book. As we have already seen, the best way of making sense of many lines of reasoning in this context is by considering autonomy as a gradual value, which could (and perhaps should) be promoted by genetic testing (see II.2.3). The enterprise is to develop a conception that can make such lines of reasoning intelligible and, at least prima facie, plausible. For instance, authenticity is a part of autonomy that has been largely ignored in biomedical ethics. However, some claims about the value of genetic testing seem to be mainly about authenticity (see II.3.3.5). One therefore should try to say what authenticity is if one considers it to be of value. This is not to say that authenticity, or autonomy, has value. I will not take a stand on that issue. I will only attempt to formulate a conception that is a good candidate for being such a value. That is, if one wants to claim that autonomy is a value, it should be construed in the way I propose. Or so I will argue. I will also demonstrate the usefulness of the conception by formulating two basic ideals of autonomy conceived of as a value (see section III.3.1). I will also try to show that the conception can be used to formulate alternative ideals of autonomy, also those which do not necessarily claim that autonomy is a value to promote but, rather, a right to respect (III.3.3). By showing that the conception can be used to formulate a wide range of different ideals, the conception will prove to be fruitful.

There are, of course, other possible conceptions than the one I will be proposing in the following. I think that this conception is general enough to

formulate most reasonable modern ideals of autonomy. I will, however, also present interpretations of autonomy that are inconsistent with this one (e.g. a very orthodox Kantian one, see V.3.1.2). However, these interpretations are not only rare in the modern biomedical ethical discussion, as we will see, they are not really needed for formulating the ideals of autonomy that they have traditionally been employed to express.

There has been scepticism about whether there is a consistent interpretation of the concept of autonomy to start with. Therefore, some authors have been reluctant to use the concept altogether (Christman, 1998, p 109). However, since the discussion about the value of and right to genetic information is to a large extent cast in terms of autonomy, the discussion is unavoidable in this context. Furthermore, since the value of autonomy is so widely cherished, one should not dismiss it easily on purely terminological grounds. And finally, the fact that a concept is vague and ambiguous does not rule out meaningful use of it.[1] I think it could be worthwhile to attempt on another round of making sense of autonomy, before dismissing it altogether.

2. A conception of autonomy

The meaning of autonomy is controversial. What is not controversial is the positive value-ladeness of the concept. In these two regards autonomy is like concepts such as justice and happiness. Nevertheless, the etymology of the word reveals a generally accepted minimal core of the meaning: autonomy is about self-determination.[2] Thus any conception of autonomy must depart from this minimal concept.

Autonomy can be attributed to various entities, for instance states. In this context I am only interested in autonomy that can be attributed to individuals and their properties. One can talk about autonomous wants (or desires), decisions, actions and persons. Wants can be more or less autonomous, or so I will argue. Autonomous wants will be called authentic. Decisions can also be

---

[1] 'Knowledge' is an example of this.

[2] From Greek: autos = self; nomos = law – to legislate oneself. One cannot presuppose a single meaning that all users of the word are aware of when they use the word autonomy. However, all influential ideas on autonomy are somehow about self-government or self-determination (Christman, 1998, p 109). The concept allows the formulation of many divergent conceptions (one is explicated in this text). The distinction between concept and conception in this context should not be conflated with Rawls', however, since this conception, unlike Rawls' famous conception of justice, allows a wide range of different ideals (which makes the meaning of conception here come closer to Rawls' meaning of concept).

more or less autonomous, or so I will argue. Autonomous decisions will be called competent ones. And actions can be more or less autonomous. In order for an action to be autonomous there has to be the right sort of relation to any person's wants, decisions and acts. A person has, at least, to do what she decides to do and decide what she wants to do in a situation, in order for the action to be autonomous in that situation.

However, this is not sufficient, since this is compatible with a contingent relationship between the desire, decision and act. There has to be (something of a) causal relationship between the desires, decisions and acts of person in order for the act to be autonomous.[3] It should thus be clear that a person has to do what she does *because* she has decided to do it, in order for her action to be autonomous. If John turns on the stove, not because he has decided to do so, but because he has spasms that make him turn on the stove, the spasms, rather than any decision, has caused him to turn on the stove. This "action" is hardly an autonomous one.

Moreover, one has to decide what to do *because* one wants it, in order for the decision to be autonomous. This is obvious if one imagines cases where the link between desires and decisions has been broken. For instance, imagine someone implanting a microchip in your brain, the triggering of which makes you decide to do something. Then your desires are irrelevant to your decision whenever the microchip is triggered. Such decisions are hardly autonomous.

Furthermore, the desire must cause the decision and the decision must cause the act in the right way. How this exactly should be understood is hard to define, but has been made sufficiently clear in other contexts.[4] Generally, lack of control of one's wants, decisions and acts, and of the relation between them, are paradigmatic examples of lack of autonomy.[5] For example, if my present wants are the sole result of involuntary hypnosis, no decision or act

---

[3] The saving clause "something of a" is included because 'cause' should be interpreted widely in this context, not demanding any strict psycho-physical laws and compatible with those who claim that causal language is not appropriate for actions (who would rather say that actions depends on or should be explained by wills and decisions).

[4] See Elster, 1990, p 53-54. One example of a wrong "causal" connection is when Jane decides to shoot someone and does so, not "directly" because of her decision, but because her decision makes her so nervous as to pull the trigger. Her act may then be caused by her decision, but not "in the right way", i.e. not in the property of being a motivating reason, or something of the kind.

[5] Does anyone ever control what she wants? The kind of "control" of one's wants that lessens one's autonomy is discussed in the following (III.2.2.2).

flowing out of these wants may make me more autonomous (this will be qualified, see III.2.2.3).

2.1 Minimalistic definition

With this said, the following "minimalistic definition" of autonomous persons will be used as a point of departure. A person, in a situation, is autonomous to the extent that she does what she decides to do, because she decides to do it, and decides to do what she wants to do, because she wants to do it (Tännsjö, 1998b, p 97). A person can thus be more or less autonomous, depending on the autonomy of her wants, decisions and actions. So this minimalistic definition can be used to characterise autonomous persons and defend ideals of autonomy. This definition will in the following be developed and made more precise in order to get a clearer idea about autonomy.

Corresponding to the three components in the minimal definition: will, decision, and action, there are three components in the conception of autonomy: authenticity, decision competence and efficiency. Independent of each other, all these components may be present in varying degrees, or so I will argue.

A couple of issues need to be added regarding this minimalistic definition. First, the definition may give the impression that autonomy is a property that should be attributed to single actions rather than persons or lives. However, it has been claimed that the *value of autonomy* should be attributed to persons or person's lives taken as a whole (see e.g. Husted, 1997, p 59, 61-63). This idea is formulated in many ways: a person lives an autonomous life when she lives in accordance with her basic wishes or values, when the person realizes his own important projects, when the person lives according to his own idea of a good life and so on. I willingly accept all these general characteristics of autonomy as a value. However, strictly speaking, they are about autonomy as an ideal rather than a conception. I will return to why I think that the conception of autonomy that will be fleshed out in the following is suitable to explicate these ideals (see section III.3.1). Which components of autonomy one thinks is most important from a moral point of view has to be defended within a framework of an ideal of autonomy. This framework can argue in favour or against taking wants, decisions, and actions into account.

Furthermore, this minimalistic definition may also give the impression that the will in itself cannot be (more or less) autonomous. However, much of the

discussion of autonomy is about the autonomous (or authentic) will (Christman, 1988). The minimalistic definition does not exclude this idea. It will be a part of this conception of autonomy as one of the three components of autonomy (authenticity). An authentic will can then be attributed with different (including no) value, depending on the ideal of autonomy one wants to defend.

Joel Feinberg, 1986, p 28, has made a distinction between the capacity for autonomy and the actual conditions of autonomy. In order to understand this distinction, consider the slave who can make authentic, competent decisions and act on them, i.e. she has the capacity for autonomy, but is prevented from actually putting the capacity into practice, i.e. the actual conditions for putting the capacity into practice are not in place. The distinction is rather vague and draws on an intuitive difference between "internal" (capacity) and "external" (actual conditions) factors determining the degree of a person's autonomy. My characterisation of the different components of autonomy will disregard this distinction, assuming that all three components can be affected by both internal and external factors, thus making the actual degree of autonomy a result of both these factors. Anyone inclined to think that there is a moral difference between external and internal factors influencing this has to account for such an idea in an ideal of autonomy, a possibility compatible with the conception of autonomy presented here.

This relates to the general point already made about the importance of distinguishing between conceptions and ideals. It is quite possible to say that there is an important moral difference between, on the one hand, the type of case where a person, P, fails to put her plans to work due to the "external" influence of others (such as physical coercion), and, on the other hand, the type of case where P fails to put her plans into work due to factors present within P's own mind independently of others (such as failure to grasp how to act in order to achieve the aim in question). However, whether or not such a suggestion is warranted is not a conceptual issue, since the claim that this distinction is not of any moral importance may be put forward by employing the same conception of what it is to be (more or less) autonomous.

As will be seen when I now start to clarify further the nature of these components, there are quite a few opinions with regard to autonomy that may be handled in a similar manner. This, I claim, is a virtue of my conception, since it demonstrates how apparently opposing views on the value or moral

importance of autonomy really are opposing views about one and the same thing: autonomy understood in accordance with the minimalistic conception.

For instance, take the similar but nonetheless different distinction between the capacity for autonomy and actually exercising autonomy (Lindley, 1986, p 68-69). This distinction is different from Feinberg's, since one can have the capacity for autonomy as well as the actual condition fulfilled for being autonomous without exercising one's autonomy: think of the non-slave with the capacity for autonomy, who never puts her plans into work. Also this distinction becomes interesting when formulating ideals of autonomy, since both the "capacity for autonomy" (including, perhaps, the actual conditions) and actually exercising autonomy can be considered to be valuable. I will discuss them under the headings of "ideals of capacity" and "ideals of self-realization" (see section III.3.1).

2.2 Authenticity

According to some influential contributors to the autonomy debate, authenticity is the most fundamental component of autonomy (Christman, 1998, p 109, 112). This since, roughly, autonomy is about living in accordance with one's *own* will and authenticity is about the extent to which one's will really is one's own. In effect, it is crucial to investigate what it takes for the will of a person to be her own, i.e. authentic.

In this subsection, after some preliminaries, I will first argue against some proposals of what authenticity is. After that, I will state what I consider to be reasonable conditions of authenticity. I will argue that the most important property of an authentic desire is that a person who has the desire would be inclined to approve of having that desire if she came to know why she has it. The connection between rationality and self-determination can be thus described as a connection of identification: if a desire endures (or would endure) criticism and still is willingly embraced, it is authentic. Of course, a desire may endure different amounts of information on why one has it, and the resulting inclination to approve of having it may differ in strength. Therefore authenticity, just like autonomy in general, is a matter of degrees: a desire can be more or less authentic.

Before entering this discussion, there is need for making some general notes on the concept of desire. Much has been written on how to analyse what desires are (see e.g. Smith, 1994, p 104-129). However, I will not have much to

say about the often subtle details of this debate. In this context desires are supposed to be understood as propositional pro-attitudes,[6] where the strength of the desire is determined by the strength of the attitude the person has towards the object of the attitude.[7] For instance, "I desire to drink a cup of coffee" should be understood as me having a pro-attitude to the fact that I am drinking a cup of coffee, where the stronger the attitude, the stronger the desire. To do what one wants should be understood as doing what one desires mostly in a situation, which is a function of the strength and number of the desires present in that situation. Therefore, a person may not want to do whatever she desires most in a situation (if there are other conflicting desires in enough number and strength).

The following point cannot be overemphasised: autonomy is not solely about satisfying desires, but also about having certain kinds of desires and about doing (or being able to do) what one wants (III.2.2.2 and III.2.4.1). Therefore not all satisfaction of desires increases a person's autonomy. The latter, doing what one wants, regards competence and efficiency, to which we will return. The former regards the desire-component of autonomy. What kinds of desires are relevant from the point of view of autonomy, then?

I will call the desires that are relevant from the point of autonomy *authentic* and *basic* desires (goals, values, wants, preferences, projects). I will soon defend a view on authenticity. Basic desires are intrinsic:[8] a person P does not desire X only because P thinks that X will (or is likely to) result in something else that P desires. For instance, Jenny desires to get up earlier tomorrow, because she desires to be a person that wakes up early by herself. Jenny's desire to get up early tomorrow is then instrumental in relation to her desire to be a person that wakes up early by herself. Moreover, basic desires are not derived from any false beliefs about the desired object. If a person wants to drink a cup of

---

[6] Pro-attitudes should be interpreted in a wide sense. Therefore 'projects', 'values', 'goals', 'preferences' may be synonymous with desires as used here.

[7] It is important to note that this does not imply that the strength of a desire consists of the pull a person feels towards the object, but is compatible with desires being analysed functionally rather than phenomenologically (Brülde, 1998, 453-461). Furthermore, it does not imply that the strength of desires should be identified with hypothetical choices, even if hypothetical choices may constitute powerful evidence that a person has certain desires with certain strengths. 'Desire' should rather be understood as a theoretical concept that can explain certain (hypothetical) choices (Tännsjö, 1998b, p 83).

[8] In opposition to instrumental desires, rather than extrinsic desires or derivative (Brülde, 1998, p 182-186).

coffee, because he thinks it will make him feel drowsy, when it really will make him feel more alert, drinking that cup of coffee does not satisfy any basic desire, since the desire to drink that cup of coffee is derived from the desire to become drowsy in conjunction with the (false) belief that drinking coffee will lead to that. The reason that instrumental and (other) derived are irrelevant from the point of view of autonomy is, of course, that it seems odd to say that the satisfaction of them makes a person live a life according to her own light to a greater extent, or a better life at all, for that matter.

Basic desires are often taken to be very general, like the desire to be happy or live a life according to the bible. This, in turn, due to the belief that most particular desires can be psychologically linked to more general desires through the presence of beliefs about how these latter desires may be satisfied. Probably, basic desires are quite often global, in the sense that they are about the person's life taken as a whole, for instance about long-term projects or about the kind of person one wants to be. However, this does not have to be so. Much more particular desires may very well be basic, like the desire to go for a walk or the desire to have one's family around when it is time to die.[9] Also people that are less inclined for long-term planning may have basic desires that are very much limited in their content (such as being about temporally isolated situations).

As already mentioned, desires relevant from the point of view of autonomy should be authentic besides being basic. Most modern discussions of autonomy assume that conditions of rationality should be placed on desires in order for them to be autonomous or authentic.[10] What, then, makes a desire rational? Can desires be more or less rational themselves? Hume seemed to

---

[9] However, these desires are probably (like most desires) complex in the sense that they are conditional, which is something else than instrumental or derived. I wish to take a walk, given that it does not begin to snow, given that I am not run over by a car, and so forth. I wish to have my family around me when it is time to die, given that they do not quarrel, and so forth. This does not make these wishes instrumental. I can wish something, e.g. happiness "for its own sake" (intrinsically), but conditioned on something else, e.g. that my happiness does not bring great hardship on someone else. This is important to emphasise, since it probably makes more desires intrinsic than what the first impression might be.

[10] See e.g. Lindley: "any conception of autonomy requires its own view of rationality. Indeed, one of the disagreements between different theories of autonomy is over the proper role of reason in the determination of desire and action", 1986, p 28.

deny this.[11] A common interpretation of Hume is that he means that desires only can be the object of criticism if they are based on beliefs that can be made the object of rational criticism (Smith, 1994, 7-8). This means that desires in themselves can never be the object of rational criticism; they are neutral with regard to rationality.

The question of interest in this context is not whether desires are rationally criticisable *per se*, but whether they are rationally criticisable from the point of view of autonomy. One has to remember that Hume was discussing means-end rationality (to maximise the satisfaction of the desires one in fact has). Even if that kind of rationality is compatible with having no conditions of rationality on desires, it does not follow that there are no conditions of rationality on desires from the point of view of autonomy. In fact, I will argue below that some such conditions should in fact be accepted with regard to basic desires (see II.2.2.2).

It is also important to make a distinction between substantial and procedural conditions of the rationality of desires. Hume can be interpreted as meaning that the *content* of desires cannot be rationally criticised. With this a supporter of the conditions of authenticity that will be defended in the following can agree. There is no desire that solely due to its content is excluded on grounds of authenticity. The conditions of authenticity here defended are procedural in this regard. They are also procedural in the following regard: they demand that desires should be approved of given a certain procedure of (hypothetical) critical reflection and the higher the degree to which this condition is met, the more authentic is the desire in question. Before arguing in favour of this point, however, I will start by addressing some proposals on what authenticity is, but which should be rejected, or so I will argue.

2.2.1 What authenticity is not

In this subsection, I will address four conditions of rationality on desires, which I think should be rejected as conditions of authenticity. The first such kind of condition of rationality that I argue should be rejected is about consistency between desires. The second kind of condition of rationality, which is about consistency between levels of desires, should be rejected, or at least modified, since the fulfilment of it, in spite of initial appearance, does

[11] Hume, 1740, Book II, Part III, Section III, p 416.

not make desires more authentic. A third kind of condition, being about the origin of desires, should be rejected altogether, due to inherent implausibility. A fourth kind of condition of rationality should be rejected, since it is more about rightness and impartiality than about autonomy and self-determination.

Consistency between desires

A fundamental condition of rationality is consistency. It is most commonly embraced regarding the justification of beliefs, but the idea can also be applied to desires. One could claim that in order for desire to be rational it has to stand in certain relations to other desires: it should not be contradicted by other desires (so that the possessor of the desire both wants and does not want a certain thing), it should not be a part of a cyclic preference structure (so that you prefer a state A to another state B to a third state C, which you prefer to A)[12] and it should be ordered in comparison to other desires. All these conditions of rationality are well known in decision theory (henceforth: decision theoretical conditions).[13] I have no business entering that whole discussion, but merely need to address the issue of how these conditions relate to authenticity as a part of the conception of autonomy.

Of course, there is the possibility that desires can be contradictory: a person may both desire and not desire the same thing.[14] It is probably more than just a possibility; who has not experienced that you both desire and do not desire something? This case of "mixed emotions" may be the result of many things: unclear or contradictory beliefs (about what will happen given that the desires are satisfied), cyclic preferences or simply due to the fact that one cannot order the desires in relation to others.

---

12 Of course, one can argue that a desire being a part of a cycle does not make the desire irrational itself, but rather that the set of desires (or, rather, preferences) is irrational. I will disregard this possibility, however, since I argue that none of these conditions are reasonable as conditions of authenticity anyway.

13 In decision theory these conditions make unequivocal orderings and measurement of the desires of a person possible. See Resnik, 1987, p 22-25.

14 With contradictory desires I do not mean "indifference" in the sense that one has considered the alternatives and is completely willing to trade the one for the other, i.e. decisions theoretical indifference. Furthermore, I do not mean that one does not know what one wants. I mean that one both wants and not wants something. It could be denied that this is possible (just like one could deny that it is impossible to hold contradictory beliefs at the same time as one is aware of them being contradictory). In such case, there is no contradiction of desire-problem.

Contradictory desires may be thought to be good examples of inauthentic desires. If a person, P, both wants and does not want the same thing, it looks like P either does not know herself or suffers from an incomplete personality in need of complementary goals, values and projects for her life. One could hold that the component of authenticity emphasises that autonomy is not just about realizing your plans yourself, but also about *making* plans for yourself and being aware what these plans are. Contradictory desires seem to indicate that one is lacking in both these respects.

However, even if one accepts the premises of plan-making and self-knowledge as important parts of authenticity, this does not imply that decision theoretical consistency is a necessary condition of authenticity. Well-considered basic desires may come into conflict. They may in fact come into conflict just because they are well considered. Pondering what kind of life one wants to live, one may find that one's two most cherished projects are incompatible (like a very time consuming hobby and a very time consuming career or a wish to work out very much and an equally strong wish not to become a narcissistic broiler).[15] From the perspective of rational choice, this is seen as a problem mainly because finding a rational answer to what to do in such cases is difficult, to say the least. This, however, is of no consequence for the issue of authenticity, i.e. to what extent these desires are really one's own. On the contrary, the fact that the desires are well considered (or could be) points towards them being more authentic (see III.2.2.2). If one happens to be a vacillating person, this should be reflected by the content of one's very own desires.

Decision theoretical consistency can neither be a sufficient condition of authenticity. A person who is brainwashed by a sect may very well have consistent desires, but is (probably, see below) not a very authentic person. Decision theoretical consistency is therefore in itself not enough to guarantee authenticity.

Decision theoretical consistency is, thus, not a condition or prerequisite of authenticity. But it may affect the capacity for decision-making of a person. If a person both desires and does not desire the same thing, she may be stuck as Burridan's ass, unable to reach a decision from the conflicting desires.

---

[15] Of course, these desires are contradictory due to them being impossible to realise in this world as it is, i.e., due to empirical facts. This does not ameliorate the contradiction, however.

Furthermore, conflicts in desires will make it harder for a person to live her life in accordance with these desires, i.e., it may affect the efficiency component of autonomy.

Consistency between different levels of desires

Harry Frankfurt, 1971, suggested, in a widely influential paper, that in order to be authentic, a person P's desires of a lower level (lower levels desire: LLD) should be in accordance with or adjusted to P's desires of higher level (higher levels desire: HLD).[16] This idea has been influential to the degree that autonomy has been identified with the fulfilment of this condition (Lindley, 1986, p 64-67; Dworkin, 1981). Despite its popularity, I will argue that this idea is, at least partly, mistaken. However, there is a sound core to be found in the suggestion that will be distilled and developed in the next subsection (III.2.2.2).

A LLD is a desire that does not have another desire as its object.[17] A HLD is a desire that has a LLD or a HLD at a lower level as its object.[18] So, there may be more than two levels of desires. This idea of autonomy is often held to be an expression of a thought of authenticity as identification: a desire is authentic (and the action performed on the basis of it is autonomous) only if the agent who performs the action identifies herself with the desire in the sense that she perceives it as genuinely her own. Another way of putting this is to say that the desire must not be "alien" to the person. More specifically, the idea is that I do not enhance my autonomy if I satisfy a desire that I would prefer to be rid of. Common examples are the junkie's desire to have the next fix or the smoker's desire to have the next cigarette. Despite the fact that the smoker desires the next cigarette, she often desires that she did not have that desire, i.e. desires not to be a smoker. The desire to have the next cigarette is thereby not authentic, or so the reasoning goes according to the idea under consideration.

Let me first rebut the idea that a HLD in accordance with the LLD is *required* in order for the LLD to be authentic. If this is the case, at least two problems

---

[16] More precisely, the will, i.e. the desire(s) that one ultimately is motivated to act on, should not be undesired (Frankfurt, 1971, p 8).

[17] The object of LLD is not (in any unqualified sense) state of affairs. In one sense, the object of LLD is acts. This may seem odd (especially when it comes to intrinsic desires). But autonomy, unlike preferentialism, is about the realization of the desire through the act of the agent (III.2.4.1).

[18] Instead of levels of desires, it sometimes customary to talk about first *order* (LLD), second order, third order, etc (HLDs) desires.

appear. Firstly, it becomes impossible to be autonomous without a HLD, contrary to intuition. My desire not to have life sustaining treatment may not be accompanied by a desire to be such a person who does not desire to have life sustaining treatment. I may only have the desire not to have life sustaining treatment, tout court. However, it seems to be unreasonable to claim that coercing life sustaining treatment upon me therefore is not a violation of my autonomy. This example indicates that requiring a HLD with which a desire is in accordance in order for this desire to be authentic is much too strong.

Secondly, an infinite regress seems to be the implication of requiring a HLD. This is the case since more than one level of HLD seems to be possible. Should a desire of the second level be desired in order to be authentic? This seems to be reasonable, since a person may have a desire of the third level that does not approve of the desire of the second level. If this is valid for the second and third level, it seems to be valid for any level. But then any desire on any level always must be approved by a desire on a higher level. The regress is thus established. In order to avoid this, the highest level at which a desire is actually entertained by the agent should be counted as the one that lower levels of desires should conform to. But then a LLD must be enough, if that desire is in fact unaccompanied by a higher level. The *requirement* of a HLD is thereby given up.

However, the idea may be modified so that one only considers the actual desires the person has. LLDs should then be consistent with the highest actual level of desire. However, this modification also has problems, general to the basic ideas of correspondence between levels of desires.

To start with, this idea is unclear. And any more precise understanding seems insufficient or implausible. Let me elaborate.

First, is inconsistency between levels sufficient for *in*authenticity and, thus, consistency necessary for authenticity? Or is consistency sufficient for authenticity? If consistency is only necessary for authenticity, the suggestion is, at best, incomplete, since we would need to know what else is required to make a desire authentic. So the suggestion should rather be the latter: that consistency between different levels of desires is sufficient for authenticity.

Second, it is unclear what kind of inconsistency one has in mind. Is it enough that LLDs are in accordance with HLDs, so that when they are inconsistent, it does not matter which we change? Or should LLDs be adjusted to (the actually highest level of) HLD?

However, the first proposal, i.e. that inconsistency between levels just has to be removed in order to achieve authenticity, has serious drawbacks. First, this proposal must be fleshed out with some idea on which desire should confirm with which and why this type of inconsistency (between LLDs and HLDs) leads to inauthenticity. The proposal is therefore, at best, incomplete. Second, and more seriously, the idea then collapses into being about consistency between desires. I have already argued that authenticity cannot consist of this.

Therefore, let us move on to the idea that LLDs should be adjusted to HLD. This is natural in the light of the examples of the smoker above. However, also this suggestion also has serious drawbacks. One important problem is that it seems possible that desires of a higher level can be as inauthentic as desires of a lower level. If that is the case, authenticity probably does not only consist in adjusting lower to higher levels of desires. If the HLDs are not authentic themselves, it seems mysterious how LLDs can be authentic just by adjusting themselves to HLDs. An example may be the desire of a woman to iron her husband's shirts. Let us assume that this desire is a result of a systematic indoctrination, the purpose of which is to install the belief that the only task of a woman is to serve and please her man. The first impression of this example is that the woman's desire to iron her husband's shirts is not authentic (even if we would like to know more before drawing a definite conclusion). The condition of being a desire adjusted to the HLD is fulfilled, however. The condition therefore seems to be too weak, judging desires as authentic that intuitively are judged to be inauthentic.

Indeed, sometimes a HLD seems to be more inauthentic than the LLD they are directed towards. An example may be the homosexual man who desires to engage in intimate relations with another man, but who desires not to have this sexual orientation. That HLD may very well be nothing but a reflection of the negative attitudes of the surrounding society towards homosexuals, rather than a self-determined desire.

From this and similar examples it could even be claimed that the LLDs of people, to a greater extent than their HLD, constitute the "core" of their personality and that it is a weakness of Frankfurt's suggestion that it is unable to acknowledge this. The theoretical background of this claim can be that HLDs often are the result of demands of the surrounding society - a "cultural varnish" or a "super ego" censuring the desires people would otherwise try to realize. If there is something to these kinds of theories and authenticity is

somehow about expressing one's core personality, the HLDs of a person has in fact less to do with authenticity than the LLD of the person.[19]

Let me emphasize that examples, such as the one with the woman above, is not sufficient to refute suggestions of what authenticity is, merely due to being at odds with our initial intuitions about authenticity. The idea of authenticity soon to be presented may very well imply that the woman in the example above is authentic. But then it seems to be for the right reason. The main problem with the idea that authenticity has to do with LLDs being adjusted to HLDs is that it is unclear why the first should be adjusted in accordance with the second. Firstly, it does not seem to be unreasonable to claim that LLD can be more self-determined than HLD, in the sense that they express the core of personality to a higher degree. For instance, a person's LLDs may be stronger than a corresponding HLD. And this may be nothing the person resents. Because of this, the present idea of authenticity is not in tune with the general idea of identification, despite the initial appearance to the contrary. Secondly, it seems possible that a LLD can be less vulnerable to criticism than a HLD. So, it seems that the fact that a LLD has adjusted to a HLD is not only insufficient for the authenticity of that LLD; it is also not necessary. In the next subsection an idea of authenticity that more appropriately captures the ideas of the core of the personality, identification and rational criticism will be presented (III.2.2.2).

Being one's own origin

Objections of the kind mentioned have resulted in stronger conditions of desires being proposed and thus stronger conditions of authenticity and autonomy. The moral of the examples mentioned about the housewife and the homosexual may be thought to be that inauthenticity somehow has to do with the origin of the desires; whether the forming of the desires has been self-governed or not.[20] However, if non self-governed forming of desires makes the desires inauthentic, what then does it mean to govern the forming of a desire? Is not this idea absurd? Are not all desires formed by factors the person cannot govern if the story of the forming is told from the start? In

[19] See Friedman, 1986, for an elaboration of this critique.

[20] To see why ideas that refer to the origin of desires (so-called genetic theories of rationally-oriented modifications of desires, see Brülde, 1998, p 253-256) as authenticity-making all are mistaken, see II.2.2.3. See also Lindley, 1986, p 46.

order to say no, we would have to presuppose an "unmoved mover" who out of nothing creates a self, and it is certainly not desirable to build such a hazy and controversial idea into the concept of authenticity. On the contrary, this conception must allow for us to be able to have authentic desires without having to assume anything more about ourselves than what we normally do.

For this reason, the idea of authenticity that will be presented in the next subsection does not presuppose any such ideas. There are no "unmoved movers" that out of nothing creates a self or an I in order for this conception to be meaningful. This conception is thus compatible with the apparent fact that we are all formed in a society with certain values, norms and rules that take part in the shaping of persons. There is no single moment in the history of a human individual at which she becomes a person with the ability to create herself. The development of a person is a continuous process influenced by many sources, but – and this will be my lever for finding a sound conception of authenticity - in which the individual becomes more capable of critically evaluating the grounds on which she makes her decisions. We do not choose a character, but we have a character from which we at times are able to make choices with character forming effects from. But to be able to evaluate the grounds from which one chooses is to have the capacity for authenticity. And this capacity we have to different degrees in different circumstances, and we use it to different degrees in different circumstances, which suggests that authenticity is a gradual concept.

The authenticity of desires should therefore not be understood as the self-governed creation of desires. In fact, since all desires entertained by a person have a causal history that is (at least partly) uncontrolled by the person herself, the self-governance of the creation of the desire cannot very well be the mark of authenticity (unless we would like a theory of authenticity implying that no actual person can have authentic desires).[21]

Idealisation and impartiality

Besides ideas of being the origin of one's own desires, another type of stronger 'idealistic' conditions of authenticity and autonomy are sometimes

[21] For much the same reasons, one should reject conditions that says that a desire that is the result of someone else's deliberate attempt to install that desire are inauthentic, since this would mean that all desires that are the result of ordinary parental efforts of raising are inauthentic. Not many basic desires may remain given such a strict condition.

presented. Such idealistic conditions require that only the desires that a person would have were she more or ideally rational are authentic.[22] One version of idealism has *substantial* criterions on what is to be taken as a rational desire. That is, an irrational desire is so due to its content (regardless of who has it and why), e.g. because its object is not worth desiring.[23] Kant can be interpreted in this direction:[24] the rational is also the morally right. The reason for this is that, according to Kant, a person governs herself only if she acts out of her rational will (otherwise she is governed by uncontrolled impulses or "empirical inclinations"). Moreover, Kant means that the will is rational only if it is in accordance the moral law or the Categorical Imperative. Only the person acting out of (and not just in accordance with) the moral law is thus autonomous, according to this line of reasoning.[25]

Rawls has a similar idea in mind when he writes: "acting autonomously is acting from principles that we would consent to as free and equal rational beings" (1972, p 516). He then claims that all such beings would agree on the same principles. What the individual in fact desires is thereby irrelevant to the question of rationality, authenticity, and autonomy. It is what we would desire if we were in these idealised conditions that is of relevance.[26]

It is obvious that one can live a life in accordance with one's actual basic desires without being autonomous at all according to all these idealised senses of authenticity. It is therefore natural to assume that these conditions of rationality are different from the ones most adherents of autonomy would defend. They seem to be about satisfying perceived requirements of rational impartiality or morally praiseworthy action rather than authenticity and self-determination. For this reason alone, it may be argued that the proper place for

---

22 In one sense, the idea of authenticity defended below (III.2.2.2) is idealistic: desires are authentic to the extent that they would be approved of, given knowledge about why one has them.

23 This is sometimes called intrinsically irrational desires (Brülde, 1998, p 257-259; Parfit, 1984, p 121).

24 Even if Kant would deny that desires ever are rational; rationality is attributed to the (noumenal) will.

25 This Kantian line of reasoning can be found in Kant, 1785, especially chapter III.

26 How rational one has to be in order to be rational enough has to be settled. Rawls can be interpreted as taking "rational" to mean something like "only taking impartial reasons into account" and his account autonomy is then very close to an analysis of moral rightness or justifiability (Feinberg, 1986, p 36).

these requirements is in an ideal rather than a conception of autonomy. I will return to this point shortly.

One primary reason not to accept this account of autonomy and authenticity in the present context is that it is at odds with most modern conceptions of autonomy, especially those that are popular in biomedical ethics (see e.g. Christman, 1988; Lindley, 1986). On the contrary, these conceptions of autonomy have often been used to formulate the idea that people to some extent should be free to make unwise and even immoral choices (Mill, 1859). As we saw in the previous chapter, this also seems to hold regarding the (sketchy) ideals of genetic testing and counselling. A conception that presupposes a very strong connection between morals and autonomy would therefore not be suitable for making sense of this type of ideas.

Another reason is that the idea seems to be mistaken; it seems to be possible to be autonomous and immoral at the same time (in every common sense meaning of the word moral). I have never seen any proof that a person who governs herself could not do that in accordance with evil or selfish values or principles. Why should it be impossible for a person to live after the maxim that she should try to inflict as much suffering as possible upon others (she might be a sadist or a Satanist)? In the words of Feinberg: "For us to hold that an evil person does not truly governs himself, we must identify his "true self" with impersonal reason, rather than with his actual values and commitments." (Feinberg, 1986, p 36)

This objection takes us back to the first objection above. It should not be a part of the very conception of autonomy that autonomous actions exhaust the field of morally justifiable actions. We might want to say that it is better to be autonomous than not, ceteris paribus. But it is not inconceivable that it is sometimes worse to be an autonomous person than not (see III.2.6.2). Perhaps it is better if a stern sadist suffers from weakness of will.

I will not, then, demand that desires should fulfil idealistic conditions à la Rawls and Kant in order to be authentic. In the discussion I will be focusing on, namely the biomedical ethical, the empirical tradition of autonomy from Mill to Glover (1977, p 77) is the more relevant and not the idealistic tradition from Kant to Rawls. Therefore I will opt for the non-idealistic version. However, this conception of autonomy does not in itself preclude that one adds such conditions and still stick to the conception's central components

and structure by formulating an ideal of autonomy, specifying under what conditions autonomy is morally desirable. Such an ideal would then use the conception and would thereby not contradict this conception.

At the same time, however, the problems with these very stern versions of idealism illustrate the sound core in the idea of consistency between different levels of desires: it is *my own* acceptance of my desires that decides whether they are authentic (*self*-determined). That is not to say that any acceptance whatsoever will do. As I have argued, to desire what one desires is not enough, since that second order desire may be as non-governed by myself as my first order. The solution is perhaps some sort of compromise, the possibility of which will now be addressed as I proceed to say something positive about the conception of authenticity.

2.2.2 What authenticity is

What, then, should the conditions of authenticity be? As already indicated, I propose that authenticity should be understood as a pro-attitude towards (or "approval of", "liking of" or "acceptance of") the desires, given knowledge of the explanation of why one has the desires.[27] The more it is approved of given a certain level of knowledge, the more authentic it is. If the approval would remain given more knowledge, the more authentic the desire is. So authenticity is matter of degree depending on two factors: level of knowledge and level of approval. It is thus not the approval, or liking, or acceptance of the *explanation* that is of relevance in itself but, rather, the approval, or liking, or acceptance of the *desire itself, given* knowledge about why one has it.

Inauthentic desires, then, are desires that we would dislike having and, thus, be inclined to abandon, if we were to find out the causal history or, more widely and correctly, the explanation of us having them.[28] More precisely: the

---

[27] The origin of a certain desire may only be a part of the explanation of why a person has that desire, since many factors in the present may be a part of the correct explanation. For instance, one factor that explains why a person is holding on to a desire might be fear, which nonetheless may be absent in the explanation of why she came to have the desire in the first place.

[28] The following question is of course vital: what (true) explanation of why some person's desire is it that the person should know? "The more detailed and objective the story is, the more authentic the desire is, given a certain level of acceptance" is the answer that immediately comes to my mind and favoured here, but this, of course, has to be developed and defended. This will be a future project. There also has to be a time limit, since (explanatory) causal chains reaches back to the starting point of the universe. "The to authenticity relevant causes" is an appealing, but unfortunately circular, suggestion. The problems are building up.

more we disapprove of a desire given that we know why we have it, the more inauthentic it is.

This gives the following proposal on what determines the degree of authenticity and inauthenticity of a certain desire:

- P's desire X is authentic to the degree that P would have approved of her having X, if she had knowledge about why she has X.
- P's desire X is inauthentic to the degree that P would have disapproved of her having X, if she had knowledge of why she had X.

Another way of putting this idea is to say that authentic desires are desires that would be embraced also in the light of criticism. There is no fact about the explanation of why an agent has them, e.g. about the forming of them, that *would* make the agent inclined to disapprove of them. In that sense, the agent *can* identify herself with her desires: if she were to find out why she had them, she can still willingly acknowledge that they are hers. It will thus be true that she will not be inclined to give them up just because she learns new things about herself.

It should be noted that according to this formulation, it is enough that P *would* have a positive pro-attitude towards X if P knew about why she has X, in order to be (more) authentic, regardless of P's actual knowledge. The "acceptance" does not have to be factual: mere hypothetical "acceptance" is enough.

A requirement of authenticity presupposed in this idea is the following: in order for it to be possible that the explanation of one's desires is of any consequence at all, a person must be able to imagine other "values" or desires than the ones she has. Otherwise critical evaluation of one's desires and values would be of no consequence. This, of course, does not imply that a person has to change his values or desires when faced with others. It only means that one realises that there are other possible values and desires, and that other persons do not necessarily value or desire the same things as one self does. A person totally incapable of understanding other values than her own cannot critically evaluate her own values.

Besides the shortcomings of alternative suggestions of autonomy, what positive reasons are there for accepting this account of authenticity? This idea has the advantage of accounting for several intuitions about authenticity. It

accounts for the idea that identification is relevant to authenticity, since it put emphasis on the person's attitudes towards his own attitudes. In this regard it is much like the 'consistency between levels of desires'-idea, but it goes further by, in a sense, making the idea of the ancient idea of "knowing thyself" an important part of authenticity: an authentic person *can* "accept" herself, also if she were to gain knowledge about why she is whom she is. This gives rationality, in the form of knowledge about oneself, a more prominent role than the 'consistency between levels of desires'-idea, which is in line with the classic idea that (at least some degree of) self-knowledge is a prerequisite for authenticity,[29] even if this idea settles for hypothetical self-knowledge. This account of authenticity thus makes the connection between identification and rationality clear.

It also further explicates the sound core of the "consistency between levels of desires"-idea. This idea is sound because it develops the thought of a hypothetical consent to the desire. The details may be wrongly put: the mere adjustments of lower levels to higher, but the "consistency between levels of desires"-idea agrees with the idea presented here on the following important point: authenticity in particular and autonomy in general is *primarily* about authorship (the person herself being the judge of her desires) and not about rationality (even if it is about rationality too). This agreement differs drastically from the idealistic views presented earlier (III.2.2.1), which see autonomy primarily as a question of rationality and impartial acceptability.

This idea of authenticity is inspired by Brandt's theory of cognitive psychotherapy (1979, p 113). There are similarities. Firstly, the ideas agree on the presupposition that beliefs can (causally) influence desires. Secondly, the ideas agree on the emphasis of knowledge or, rather, how one would react if one had certain knowledge (Brandt, 1979, p 111): both self-knowledge and knowledge about the object of desire (since both these kinds of knowledge plausibly affects the attitude a person has towards the desire in question). Thirdly, they agree that the relevant knowledge is of a value-free kind, i.e. it is not any kind of moral acceptability of the desire that matters.

Nevertheless, there are differences. Firstly, Brandt's theory is about what kind of desires there is value in satisfying (for the person having the desire). This idea here is more narrowly confined to what desires that are authentic.

---

[29] This idea of an authentic life originates from the "seven wise" of pre-Socratic Greek philosophy (Marc-Wogau, 1970, p 15) and is a central tenet in the existential tradition.

Secondly, this idea does not require that the person having the desire should *survive* the knowledge of why it is produced and maintained (Brandt, 1979, p 113), but only that a negative attitude towards it, given knowledge about it, affects its authenticity. The reason for this modification is to preserve the idea of identification: it is whether you can approve of having the desire with knowledge of why you have that is of relevance to the idea of authenticity (to know yourself and "accept it"). Furthermore, the psychology of this idea becomes more realistic than Brandt's, since it may be difficult to give a desire up, even if you want to and realise that you should, given your own basic aims.

However, settling for hypothetical approval may seem insufficient. It may be reasonable to claim that *actually using* the capacity for evaluating one's values makes one even *more* authentic. That is, one may hold that someone who has in fact thought about why she has the desires (or more generally, pro-attitudes, including values) she has and has contemplated whether these desires hold for this scrutiny is more authentic than a person who has not done so, even if the other person's desires also were approved given this process. The reason is simply that it is difficult to think of someone as authentic if she never seriously contemplates about who she is and why.[30]

Mill most famously formulated the argument in favour of this idea. When defending freedom of speech in *On Liberty* (1859) Mill argued that, especially in matters of opinion, i.e. controversial and value-laden issues of religion, moral, and politics, an authentic person is a person who has considered opposing views.[31] To consider opposing views is, naturally, also to consider the view one holds – to critically evaluate one's own opinions. Mill's idea was that this was the best way to avoid mindless dogmatism and uncritical conformism. There are namely two ways of acquiring opinions without considering alternative ones: by authority or by inclinations (Mill, 1859, p 97). To have an opinion only because of authority or inclination is not to have because of one's consideration that this is the opinion one ought to have. In opposition, to actually consider alternative opinions is to critically evaluate one's own opinions. A person who never does this runs a greater risk of leading a life not

---

[30] It is probably something like this Lindley has in mind when he writes: "An autonomous agent does not just act on existing desires and beliefs, but subjects the desires and beliefs to rational scrutiny." (1986, p 56)

[31] Although Mill did not use the term authenticity, but freedom, since he did not distinguish between the components of autonomy, and autonomy and freedom.

according to a standard she would like if she gave it a closer look, but to a standard she merely has conformed to. And uncritical conformism seems to be in opposition to authenticity in particular and autonomy in general.[32] Besides Mill's argument, the link between identification and self-knowledge, on the one had, and authenticity, on the other, becomes even stronger than if one settles for the hypothetical version, since Mill's idea puts emphasis on actual identification and self-knowledge, and not just hypothetical.

However, this Millian conception of continuous critical self-evaluation as a precondition of authenticity might have too intellectual a ring to many. Of course, a person could lead a fulfilling life without ever considering her basic values and aims. But many, including myself, have the intuition that a person who, at least sometimes, engages in critical self-evaluation in the Millian sense is, at least, more authentic than someone who never does. However, those who do not share this intuition could still agree to the basic idea of authenticity here presented and drop this further condition. Generally, someone who has a different idea of what authenticity is altogether, can replace the idea presented here with her own, and still keep the basic structure of the definition of autonomy presented here.

To sum up: the authenticity of desires is determined by the (hypothetical) attitude the person has towards the desire: given a certain level of (hypothetical) knowledge about why one has the desire, the more positive the person is to the fact that she has it (and therefore the more enthusiastic she is about keeping it), the more authentic it is. And given more knowledge, if the attitude remains the same, the more authentic it is. To this it could be added (as I am inclined to do) that a person is even more authentic if she actually engages in critical self-evaluation: finding out why she has the values and attitudes she has and questioning them in the light of other values and attitudes.

---

[32] Lindley (1986) defends this Millian idea as a central component in authenticity, but puts emphasis on "active theoretical rationality", that is, "a disposition to seek the truth" (p 47) since he thinks that this is the best way to ensure critical self-evaluation. Though this might be a plausible interpretation of Mill, it is by no means obvious that such a general disposition is needed in order to consider alternative opinions.

2.2.3 What authenticity is affected by

It is easier to present examples of what is, or at least seems to be, paradigmatic cases of inauthenticity than to present a crystal clear definition of what authenticity is. In this section various such examples will be mentioned. If the idea of authenticity presented is reasonable, it should be able to account for these examples, showing why they are examples of inauthenticity if they are, and why they are not, if they are not.

Now, the following empirical hypothesis concerning the examples to come seems reasonable: most people would typically be inclined to disapprove of these desires if they learned that this is the explanation why they hold them. Of course, it might be the case that a person, P, is not inclined to change some desire at all, even if P has realised that it is the result of some of the processes below. P might think that this desire is something he would have tried to develop anyway or goes well along with the kind of person she is or wants to be. I think it would take an unduly strict view on the self-government of desires to consider these desires as inauthentic anyway, in opposition to the more idealistic and self-governed accounts of authenticity (III.2.2.1).

In order to make this last point more credible, consider the example of hypnosis, which seems to present an intuitively strong image of inauthenticity. If hypnosis may cause someone to hold a desire, then, generally speaking, the forming of the desire is in a sense not self-governed. But there is a huge difference between, for instance, the hypnosis of an unsuspecting victim in order to use her for some end she would not approve of herself and the voluntary subjection to a hypnotist in order to quit smoking. Presumably, in the first case, the person would not approve of the desire she has come to hold in the face of knowledge about why she has come to hold it. This is probably not true of the last case. Even if the person unsuspectingly and against her expressed desire were made to desire to quit smoking, she might not be inclined to give that desire up when she found out why she has this desire. Therefore it is not true of any *origin* as such that it makes a desire inauthentic. It is the person's own attitude towards the origin that matters on this account of authenticity. And in the light of this example, this only seems reasonable. It is made even more reasonable if I am right that the following examples typically are such that one would be inclined to disapprove of the desires in question if one came to know that the desires were the result of some of these mechanisms. It would show that this account of authenticity is in line with how we normally conceive of authenticity.

Desires and values that are the result of indoctrination, brainwashing, hypnosis, self-deception, fear, phobia and other psychological pathologies are typically such that we would be inclined to disapprove of having if we were convinced that this is how they came about.

Other examples are desires that are the sole result of non-reflected reactions to our social surroundings: desires that we acquire *just because* everyone else has them (conformism) or *just because* they go against everyone else (anti-conformism). Just because we would feel, if we realised that this is why we have these desires, that they are not self-governed, we would feel reluctance towards them.[33]

Other examples of desires that most of us would react to in a similar way are what Elster has called the "sour grapes"-attitude and "the grass is always greener on the other side"-attitude (Elster, 1983, p 22-25). The first mentioned attitude is to put into your head that you do not want a thing just because you cannot get it for the time being or because it is hard to achieve (so-called "adaptive preference formation").[34] The latter attitude is to put into your head that you wish for everything you cannot get, just because you cannot get it (so-called "contra-adaptive preference formation"). Both these attitudes could be described as forms of self-deception.

The relation of desires to beliefs can also cause the desires to be less authentic. Wishful thinking is a good example (also a form of self-deception).[35] Furthermore, previously unknown information can, of course, assist one in

---

[33] These examples, like the following ones in this section, are Elster's, 1983 (p 22). However, Elster's idea is about the rationality of desires in general, and he advocates the idea that desires are irrational if and only if (and because) they have been shaped or formed in the "wrong way", i.e. due to their causal origin (p 15-16), the relevance of which this idea of authenticity denies.

[34] This attitude should be carefully distinguished from intentional character formation, i.e. to try to mould one's character with the aim to conform one's desires to one's possibilities. Adaptive preference formation typically results in degrading what you do not have, and intentional character formation typically results in upgrading what you have (Elster, 1982, p 224). Adaptive preference formation is also something else than changing your values in the light of new experiences. If this change of attitudes is a result of adaptive preference formation, the change will typically be reversible and have a tinge of resignation. If it is a result of new experiences she starts to value, the change will not be reversible and resigned (Elster, 1982, p 220-221).

[35] Wishful thinking may be conflated with adaptive preference formation. I could to cease to desire a promotion, either because I persuade myself that the job probably is not much fun anyway (wishful thinking) or because I persuade myself that I do not value it (adaptive preference formation).

realising that a desire is not as authentic as one thought, since such new information of why one holds the desire can lead to the disapproval of it.

This relates to another point that does not regard the question of whether a desire is authentic, but whether it is basic. New information can help a person to form a desire if the person is unsure about what she wants. If I find out more about a medical procedure, my initial reluctance towards it may fade away, for instance. This shows that proper information can be crucial to achieve what one really wants, i.e. to achieve one's basic desires. We will return to this point (see III.2.3.2 and III.2.4.2).

To conclude, both internal and external factors affect the degree of authenticity. External factors that, as a matter of empirical fact, tend to reduce the authenticity are indoctrination, deception and other forms of manipulation from others than the individual herself. Internal factors that tend to reduce the degree of authenticity are self-deception, ignorance, psychological pathologies, fear and confusion.

2.2.4 The regress revisited

The strength of the idea of authenticity presented here (from now on called the 'informed approval idea of authenticity') is that it accounts for several intuitions of authenticity, while avoiding shortcomings of alternative ideas. However, it also has some problems of its own, of which I will address one here. I will try to explain why I think that this problem really is no problem, or at least why it is not insurmountable.

It might seem as if an argument of regress can be levelled against the 'informed approval'-idea, similar to the one levelled against (one version of) the 'consistency between levels of desires'-idea. The line of reasoning behind this goes a follows. If I come to know why I have a certain basic desire and approve of having it, the question remains if I would have approved of this approval, had I learned about why I had it. So the question is, do I have to (hypothetically) approve of an (hypothetical) approval of a desire in order for the desire to be authentic? If the answer is yes, a regress is looming, since the "second order-approval" also can be approved or not, given knowledge of the explanation of this approval, and so on.

However, I think the answer to the question of whether I have to approve of the approval in order for the desire to be authentic is no. One may think

that this way of biting the bullet is to blunt, but I believe the following example demonstrates (or, at least indicates) this to be a legitimate move.

Imagine an enthusiastic citizen of a totalitarian regime. She has been indoctrinated all her life to be willing to sacrifice her life to the great leader. It is a basic desire of hers to do so, if she has to. Let us assume that this citizen were to find out why she had this desire, e.g. that it was the result of systematic indoctrination, that the purpose of the indoctrination was not the best interest of the citizens but the maintenance of the regime,[36] that the leader would not sacrifice himself for her,[37] and so on. Let us moreover assume that this would result in her disapproving of her having the desire to sacrifice herself for the leader. However, she also comes to realise that this disapproval is explained by her desire "to be the own architect of her own life", a desire founded on individualistic bourgeois values she disapproves of. Thus, she comes to disapprove of her disapproval.

When considering this example, it seems to me as though the fact that she comes to disapprove of her disapproval to sacrifice herself to the leader does not affect the inauthenticity of her desire to sacrifice herself for the leader. It seems strange to say that her disapproval of her disapproval to sacrifice herself for the leader would make her desire to sacrifice herself for her leader more authentic. Possibly, it makes a possible desire not to have that desire anymore less authentic. But that does not rob the hypothetical disapproval of its ability to reduce the authenticity of desires. The 'informed approval'-idea says that the (hypothetical) approval of a desire if one knows why one has it affects the authenticity of that desire, nothing more. So, in fact, the regress never arises. To put it in terms of a slogan: authenticity is not hereditary.

This is unlike the version of the 'consistency between level'-idea that *requires* a higher level of approval in order for lower levels to be authentic. Then the regress arises. This is not so regarding the 'informed approval'-idea. This idea only admits the possibility that the disapproval of a desire may be disapproved, if one has knowledge as of why one disapproves of the desire, but denies that this affects the authenticity of the desire due to the disapproval of it.

---

[36] This is (a part of) the explanation of why the indoctrination takes place (or so I assume), and, thus, (a part of) the explanation of why she has the desire. Generally, the explanation of a person's desires is (partly) "external", i.e. not about the person herself.

[37] Let us (realistically) assume that the explanation of the maintenance of her desire is conditioned on beliefs like this.

However, one may still feel that the 'informed approval'-idea is too liberal, counting too many intuitively inauthentic desires as authentic. Change the example above to say that the enthusiastic citizen still approves of the desire to sacrifice herself for the leader. However, I think it would take an overtly rigorous idea of authenticity to say that this desire is still not (more) authentic (than it would be if she were to disapprove of it given this knowledge). It would probably require some reference of a notion of a "true self" or impartial reasons ("what really is in her best interest"). I have already argued why I think those to be mistaken (II.2.2.1).

However, if we were to say that one would be even more authentic if one actually has knowledge of why one has a desire (which I am, see II.2.2.2), then, of course, the process is, in principle, indefinite. That is, if you have subjected yourself to something like the process of cognitive psychotherapy and the result is approval of some attitude, this approval (or "the person you have become") can also be subject to the same process. But this only goes to show the well-known fact that the process of knowing and developing oneself is and endless one. And it is not implausible to claim that a person who engages in such a process is more authentic than someone who does not.

2.3 Decision competence

In biomedical ethics, much discussion has revolved around autonomous decision-making, rather than authenticity, i.e. properties of the will that may affect the autonomy of someone. When talking about the capacity for, or ability to, make autonomous decision, one often refers to the term competence (Beauchamp & Childress, 2001, p 69-77). Just like authenticity, decision competence is linked to rationality, since being at least minimally rational seems to be a prerequisite of competence: one has to be able to consider some alternative courses of actions and some possible impact of one's own doings, even if only very sketchily, in order to reach a decision on what to do. However, unlike authenticity there is less controversy about what competence consists of, namely the ability to make decisions from one's own desires.

Obviously, the conditions of rationality for competence may vary in strength. Most theories of autonomy includes an idea of a threshold, over which everyone should be counted as decision competent and under which everyone should be counted as incompetent. In order to avoid excessive paternalism, many writers have been generous in trying to establish when one

should be counted as competent, so that at least all normal grown up individuals are above the threshold (Beauchamp and Childress, 2001, p 72-73; Tännsjö, 1999, p 13-15).

However, the question: "When should an agent be considered to be decision competent?" is normative and the answer thereby falls in the domain of the ideal of, rather than the conception of, autonomy. Since the purpose here is to elaborate a conception that can be useful to formulate different, and possibly contradictory, ideals of autonomy this question will not be addressed further in this context. It suffices to establish the fact that different individuals may be more or less competent and that an individual may be more or less competent in different situations. It certainly seems reasonable to postulate a lower limit under which it makes no sense to ascribe a person any competence at all. But the question about when we should consider an agent to be competent does not automatically settle the question of when we should *treat* an agent as competent in particular and autonomous in general. I will return to this point when discussing ideals of autonomy (see III.3.3).

2.3.1 What decision competence is

Decision competence, that is, the ability to make decisions from one's desires is, then, another component that affects the autonomy of someone. For someone to be able to make a decision about what to do, it is not enough to want something. One also has to have an idea about how to act in order to achieve what one wants. However, any old idea will not do – hence, the need to talk about *competence*. Therefore, this component is essentially about the rationality of beliefs.

More precisely, to be decision competent is to be able to decide what to do on the basis of one's desires and beliefs in cases where several options are open. This presupposes, among other things, a minimum of imagination, so that one's options and what they might lead to may be contemplated. This is necessary in order to realise that there are alternative courses of action at all, but also for the next ability of importance for decision competence: that of being able to judge the alternatives one considers. This presupposes that one understands that what one does (but not only what one does) affects the outcome, and that different outcomes are possible. To be able to make the judgement one must also have an idea about how much one values the possible outcomes of the alternative actions. In other words, one roughly has

to know what one wants[38] (this has already been discussed in the section about authenticity). However, besides this, one also must be able to scrutinize one's options in the light of this knowledge about what one wants and beliefs about how these wants may be achieved. This last point calls for some elaboration.

Consider the following illustration. Jenny wants to gain some weight. This desire, of course, presupposes that she can imagine a possible state of affairs that is not realized (the state of Jenny weighing more). Let us moreover assume that this desire is basic and authentic. In order for Jenny to be able to reach a decision at all on the basis of this desire, she must have some idea (belief) about how she is to act in order to achieve what she wants. If she has many alternatives she believes might accomplish this end she will have to deliberate. However, any way of going about this will not do if Jenny is to be competent. Consider, for instance, if Jenny knows that eating more sugar and fat will help her gain weight, but concludes that, therefore, she should *avoid* sugar. Or consider if she in her deliberation pays most attention to her belief that gin and vermouth makes a dry martini, and then concludes that she should switch to green pants instead of blue.

These examples show that decision competence is not just about having beliefs relevant to one's desires. It is also about having the capacity of relating the relevant beliefs and desires to each other in a psychological process that has the potential of becoming a decision. Of course, having the capacity for competence does not imply that one actually uses this capacity to make rational decisions. And if one does not, one is less likely to be efficient I realizing one's decisions. I will return to this shortly.

To avoid further confusion, one should carefully distinguish between being a decision competent person in general and in fact being decision competent in a certain situation regarding a certain desire. It is the last sense of decision competence that will be of relevance in the following. A person may of course have the capacity for competent decision-making in general without having any desires and beliefs at all (if she had them, she would be able to make a decision). However, to be able to make a decision in a certain situation

---

[38] This, of course, is not to say that a person has to know exactly what she wants and how strong she wants it in order to reach a decision, but a person has to have some desire to act from in order to reach a decision. Too much confusion about what one wants may make it impossible to reach a decision (see III.2.3.2).

to realize a particular desire, one has to have certain beliefs, e.g. about how to realize that desire. Moreover, it may be more difficult to reach decision in a certain situation if I have vague conceptions, if I am confused and so on (see III.2.3.2). In that sense my decision competence (the psychological process I mentioned) can be affected negatively from more or less information.

This leaves one final point to investigate. Consider again Jenny and assume that she is fully capable of relating her beliefs to her desire to gain weight and to make the rational conclusion in the form of a decision. However, it so happens that her beliefs are the opposite of the facts of the matter. She believes that eating more fat and sugar will cause her to loose weight and thus decides to avoid eating food containing much of such ingredients. Moreover, she lacks any rational reasons for believing what she does. In this case, it is a tempting thought that the fact that she lacks true or rational beliefs relevant for her decision makes her less competent. And conversely, the better reasons she has for the decision in question, the more competent she would be. So, given an authentic and basic desire, is a person more decision competent (and thereby more autonomous) the better reasons she has for her beliefs about possible outcomes (and the probability for them)?

In one sense, it seems reasonable to answer yes. To be true, I increase my possibilities of *succeeding* in living my life in accordance with my plans if I make decisions from well-founded and carefully deliberated judgements. To really succeed in realizing one's desires one should have (to a large extent) true beliefs, since false beliefs about the consequences of one's decisions and acts may result in one's desires not being realized.[39] In other words: my ability to succeed in acting in accordance with my decision in the way I desire (probably) increases the more relevant and well-founded information I have. So, while my decision competence does not necessarily increases with more knowledge (III.2.3.2), my ability to successfully act according to my basic desires (probably) increases.[40] In consequence, having well-founded beliefs is

---

[39] Lindley expresses a similar line of reasoning in a concise way: "If anyone arrives at a decision through bad reasoning, it is a matter of luck whether the decision best promotes his fundamental projects." (1986, p 26) It made thus be added that the same goes for erroneous information.

[40] The careful reader will here notice an ambiguity in the conception of autonomy: is autonomy about doing what one decides to do (because one decides to do it) and deciding what one wants (because one wants it) or getting what one wants (when my desire causes my decision and my decision causes my action). I will return to this question (III.2.4.1).

more relevant to the efficiency-component, which I will return to below (III.2.4). Remember that decision competence is about the ability to make a decision. This does not require one's beliefs to be well-founded at all. Of course, one may be psychologically unable to reach a decision in a situation because one feels that the information one has is too uncertain for making a decision in that situation. So, even if rational beliefs foremost affect the efficiency of a person, it may affect her decision competence.

2.3.2 What decision competence is affected by

As already mentioned, getting information may affect a person's decision competence. With more information regarding what alternative courses of action one has and what will happen given these different alternatives, it may be easier to know what to decide in order to achieve one's aims. However, it is important to emphasize that all additional information does not necessarily increase the decision competence of a person. The competence of a person *may* be damaged by a lot of things, for instance further information. Fear and confusion are two types of states of mind that may impede a person's ability to make a decision. A person may be paralysed or may "shut down", thereby becoming unable to weigh alternatives or, at least, less discerning due to fear and confusion. A lot of, very complicated and/or dramatic information, e.g. information about genetic susceptibility for fatal disease, can result in such fear or confusion and, thus, reduce autonomy. On the other hand, the information may mitigate the worries of a person who feels uncomfortable with uncertainty, making her sufficiently confident as to decide on plans for the future. This relates to the argument in the previous chapter, that genetic information may both reduce and enhance autonomy (see subsection II.2.3). In the light of this, I already at this point dare to hint that it is hard to unequivocally argue for duty to know or even a right to know about genetic information about oneself on the basis of autonomy (a point I will argue in chapters IV and V).

Other factors that can influence a person's decision competence are obsessions, phobias, unclear beliefs and cyclical preferences. A person who is obsessed with the thought of returning to her home in order to check the stove at least three times on every occasion she walks out may very well wish she did not have to do this, but may be unable to make that decision (or unable to act on it once she made it). It seems obvious that this person's autonomy is thereby reduced. Phobias, neuroses and other psychological

pathologies can naturally result in the same sort of incompetence to make a decision (the decision one would like to make in that situation, that is). Unclear beliefs about what will happen may make it difficult to make a decision. Cyclical preferences and other inconsistencies of desires can make it difficult to reach a decision (see III.2.2.1).

Just like values that are immune to revision defeats authenticity, beliefs that are immune to revision defeats decision competence. "Immunity towards revision" should be taken in a very narrow sense, however. It is enough that there is a possibility of revision of beliefs in the light of new information or new experience. This does not exclude strange or unusual beliefs. However, they must not be of a compulsory nature. It is hard to demarcate "compulsory beliefs" in another way than to refer to impossibility to revision in the light of new information or new experience, and this is not crystal clear either. An example might be illuminating, however. Assume that Jane believes that she cannot talk to a certain doctor because the doctor is possessed by the devil. If Jane is unable to revise this belief, because she hears voices in her head telling her that this is so, her belief is of a compulsory nature. However, the belief is not of a compulsory nature due to its content, although it is strange. Jane might have that belief because she has seen the doctor speaking deliriously at a secret order and she believes that the devil exists and is capable of possessing people. In that case, the belief about the doctor does not have to be of a compulsory nature.

2.4 Efficiency

As we have seen, the extent to which a person is autonomous, i.e. "her own master", "in control of her own life", "self-determined" or something of the like, hinges on the extent to which her plans, projects, wants, or, as I have called it most of the time, desires, are really her own, that is, authentic. Furthermore, it depends on the person's ability to make decisions from her desires, that is her decision competence. However, in order to be autonomous in a fuller sense, we also want to "put our plans into action", so to speak. It is fine and well to rule one's inner world, but we also feel that autonomy is about (having the capacity to) achieving or accomplishing or realizing what we really want and decide to do. This is what efficiency is about.

2.4.1 What efficiency is

Autonomy, thus, is about efficiency too. Efficiency, in the context of autonomy, consists in the ability to implement one's decisions through action. More precisely, the more ability a person has to, through her own acting, realize what he has decided to do (determined by what he wants), the more efficient she is. Of course, ability to act in *some* way is not enough efficiency in any interesting sense of the word. Efficiency rather consists in the ability to realize the desires one has.

However, one may think that having the *ability* to realize one's decisions is not enough for efficiency and, thus, autonomy. Instead, one may hold that efficiency consists of the actual realization of one's desires, i.e. actually achieving one's goals. I would say that this is a perfectly legitimate use of the term "efficiency" in the context of autonomy. This means that efficiency can have two meanings: having the ability to act as to realize one's desires, and actually doing so. Which one of those, if any, or both, is valuable is a question for an ideal of autonomy to settle.[41]

Thereby, another ambiguity in the conception of autonomy rises to the surface. Am I autonomous when I do what I have decided to do (because I have decided to it) and decide to what I want (because I want it) or when I get what I want (when my will causes my decision and my decision causes my act)? The answer is that autonomy is not only about acting or only about getting what you want; it is about achieving or realizing what you want through your own action. Let us use an example to elaborate the point.

Jill wants to lose some weight. Jill thinks that she will accomplish this by eating loads of pastries every day (a false belief). Therefore she decides to eat loads of pastries every day. Since Jill is efficient with regard to this decision, she effectuates this plan: Jill starts to eat loads of pastries. This action (or, rather, these actions) seems autonomous. But Jill does not achieve her end to lose weight; to her own surprise she starts to gain weight. Is Jill autonomous? In one way it seems reasonable to say she is: she acts on the basis of a (let us assume) basic desire, without (let us furthermore assume) being manipulated

[41] The ideal of self-realization holds that it is actually achieving what one wants that is of value (see III.3.1.1), and the ideal of capacity holds that it is the ability to do so that is of value (see III.3.1.2).

or forced in any way. In another way it seems reasonable to say that she lacks autonomy, since she does not realize her basic desire to lose weight.

It should be observed that the point is not only about making the distinction between basic and derived desires. Of course, the basic desire Jill wanted to fulfil was the desire to lose weight. Jill mistakenly thought that eating loads of pastries is a good means to reach that end. That false belief is the explanation why Jill did not succeed in fulfilling her basic desire, although she succeeded in fulfilling her derived one. This relates to another point that has already been made: in order to succeed in living in accordance with one's basic desires by one's decisions and actions one has to have, to a large extent, true beliefs (see III.2.3.1). Irrational, in the sense ill founded, beliefs can damage a person's efficiency.

The crucial point in the present context, however, is that autonomy is not about maximising the satisfaction of preferences – it is about being able to realize and, in fact, realizing one's own basic desires through one's own decisions and actions. The lack of autonomy in the example above is due to lack of efficiency; Jill could not effectuate her basic desires due to false beliefs. Granted, she satisfied one of her desires (eating pastries) and she did it through her own acting. But that is not enough to make her more autonomous, since she did not satisfy her *basic* desire. But even if her basic desire had been satisfied, for example through divine intervention, this would not have made her more autonomous either. The central idea of autonomy is *self*-determination – that you yourself realize your plans. In opposition, the central claim of any form of preferentialism is that it is of value for a person, P, to have her preferences or desires satisfied. How, and by whom, the preferences are satisfied is, in itself, irrelevant. It is thus essential to any idea of autonomy that an autonomous person does not only *get* what she wants, but that she *achieves* what she wants: there has to be connection between my acts and the satisfaction of my desires. A person in "the matrix"[42] can have all of her desires satisfied – even desires about the world outside the machine if we track the person's experienced desires and realize them in the external world. However, this person does not govern her own desires, never makes a decision and never acts. She is completely non-autonomous and gets it exactly

[42] I am thinking about the great computer from the movie "The matrix", where all people are hooked up, believing that they are leading a life in the external world. The same point applies to Nozick's "experience machine" (Nozick, 1974, p 44-45), for those familiar with that example.

her way. Thus, autonomy cannot just be about getting what one wants. Rather, it is about accomplishing one's basic projects (or being able to do so). This is the crucial difference between preferentialism and autonomy. And this is why efficiency has to be a component of any conception of autonomy: an inefficient agent cannot realize her plans through her own acts.

However, the fact that efficiency is a component of autonomy does not imply that one cannot reduce the autonomy of an inefficient person. The following example can be used to illustrate why. I am facing death, paralysed and in terrible pains. I do not desire anything stronger but to end my suffering. The only way to accomplish this in this situation (we assume) is to inject such a large dose of morphine that I will die as a result. I understand this, but still want to have the injection. This is so, since ending my suffering is a basic desire of mine, and much stronger than the desire not to end my life. However, since I am paralysed, I cannot effectuate the decision to take the injection myself. However, I ask my doctor to administrate the morphine. He, alas, refuses.

In the light of this example, it seems reasonable to claim that I am less than fully autonomous in this situation and that this is due to my inefficiency. However, despite the fact that I am inefficient, it seems as though the doctor reduces my autonomy. In order to live my life according to my own basic desires and values it is not enough to try. I have to succeed in doing this. This may require the help of others. Of course, there may be reasons for them to refrain from helping me. Nevertheless, it seems reasonable to claim that the more I succeed in living according to my own basic desires, the more autonomous I am. Through refraining from giving me this help, the doctor makes my life less autonomous than it would have been if he had helped me. Therefore, in a way, the doctor is reducing my autonomy.

This example demonstrated that one can, in a sense, talk about an inefficient person being autonomous. For instance, one may very well have authentic desires and make autonomous decisions on the basis of those, even if one cannot effectuate them. Then, naturally, we can talk about autonomous decisions and the person making these decisions being autonomous (in this sense). One can also formulate ideals of autonomy that do not deal with efficiency at all, but rather respecting autonomous *decisions* (in fact, this seems to be the standard in biomedical ethics). According to such an ideal, it could be claimed that the doctor, by refusing to give me the lethal injection, is not

respecting this decision and my autonomy is, in this way, violated. Of course, such an ideal would have to be further elaborated in order to be reasonable.[43] However, any such ideal is perfectly compatible with, and even well formulated by, this conception of autonomy. Even such an ideal would not deny that a person, who can realize her plans herself without the aid of others, is *more* autonomous than someone in constant need of the help of others. This is compatible with claiming that the only duty or value of autonomy is to respect the autonomous decisions of others.

Another ideal of autonomy could claim that we should make the agent herself maximally autonomous. The doctor may be able to accomplish this by palliating my paralysis enough to enable me to administer the drug myself. In this way, the doctor has helped me to live my life according to my own basic desires. Being such a person, or living such a life, may be taken as valuable. If the doctor refrains from doing this, he omits to realize value for me he could have realized. In this way, my autonomy could be claimed to have been "violated".

2.4.2 What efficiency is affected by

Many factors affect the ability to, through action, realize one's decisions, and the extent to which one actually does so. The example with the doctor in the previous subsection demonstrates that other persons can help one to become more autonomous (e.g. through palliating the paralysis). Repeatedly, I have pointed out how ignorance or lack of information may render one inefficient, since ignorance about the effects of one's actions may lead to opting for a course of action that one thinks will realize one's aims, when it actually will not. So knowledge affects efficiency. However, we have also seen that knowledge may affect efficiency negatively, e.g. due to giving rise to paralysis or depression (see II.2.3.2).

This relates to other examples of factors affecting efficiency, which are "internal" forms of obstacles to carry through one's desires, e.g. weakness of will, inertia, or compulsive acts, like the compulsion of the alcoholic to start to drink again (despite not wanting to) and the compulsion of the kleptomaniac to steal whenever she enters a store. These people fail to effectively carry

---

[43] For instance, it seems unreasonable to claim that we *always* have to respect the autonomous decisions of others, especially when we have to carry them through due to the inefficiency of the agent herself.

through their decisions – even if they decide to stop drinking and stop stealing they may fail to act on these decisions. This kind of inefficiency can of course come in degrees, depending on the extent to which the person is still able to avoid the failure in question.

Also external coercion and obstacles can affect a person's ability to act on her decisions in a way that makes her achieve her own basic aims. Threat of reprisals may make it more psychologically difficult for me to carry through my decisions (given that I do not want to expose myself to these reprisals). In this way, threat of reprisals can reduce my autonomy. Just as other persons can decrease my efficiency, they may also increase it. A partially deaf person may become more able to realize her desire to complete a course at the university if she is provided with hearing aid and other facilities.

All this may come through as farfetched to some. Does this mean that I am not autonomous unless I can realize all my authentic and basic desires? If I wish to fly like a bird or abolish global capitalism but cannot do this, am I thereby not autonomous?

To answer this I must once again stress 1) that autonomy is a matter of degree, and 2) the distinction between conception and ideal. I may have the authentic and basic desire to fly like a bird. I do not find it strange at all to say that I would live a life more in accordance with my basic desires if I could do this compared to now when I cannot. This does not mean that I am not autonomous since I cannot fly like a bird (except perhaps if this was the only thing I ever wanted), but that I would be more autonomous if I could. Nor does this mean that other people have an obligation to help me to succeed in flying like a bird. Possibly, my life would be better if I could (given that increases in autonomy always is valuable), but this still leaves open to what extent people are obliged to make my life better.[44]

Likewise, it is probably unreasonable to demand that other people should give me the capacity to abolish global capitalism. But if I controlled the external circumstances to such a degree that I could do this if I wanted to I would be more able to realize my decisions than I am at present, i.e. more efficient. And it is not inconceivable that this would be something of value for me.

---

[44] But what is it that is valuable? To fly like a bird or to be able to? We will return to this (III.3.1.1 and III.3.1.2).

2.5 What autonomy is not

The notion of autonomy is ambiguous and has been understood in a multitude of ways throughout history.[45] The purpose here is not to account for every possible use of the concept of autonomy. The purpose is rather to elaborate a conception that is useful in order to explicate recent ideals and, foremost, ideals that has been discussed or presupposed in the area of biomedical ethics during the last decades (III.1). In this section I will address some ideas that are closely related to autonomy. These ideas are not identical to the idea of autonomy presented above, but are sometimes taken to be so. In order to avoid conflations and misunderstandings I will therefore present these ideas and explain how they differ from the conception of autonomy just presented.

Autonomy has often been taken as being equivalent, or at least closely related, to the idea of free will. Kant is perhaps the most well known spokesman for this view: a person is only free if she is autonomous. In this relation Kant saw the meaning of free will. According to Kant, we act freely when we act out of reason, not governed by our "empirical" motives.[46] To act out of reason is to act on the maxim through which you can at the same time will that it should become a universal law, i.e. the Categorical Imperative. But this is also what it means for Kant to act autonomously. According to Kant, acting autonomously (to govern one's own behaviour by acting out of reason) is thus equivalent to acting freely. I will not try to investigate the possible merits of this conception of autonomy,[47] mainly because I am able to formulate the Kantian ideal of autonomy with my own conception and that the Kantian conception of autonomy is of no help to formulate any other ideal of autonomy than the Kantian one. In addition, it has few modern spokesmen in biomedical ethics.[48]

Modern discussions of free will are often about the possibility of acting differently than one actually does and whether this possibility (if it is a

---

[45] See Schneewind, 1998, for a robust discussion of the history of the idea of autonomy in western philosophy, especially up till and including Kant.

[46] For a discussion on the difference between empirical and pure motives, see Nell, 1975, p 103-104.

[47] There are some good reasons to be sceptical towards it. See Lindley, 1986, 22-26.

[48] To my knowledge, the only one relying on a conception that can be interpreted in this direction in the debate of genetic testing is Rhodes (1998, 2000). For a discussion, see V.3.1.

possibility) is compatible with determinism. My own conception of autonomy is neutral regarding that discussion.[49] Seemingly, there is a connection between determinism and the conditions of non-compulsive desires and beliefs. However, contrary to impression, these conditions do not say that it should be (nomologically) possible to have different desires and beliefs in a certain situation than the one's you actually have, but only that the desires and beliefs you have should be possible to revise in the light of new information or experience (see III.2.2.2 and III2.3.2). This does definitely not imply that anyone should be able to act differently than she actually does in any way incompatible with determinism. Free will in the sense "can act differently than one actually does" is thus not identical to autonomy as explicated here.

Freedom, in another sense of the word than "free will", also tends to crop up in relation to discussions of autonomy, namely freedom understood as liberty to act. However, questions about restrictions of someone's liberty to act are rather about social freedom than autonomy. The idea of social freedom is not the same idea as the idea of autonomy. (Even if there is a relation between the ideas, since restrictions in a person's social freedom may also reduce her ability to realize her basic desires (see III.2.4.2).)

Social freedom is often defined as absence of social obstacles (to do what you want). More precisely, a person P is free to perform a certain action X if there is no other person (or groups of persons) Q that prevents P from doing X.[50] This makes freedom a relation between three variables, two persons (or groups of persons) and one action. It is possible to be free without being autonomous. If I am hypnotised to want something and no one prevents me from realizing this wish, then I am socially free (to perform the action), but (probably) not autonomous. This since my wish is (probably) not authentic. To be socially free is thus not sufficient for being autonomous.

Social freedom is not necessary for autonomy either. If I am faced with the alternatives "your life or your money" I think I would prefer "both, please". In such circumstances, this alternative is not open to me. This does not prevent

---

[49] This seems to be the case for most modern conceptions of autonomy. See Lindley, 1986, p 24-25.

[50] This idea seems to presuppose some notion of a free will, since absence of the prevention of others can be of interest only if the person can perform the action if not prevented. "Prevent" is, of course, unclear. For instance, is the threat of sanctions always prevention?

me from autonomously choosing between the alternatives I am facing, however.[51]

Freedom can also be interpreted as access to alternatives or options: the more alternatives a person, P, has in a certain situation, the freer P is in that situation (Räikkä, 1998, p 51).[52] Let us call this interpretation "freedom as opportunities". Jill may have opportunities that others lack, like the opportunity to buy a yacht. Despite this, Jill may be non-autonomous (she may be inauthentic due to manipulation or she may be decision incompetent).[53] Jill may also lack the opportunity to buy a yacht, but may nevertheless be able to form her own idea of a good life and live in accordance with this idea.

The fact that autonomy should be separated from these ideas does not preclude that autonomy is about acting. On the contrary, it certainly is. An authentic and decision competent person may nonetheless be unable to act according to her out of her basic wants and decisions. That is, she may be inefficient in the sense here adumbrated (III.2.4.1). A person who is constantly suffering from weakness of will or a person who all the time hears voices in her head forbidding her to act in accordance with her decisions is hardly autonomous. Nor is a person who is prevented from realizing her basic desires due to external obstacles, e.g. through imprisonment.

2.6 Autonomy's relatives

How should one assess this conception of autonomy? As already mentioned, the most important measure of success in this context is if this conception captures and makes sense of modern discussions in biomedical ethics and then primarily those that are about the right to and value of genetic information. I think the discussion in the previous chapter proved that to be the case (II.2.3). This will be further demonstrated in the chapters to come. However, a good conception should also be in accordance with and explain

---

[51] However, the person robbing me can be said to circumscribe or affect my autonomy negatively (see III.2.4.2).

[52] This idea is probably pointless, since a person may be facing an infinite or at least indeterminable number of alternatives in every situation ("alternatives" in the sense "actions that could have been performed by the agent, had he chosen any of them"). (Tännsjö, 1998b, p 40).

[53] It may be claimed that a person, P, who is decision incompetent in fact has no possibility of buying a yacht. "Possibility" should, in this context, be interpreted as "P could do so if P decided to" (P has enough money, is not prevented by someone else and so forth).

our linguistic intuitions or *platitudes* about autonomy. A test of the conception is therefore to see whether such platitudes of autonomy can be formulated in terms of this conception. The most important platitudes about autonomy (authenticity, decision competence and efficiency) are already a part of the conception. However, there are more particular ideas of what autonomy is, or platitudes of autonomy, that can be used to test and clarify this conception. The method consists in formulating a number of properties often ascribed to the ideally autonomous agent and then seeing how they match the conception of autonomy presented. This section will be about this.[54]

2.6.1 Platitudes of autonomy

Control. The autonomous person has control of his life. She is neither under the uncontrolled mercy of inner compulsions and impulses, nor outer obstacles like the coercion or manipulation of other people.

This platitude expresses, I would say, the heart of autonomy and in obvious ways connects very well indeed to the conception of autonomy fleshed out above. However, "control" must be specified. Consider the following characterisation of autonomy:

> To have autonomy is to have the various aspects of one's life under one's control. Typically, if I have autonomy over some aspects of my life... then I can deliberate over how I want that aspect of my life to go, choose among the various alternatives open to me, and act so as to make my life the way I want in this regard. (Kagan, 1998, p 111)

Firstly, the control relevant for autonomy is the control one has over one's wants, decisions and actions, as this quote indicates and as the conception of autonomy favoured here spells out. Secondly, the "control" is not of some metaphysically extravagant kind, presupposing a homunculus or noumen managing the wants, decisions and actions. The idea is rather "control" of wants in the sense of an at least potential conscious reflective relation of the person to herself, embedded in social context that is the root of most values

[54] This enumeration of properties draws heavily on the one made by Feinberg, 1986, p 32-44.

and desires (see III.2.2.2).[55] And control of decision is the actual ability in a particular case to deliberate over the alternatives one faces in order to reach a decision. And control of action is the actual ability in a particular case to act "so as to make my life the way I want in this regard" (Ibid.). This, of course, presupposes of any person that she is not in the grip of "internal" compulsions or "external" obstacles.

Self-possession. An autonomous person has no guardian. The autonomous person is definitely no one's slave, no one else's property.

This clearly is an ideal that prima facie is related to autonomy. In the next section, an ideal of autonomy that put emphasis on being an autonomous person (the ideal of capacity) will be presented. This ideal corresponds well to the idea of self-possession. A person who is governed by others can to various degrees be prevented from realizing her own decisions. This person's efficiency is thus reduced. This also reduces the person's possibility to live an autonomous life (see the ideal of self-realization, III.3.1.1). Furthermore, a person who is not allowed to run her own affairs is not being treated as if she were autonomous, which is another ideal of autonomy that can be formulated with the help of my conception (see III.3.3). Moreover, such a person is not encouraged to form her own plans and projects by critical evaluation, which can be viewed as bad from the point of view of authenticity (III.2.2.2).

Self-identity. An autonomous person does not define herself solely in relation to someone else, but has an identity of her own.

The idea of self-identity is loosely connected to the component of authenticity. However, it is important to account for the relationship more precisely, since self-identity is not a part of what authenticity is, but rather a likely result of being authentic. It may be the case that the most important project in a person's life is being a good husband (to X). The most important trait of the person, according to the person himself, is thereby defined in relation to someone else (X). If this basic desire is the result of a mechanism,

---

[55] I emphasise this once again in order to avoid popular, but often tedious and misconceived, allegations of "social atomism" and/or "Kantian noumenalism". It should be clear by now that such ideas are incompatible with my favoured conception of autonomy.

knowledge of which in no way would make him inclined to disapprove of it, then this conception of autonomy will not regard this desire as inauthentic.

This conclusion may seem to be at odds with the idea of self-identity. I think we should accept it, however. The correct connection between autonomy and self-identity is that a person may sometimes properly object to the picture other people have of that person. If someone says that Jack is nothing but his wife's husband he may object in two ways. Firstly, he may object that he has other projects and values that are genuinely his own. Secondly, he may retort that this is described as something not self-governed, and thereby as something condescending, when it in fact is something he himself has chosen or he himself has no problems with.

The idea of self-identity could be understood as an idea of independence or authenticity in a more direct sense: to be short of self-identity could be understood as not having the capacity to critically reflect upon who one is and wants to be. The idea of self-identity will then be almost identical to the idea of authenticity. The person who in fact critically reflects on his person and values could be said to be more autonomous than a person who does not (see III.2.2.2) but does not have to be. This depends on the version of authenticity one thinks is the most defensible in the end, i.e., what idea of authenticity one believes is most plausibly combined with the idea that authenticity is valuable.

Moral independence. A proponent of autonomy could be interested in autonomy in a "fuller" or "more substantial" sense than the one presented here. She could hold that it is not enough to live one's life according to one's basic desires or something like this. Instead the claim is that one has to live one's life independent of others to the largest extent possible in order to be autonomous. More specifically, an autonomous person is a person that has as few and weak commitments towards others as possible. A person who constantly has to consider obligations towards others may be thought to be too dependent to be ideally autonomous. This idea has the minimization of moral commitments towards others as an ideal for the autonomous person; one should promise as little as possible, avoid engaging in obligating relationships (such as marriage and parenthood) and avoid binding contracts. The idea, then, is to maximise some kind of "private sphere" where one can engage in projects that only concern oneself.

This idea of autonomy *can* be formulated with the conception of autonomy presented. To be sure, this conception does not in itself exclude

any kinds of basic values, projects and plans (i.e. desires in the wide sense used here) for a person, as long as they are authentic. However, anyone attracted by the ideal of moral independence could argue that a reasonable ideal of autonomy includes the idea that the fulfilment of certain authentic projects lacks value, at least from the point of view of autonomy, e.g. the fulfilment of projects that are the result of obliging relations to others

However, I myself find the platitude deeply implausible. It is hard to see why voluntary, well-considered commitments towards others should reduce the autonomy of a person. The idea of moral independence implies that a person who intentionally chooses to concentrate on her family or political engagement is less autonomous and leads a less desirable life than the person who intentionally devotes her life to her collection of stamps. This implication is not attractive, neither from the point of view of morality in general, nor from the point of view of autonomy in particular. Nonetheless, it can be formulated as an ideal within this conceptual framework.

Self-reliance. This idea is similar to the previous. The idea is that an autonomous person does not have to trust in the help and support of others.

The idea can be interpreted as stating that others should have as little commitments towards oneself as possible. Interpreted in such a way, the idea of self-reliance becomes the reversal of the idea of moral independence and susceptible to the same sort of objections: why should voluntarily and authentically entered relations with others make me less autonomous?[56]

Another, more plausible, interpretation takes self-reliance to be the ability to manage on ones own, if necessary. More precisely, the thought is that one has the inner and outer recourses required in order to live one's life as one sees fit. Interpreted in this way the ideal of self-reliance becomes an integral part of the thought that it is of value to be an autonomous person (the ideal of capacity, III.3.1.2).

The idea of self-reliance can also be interpreted as the idea that self-realization presupposes that it has to be my own desires that are realized by myself (otherwise the accomplishment is of no value and could hardly be called *self*-realization). This idea is well integrated in my conception (the ideal of self-realization, see III.3.1.1). This is a further reminder about the difference

[56] Although it can be formulated by this conception, then.

between autonomy and preferentialism: in order for you to be autonomous it is not enough to get what you want. The will and its realization have to be your own in a more qualified sense.

Initiative. The plans and projects of an autonomous person are not solely the result of the initiative of others. She does not just "tag along", but has her own suggestions of projects she considers to be of value.

This idea seems to connect with autonomy in a natural way. A person who never initiates her own projects may be thought of as lacking in independence. However, "initiating a new project" can be understood in various ways. How common is it that a person is initiating a totally unique project that no one ever has initiated before? And is this a requirement of autonomy? Of course, projects are formed against a background of interests. These interests are a result of influence from growth and environment. If Jill decides to start up a choir it is probably because she is interested in music and singing. This interest has an explanation. Not even the most original projects (like the artistic movement of the dadaists) lacks reactive elements. They are initiated as a response to the acts and expected reactions of others. It is thus unreasonably strict to have a condition of uniqueness on the ideal of initiative. The projects of a person will always be similar to or affected by others in some substantial way.

It all seems to boil down to the question of how independent the plans and projects of a person should be in order to be authentic (genuinely her own). It is hard to see why an honest acceptance of the explanation of the project of a person is not enough for authenticity, even if that person has not contributed to the plan of the project. Why should a person who wholeheartedly commits herself to the project of the Salvation Army be considered less autonomous than William Booth? On the other hand, the impression may remain that a person who never has any own ideas about the projects she wants to realize is somewhat lacking in independence and thus, maybe, in autonomy. However, it is not obvious that an alleged value of initiative should be subsumed under autonomy. It could be considered to be a value of its own ("the value of being original" or something like this).

Integrity. A person has integrity if she follows her own principles.[57] A person of integrity is characterized by not being tempted to depart from her basic goals and principles. She is, in a sense, "untouchable".

As previously explained, basic desires should not be interpreted in such a way that a person automatically acts in accordance with them (III.2.2). Temptations can overrule a person's basic desires. If that is the case, that person is short of integrity. If this is how integrity should be understood, the conception of autonomy presented clearly can account for a perceived value of integrity, since lack of integrity is due to lack of decision competence and/or efficiency (see III.2.3.2 and III.2.4.2).

However, it is far from obvious that integrity in this sense always is something desirable. A person may depart from her principles due to short-term self-interests or passions. But a person may also depart from her principles due to benevolence or compassion. Dworkin has provided an excellent example of this. Huckleberry Finn betrayed his principle that slavery is morally justified, and that one therefore should not help slaves to escape, by helping Jim to escape. Finn was thus "willing to sacrifice his integrity in favour of his humanitarian impulses" (Dworkin, 1988, p 41). I have already argued the point that autonomous principles do not have to be moral ones (III.2.2.1). The principle "inflict as much pain to others as you possibly can" (Charles Manson) and "To any human price maintain your political power" (Josef Stalin) also are principles one could try to live after.

One could perhaps say that there is something admirable about a person who without compromise lives according to her own principles without ever being the prey of temptations and weakness of will. However, this may only hold ceteris paribus: it may be a good thing, all-things-considered, if principally egoistic or evil persons also lacks integrity. Autonomy does not fill the moral space. However, this conception of autonomy allows us to formulate an ideal that tell us what is good about integrity, namely the ideal of capacity, which says that, ceteris paribus, it is good to be a person who can live by her own basic "principles" (one kind of basic desires).

---

[57] This is not the only interesting sense of "integrity", but the one of relevance in this context.

2.6.2 Fruits of autonomy

There are some further ideas intimately linked with discussions about the concept of autonomy, namely certain suggestions regarding what makes autonomy valuable (Young, 1982, p 39; Feinberg, 1986, 43-47). The most common of these are responsibility, self-esteem and dignity.[58] I will not probe deeply into the question of the relationship between these (alleged) values and autonomy. The reason is that none of these things are identical to or a conceptual part of what autonomy is.[59] For instance, self-esteem is not identical to or a part of autonomy. Indeed, it may plausibly be claimed that being autonomous and living an autonomous life is crucial for a person's self-esteem (Young, 1982, p 39). But this connection between self-esteem and autonomy is, then, an empirical one about our psychology.

However, it may be argued that the connection between responsibility, self-esteem, and dignity is stronger. They are not part of what autonomy is but, rather, autonomy can be thought of as the necessary precondition for them.[60] They may thus be thought of as fruits of autonomy rather than as parts of autonomy. However, it should be noted that it by no means self-evident that autonomy is valuable, even if one grants that responsibility, self-esteem and dignity is valuable and autonomy is a necessary precondition for these things. Consciousness is a necessary precondition for happiness, but it is not obvious that consciousness is valuable even if happiness is valuable. Furthermore, the conception of autonomy presented here can be used to formulate ideas that take autonomy to be finally valuable, regardless of connections to other possible values. Since the conception and value of autonomy is one thing, then, and the conception of responsibility, self-esteem and dignity is quite another, I will not go much further into these ideas.

However, one important note on responsibility must be added, since some ideas of responsibility may have a significant impact on *ideals* of autonomy. The

---

[58] I will return to responsibility. Self-esteem is a concept with a contested meaning, but "the sense of worth that an individual has" (Thomas, 1995, p 254) should be a characterisation general enough to satisfy most users. The meaning of dignity is even more controversial, but is often treated as similar to Rawls' concept of 'self-respect' in contexts of autonomy (Rawls, 1971, p 440; Young, 1982, p 39).

[59] See previous footnote.

[60] This is how Kant seems to have thought about dignity: that autonomy is a necessary, and perhaps sufficient condition for it (1785, p 77-79).

connection between autonomy and responsibility has been strong indeed in the history of philosophy. For instance, according to one interpretation of Kant, a person is responsible only if she acts autonomously.[61] This is surely plausible, given one very minimal conception of autonomy, which says that an act is autonomous if, and only if, it is intentional under some true description of it (see V.3.1).

Nevertheless, it is not without at least prima facie plausibility to claim that being more autonomous, according to the conception of autonomy presented here, also makes one more responsible. The reason for this is twofold. First, one may argue that the more authentic one is, according to the idea of authenticity presented here, the more responsible one is. The argument could be something like the following. Acting on authentic desires is acting on desires that one can approve of in the light of knowledge about why one has them. This trait of (more) authentic desires makes them good candidates for being (part of) the "core" of the person (see II.2.2.2). And it is common to think that the more one is acting from one's "core personality", the more responsible one is (Feinberg, 1986, p 43). Second, the conception of autonomy presented here is about "being in control" (see III.2.6.1) in, e.g., the sense of having the ability to realize one's desires, if one chooses to do so (see II.2.4.1). And it is also common to think that the more in control (in this sense) one is, the more responsible one is.

But what is the idea of responsibility connected to autonomy in these ways about? Well, being *morally* responsible is to be praise- or blameworthy for one's actions. And an intuitively appealing idea to many is that the more autonomously one acts, the more responsible one is. So autonomy adds, so to speak, to the responsibility of the action. That is, an evil or wrongful act is more blameworthy the more autonomous it is and a good or right act is more praiseworthy the more autonomous it is.[62] Furthermore, it is not farfetched to think that praiseworthiness adds to the goodness of and act and blameworthiness to the badness of an act.

There is not sufficient space here to evaluate this line of reasoning. However, if one is inclined to accept it, the implications for any *ideal* of

---

[61] Since Kant's idea of autonomy is rather different than the one presented here, I will ignore his idea of the connection between autonomy and responsibility in the following.

[62] This requires that we have an account of right/good and wrong/evil that is, at least partly, independent of autonomy.

autonomy will be profound. Perhaps the most noteworthy implication is that autonomy cannot then simply be a positive intrinsic value, not even ceteris paribus. Rather, autonomy will be a *contributive* value, adding to the goodness of otherwise praiseworthy actions and to the badness of otherwise blameworthy actions.[63] The connection mentioned above between autonomy and responsibility will thus result in a complex moral theory in the spirit of Moore's idea of "organic wholes" (Moore, 1903, p 236-273). To some, the "messiness" of such a theory will come through as an unattractive feature.

3. Ideals of autonomy

Up till now, this chapter has dwelled on the question of how autonomy should be understood (the conception of autonomy). In this section, different *ideals* of autonomy will be discussed. Generally, ideals of autonomy tackle questions of what is valuable about autonomy and/or what moral reasons we have that connect to autonomy. More precisely, the following questions regarding ideals of autonomy can be posed: 1) In what way is autonomy valuable (or what is it about autonomy that is valuable)? 2) Why is autonomy valuable (if it is)? 3) When (under what circumstances) is autonomy valuable? The answers to these questions are, of course, related. Moreover, for each of these questions, one may add queries about the moral reasons for actions autonomy gives rise to, both as a value or as something else, e.g. as a non-derived right.[64]

The first question is about how the value of autonomy should be understood. What kind of entity should be ascribed "autonomy value"? Single decisions or acts or lives taken as a whole? Is it the capacity to be autonomous or in fact being autonomous that is of value? Is it a right that ought to be respected rather than a value that ought to be promoted? Or both? In that case, how ought conflicts between promoting the value and respecting the right be resolved? If it is a value to be promoted, can this value ever give rise to moral duties to act as to promote ones own autonomy?

The second question is about the normative justification of the value. Is autonomy a value in itself or an instrumental value? Is it a personal value (an

---

[63] Personally, I am inclined to think that it is more plausible to hold that autonomy is an intrinsic value rather than a contributive one. That is, it is better (for me) to be in more control of my life, even if my using of this control to "do bad" may make things worse all-things-considered.

[64] I will return to a closer inspection of non-derived rights (IV.1.1.2).

ingredient of the good life) or an impersonal value?[65] If autonomy is a right that should be respected, what kind of right is it? Is it an absolute right? Or is it a right, the violation of which is always intrinsically negatively valuable? Or is it a right we should acknowledge because the acknowledgement of this right results in something else of value? Obviously, autonomy as a right and as a value are not mutually exclusive accounts of autonomy. For instance, maybe we should acknowledge some right to be autonomous because autonomy is valuable or results in something else of value.

The third question is about the scope of autonomy. Given that it is a value in itself, how does it relate to other values when they conflict? Does it weigh more or less? Given that it is a right, how strong is that right? Can it be overridden and, if so, when? To what extent should person have the capacity of autonomy in order for the right to be respected? To what extent should we treat persons as if they are autonomous even if they in fact are not autonomous or autonomous only to a very low degree (the actual conditions and capacity is not at hand)? The question of the scope of autonomy is of course related to the question of its justification. For instance, if autonomy is an absolute right, it should probably have a greater scope than if it is an instrumental value.

Naturally, all these questions will not be settled in the discussion to come. I will take a stand on some of these questions, but not others. For instance, I will not take a stand on the question of whether or not autonomy is a value in itself, although I assume that it is taken to be so in some contexts.[66] The most important in this context is to discuss ideals of autonomy relating to the overarching question of the right to and value of genetic information. Many substantial questions of the value of autonomy have been and will be tested on this applied level.[67] The methodological point of departure is the idea of a reflective equilibrium (see I.3). Particular judgements about the value of genetic information may then influence judgements on the value of autonomy, and the other way around. The applied level is then also a test of whether or not the conception of autonomy that was presented in the

---

[65] "Impersonal value" is a value of an outcome that cannot be assigned to any particular person.

[66] Like the context of genetic counselling in the previous chapter. A lot of what is said about this practice becomes hard to interpret in a way that is not farfetched otherwise (see e.g. II.3.3.5).

[67] For instance the question of whether there is a basic right to genetic information. I argue that there is no such right (see IV.2.1).

previous section is tenable. I think the usefulness of it in the previous chapter shows that it is.

I will thus not argue in favour of one particular ideal in this chapter. Instead, I will present a number of possible ideals of autonomy. I will not have very much to say about what can be considered to be arguments for and against them. This discussion has two related purposes. One is to try to create some order in the existing discussion on autonomy in biomedical ethics. The presented ideals of autonomy can help us to ask what ideal of autonomy, more precisely, a spokesman of autonomy is defending. This will enable us to better evaluate the argumentation at hand. The other is to elaborate more carefully a tool to analyse the discussion of the right to and value of genetic information from the point of view of autonomy.

3.1 Autonomy as a positive value

In defending the value of genetic testing and genetic information, the most widespread ideals of autonomy are those that regard autonomy as a positive value (see chapter II). This is not always explicit. But much of what has been said in this context is intelligible only given this interpretation of autonomy (see chapter II).[68] Autonomy as something that should be promoted is different from seeing autonomy as a right that should be respected. This has already been argued (see II.2.3) and will be further elaborated in this chapter.

Furthermore, in discussions of genetic information in particular and biomedical ethics in general, autonomy is claimed or presupposed to be something that is of value in itself, as opposed to something that merely inherits its value from something else that, ultimately at least, is of value in itself (Beauchamp & Childress, 2001, passim). That is, autonomy is often taken to be *finally* valuable (Brülde, 1998, p 390-391), rather than just an instrumentally valuable.[69] Furthermore, it is common to assume that if autonomy is finally

---

[68] To an increasing degree, this goes for bioethics in general. One example is Beauchamp and Childress, 2001, p 90-91, when claiming that it can be justified not to respect the autonomy of a patient in order to increase his autonomy (e.g. by giving the patient information he has declined in order to make it possible for him to make an informed decision).

[69] Something inherits its value by causing, or being a necessary precondition, or the like for something that is of value in itself. That is, instrumental value in this context is understood rather widely, as synonymous with derived value (Brülde, 1998, p 6).

valuable, it is of *intrinsic* value, i.e. it is valuable because of its intrinsic properties (Lindley, 1986, p 73).[70]

What does it mean to say that something has intrinsic value? I will not enter this complicated issue at length. I will just assume the standard view that X being intrinsically valuable is closely connected to anyone having a *pro tanto* reason to promote X (Kagan, 1989, p 61; Tännsjö, 1998b, p 119).[71] A reason is pro tanto if, and only if, it always has "weight" or "force" (even though it may be overridden by other weightier reasons). So, if e.g. autonomy is an intrinsic value, there is always a reason to promote it.[72] This is not crystal clear, but clear enough for our present purposes.

Now that we have a general grasp of what it means to be intrinsically valuable, what kind of value is autonomy? That is, what aspects of autonomy ought we to promote? I think that it is appropriate to make a distinction between two basic ideals of autonomy: to live an autonomous life (the ideal of self-realization) and to be an autonomous person (the ideal of capacity). After developing these ideals, I will move on to say something about how they can be used to formulate normative ideals, i.e. suggestions of what one ought to do (III.3.2). This will give rise to questions of how autonomy should be measured when comparisons of autonomy are necessary, due to conflicts of autonomy or conflicts with other values.

3.1.1 The ideal of self-realization

A reasonable interpretation of the idea that autonomy is a value that should be promoted is the following. The value of autonomy consists in living one's life in accordance with one's own authentic and basic desires, through one's own

---

[70] So all intrinsic values are final, but not necessarily the other way around, since there may be things that are valuable for their own sakes, but which is not valuable because of any intrinsic properties (e.g. something that is valuable because of its relational properties, e.g. being the first manufactured object of some kind).

[71] There are different views on the relationship between having a pro tanto reason to promote X and X being intrinsically valuable. One view is the Moorean idea that X is intrinsically valuable if, and only if, X's value supervenes on the intrinsic (or non-relational) properties of X, and add that anyone has a pro tanto reason to promote X if X is intrinsically valuable. Another view says that X is intrinsically valuable if, and only if, X has intrinsic properties that gives anyone a reason to have a pro-attitude towards X for its own sake (a so-called "buck passing"-theory of intrinsic value). I wish to thank Sven Nyholm for bringing these views to my attention.

[72] I will return to the implications of this idea (see III.3.2.1).

decisions and actions.[73] Crudely put, the more a person in fact succeeds in living according to her authentic and basic desires in this way, the more autonomous she is. And the more autonomous the person is (in this regard) the better is it for that person, ceteris paribus.[74] The ideal of self-realization, then, sees autonomy as a personal value. The ideal emphasises the individual's actual realization of her own ends through her own acts and decisions, rather than just being a person that is capable of this. It is thus not an ideal of character.

A person's degree of autonomy is then a function of the realized basic desire's authenticity (the more authentic they are, the more autonomous the person become given their realization), number and strength in comparison with the non-realized basic desire's authenticity, number and strength. In other words, the more "important" (strong) and "self-governed" (authentic) desires that the person succeeds in achieving or realizing (of the desires she has), the more autonomous the person is, and the better for her. This ideal may thus naturally be dubbed the ideal of self-realization.

The strength of this ideal[75] is that it accounts for the idea that the valuable thing about autonomy is actually leading an autonomous life. The ideal explains why it is bad for a person not to realize his important projects and plans, and delivers the explanation in terms of autonomy.

However, there is not one ideal of self-realization. This ideal can be specified in various substantial but non-equivalent ways. For instance, there is an absolute version, which says that the more desires[76] that a person realizes, the better off she is, and a relative version, which says that the higher the quota of desires that a person have that she realizes, the better off she is. An example may illuminate the difference.

Imagine two persons, A and B. A has 100 basic, authentic desires and realizes 90% of these. B has 200 basic, authentic desires and only realizes 50% of those. According to the absolute version, B is better off than A, since B

---

[73] The last mentioned proviso is of course necessary to distinguish ideals of autonomy from preferentialism (III.2.4.1).

[74] This can be modified if the idea is combined with some thought of responsibility (III.2.6.2).

[75] Besides that it makes various arguments on the value of genetic information intelligible.

[76] Of course, given a certain strength and degree of authenticity and given that they are basic.

realizes 10 more basic, authentic desires than A.[77] However, according to the relative version, A is better off than B, since A realizes a higher quota of the desires she has than B.

Even though both versions can be formulated with my conception of autonomy, I think that the relative version is much more plausible. The most important reason in favour of the relative version is that the absolute version seems to fly in the face of how we perceive an autonomous life. This is easy illustrated if one keeps in mind that the number of autonomous decisions can be large even if the number of basic, authentic desires is small.[78] Assume that Jolene only has one basic, authentic desire: to write as innovative and well-composed novels as possible. This desire can be realized to different degrees, depending on her decision competence and her efficiency. Assume that she succeeds in realizing this desire to a high degree. Every year she decides to write a new, innovative and well-composed novel and succeeds. Compare this to Jane, who has many basic, authentic desires: to wear the most fashionable clothes, to learn French, to go to a restaurant at least once a week, to work as a veterinary surgeon, and so on. Jane realizes some, but not all of these desires. Altogether, Jane realizes a greater number of desires than Jolene. However, I do not believe that anyone would claim that Jane leads a more autonomous life than Jolene just because of this. This indicates that the relative version is the more plausible one.

Besides the fact that there are versions of the ideal of self-realization, this ideal can be combined with other ideals of autonomy that holds autonomy to be valuable. A *pure* ideal of self-realization does not contain the idea that only *having* authentic desires is valuable in itself, since it says that it is the realization of them that is valuable. Neither does it say that it is valuable in itself to be competent or to have the capacity to efficiency. Of course, efficiency in the sense of actually accomplishing one's basic and authentic desires is part of what has value according to the ideal. Furthermore, authenticity has value in the sense that only the realization of authentic desires is valuable, and the realization is more valuable the more authentic and the stronger the desires are. Moreover, decision competence and capacity for efficiency are necessary

---

[77] Let us assume that all these desires are of an equal strength. Another simplification is presupposed. Single desires can be realized to different degrees, which this example ignores.

[78] This actualises the question of how to individuate desires. I will not tackle this problem.

presuppositions to realizing the desires autonomously, since the decision competence and efficiency of the person will causally determine the extent to which the person will succeed in realizing her desires. However, the capacity for efficiency is not considered to be a value of itself, according to the pure ideal of self-realization, and neither is decision competence as such.

However, even if the ideal of self-realization does not in itself include that having authentic desires, decision competence and capacity for efficiency are valuable states in themselves, it can be combined with such ideas. This demonstrates that that the ideal of self-realization can be combined with the ideal of capacity (III.3.1.2), which claims that having authentic desires, competence and capacity for efficiency is intrinsically valuable.

Let me try to illuminate with an example. Imagine two persons, A and B. A has a very authentic (or strong) basic desire. B has a not so authentic (or strong) basic desire. Both manage to realize their desires, i.e. they decide and act as to satisfy the desire they have. However, A regularly suffers from weakness of will, and her capacity to act on the decision in question is thus much lower than the other person, i.e. due to her weakness of will, she was much less likely to actually succeed in accomplishing her end. However, in this situation, she overcomes her weakness and succeeds in realizing her desire. According to the pure ideal of self-realization, which does not think that the capacity for efficiency has value, A is clearly better off than B, due to her desire being more authentic (or stronger) (even though the fact that she had the desire did not make her life any better, before she realized it). However, the possible ideal of autonomy that says that the capacity for efficiency has value in addition to the actual realization of one's desires (through one's decisions and acts) can reach a different conclusion regarding who of the two persons in the example above that is better off. Maybe the second person is, if her higher capacity for efficiency outweighs the lower authenticity of her desire.

A residual ambiguity could be seen in this ideal, however. Is it valuable to realize single desires or living an autonomous life? I think one soon realises that there is something odd about this question. It is not the one or the other. Autonomy is a matter of degrees. How autonomous a life one leads depends on how one manages to achieve one's basic aims. The degree of autonomy of a

life cannot be independent of how one manages in the parts of one's life of which the life total is composed.[79]

3.1.2 The ideal of capacity

The ideal of capacity says that, rather than living an autonomous life, the value of autonomy consists of *being an autonomous person.* This is a person with authentic desires, and enough decision competence and efficiency to implement these desires. The autonomous person, then, both has the capacity required and the actual conditions fulfilled in order to independently consider her own basic projects and values, make decisions on the basis of them and realize them through her own action. This ideal is to a great extent an ideal of character, since it claims that having certain traits and capacities is of value. An autonomous person is not weak of will, self-deceiving, confused, phobic, and so on, since all these things tend to reduce autonomy in the sense defined here. This ideal also emphasises the importance of on not being manipulated, coerced or in other ways prevented by others from realizing one's life plans. This ideal is widely cherished (Young, 1982).

Also this ideal makes autonomy a matter of degree. The more authentic, decision competent and efficient I am, the better for me. The value, then, is to be such a person that *can* realize his desires, that is, *if* the person has desires, it is better if they are authentic and the person is capable of realizing them. However, the extent to which she actually does achieve her ends is of no consequence as such for her degree of valuable autonomy. Rather, such achievements are to be seen as side-effects of the presence of those features of autonomy that affect one's quality of life (at least according to a pure version, not combined with the ideal of self-realization).

Moreover, also this ideal can be specified into different versions. One version can emphasise the capacity to be autonomous rather than the actual conditions of autonomy (III.2.1), i.e. elaborate a pure ideal of character. As previously noted, both external and internal factors affects one's actual capacity to be competent and efficient. Some may want to include internal but not external factors in their ideal. This version may seem attractive for those who would like to claim that actual conditions of autonomy belongs to the realm of freedom rather than autonomy. I will not enter a debate with those who have

[79] Of course, this is not incompatible with claiming that the distribution of autonomy over a life makes a difference to its value.

this terminological inclination. They can also use the conception adumbrated here to formulate their ideals.

3.2 From value to morality

Even if one has formulated and defended a certain idea regarding the value of autonomy, this is not sufficient in order to argue in favour of a certain practice or line of conduct on the basis of autonomy. In order to make a value of autonomy *practically useful* or *action-guiding* one has to answer several additional questions. First, one has to formulate *norms* of autonomy – what is right or what we ought to do with respect to the value of autonomy. For instance, ought one to maximise autonomy or ought one to realize autonomy to a certain degree, e.g. equally for everybody? Without answers to questions like this, we will not know *how* we should promote the value of autonomy. Second, just as one has to say how autonomy should be distributed among people (as the norms do), one also has to say how it should be distributed over time. To what extent, and why, should one consider past and future desires from the point of view of autonomy? Third, there is the methodological question of comparing degrees of autonomy. In order to determine whether a norm has been fulfilled (e.g. the norm that the total self-realization should be maximised) one has to be able to measure the relevant individuals' level of autonomy and compare these levels. Is this possible, and to what extent?

My primary focus in this section is to pose these questions and to make them more precise. The aim is to show what kind of questions someone defending an action, institution, policy, or other practice on the basis of autonomy must consider. Nonetheless, whenever I can, I will argue that some answers are more plausible than others. For instance, I will propose that neutrality regarding time is plausible (even though this conclusion may not have much practical relevance) and that autonomy may be difficult indeed to measure with any accuracy. But I will not answer all three questions at any length, and especially not the first. Nevertheless, a full ideal of autonomy would have to answer such questions, and it may thus be useful to point them out.

It should be noted that not all norms of autonomy are based on the idea that autonomy is a positive value. On the contrary, the most widespread discourse on autonomy in biomedical ethics conceives of autonomy as a right that should be respected, regardless of the values this promotes (at least to some extent). I will return to autonomy as a right in the next section (III.3.3),

where we also will see how the conception presented above can be used to formulate such ideas.

3.2.1 The norms of the value

The following line of thought has seemed attractive to some moral philosophers: if something is of value in itself, then the more of this, the better. And, surely, we should choose and act so as to make things better rather than worse. Thus, for these thinkers, the idea that the mark of intrinsic value is that it ought to be maximised has seemed natural. Indeed, this may come through as part of the very meaning of intrinsic value,[80] as opposed to instrumental values, such as resources of different kinds, which can have diminishing marginal utility. The reasoning behind this move, which has made it seem natural, can be spelled out in something like the following manner:

(1) If something, V, has intrinsic value, anyone has a pro tanto reason to promote V.
(2) It holds for any agent that, if she has a pro tanto reason to promote V, if there are no independent reasons not to promote V,[81] and she can promote V, she ought to do so.
(3) It holds for any agent that, if she has more reason to promote a feature F1 rather than a feature F2, she ought to promote F1 rather than F2.
(4) V has intrinsic value (or "is good for its own sake").
(5) V can come in different degrees (more or less).
(6) The higher degree (the more) of V that an agent can act as to realize, the more reason she has to do so.

∴

(7) If F1 realizes more V than F2, and the agent can act as to realize F1 and act as to realize F2, and there are no independent reasons not to realize F1, the agent ought to act as to realize F1 rather than F2.

This conclusion amounts to saying that, in the absence of reason to the contrary, it is wrong (an agent ought not) to act as to realize less of the good than one can do. If there is just one kind of value (e.g. "pleasure" or well-

[80] I use the term intrinsic rather than final value here. However, see III.3.1.

[81] For instance, there is an independent pro tanto reason not to promote V if that promotion would realize something of negative intrinsic value, or if it would require the violation of a moral right or duty.

being) and only one corresponding kind of disvalue ("displeasure"), and no reasons that depend on other things than how much value is realized, then the only thing we have reason to do is to maximise the net balance of pleasure over displeasure. This is, of course, the credo of utilitarianism. Following the same line of reasoning, it might thus be tempting to conclude that if autonomy is an intrinsic value, autonomy being a matter of degree, it is one that ought to be maximised. Of course, the clause of reasons to the contrary in premise (2) probably would kick in, since there are plausibly other values than autonomy. That is, one has to say something about the moral weight of autonomy in comparison to other intrinsic values but, nonetheless, if premises (1) to (6) are accepted regarding autonomy, then autonomy ought to be maximised, ceteris paribus.

However, the above line of reasoning can be, and has been, questioned. Even if one subscribes to the premises (1) to (3) and to autonomy being an intrinsic value that comes in degrees, premise (6) is far from uncontroversial. In fact, even writers with an openly utilitarian bent of mind have been inclined to reject it (Lindley, 1986, p 82-83; Tännsjö, 1998b, p 119-120).

So, one cannot legitimately infer from something being an intrinsic value that it ought to be maximised. How the value in question should be realized or, put differently, what *norms* that are implied by the statement that something is of value is an open question. One possibility, besides maximisation, is that the value in question ought to be distributed equally. Whether the equal distribution of, say, autonomy also is the distribution that realizes most value is, of course, a contingent matter. It may well be, in a situation, that an equal distribution is less effective than some unequal one and if autonomy should be distributed equally, autonomy should not, then, in this situation, be maximised. If equality in distribution is not possible, it may nonetheless be claimed that the less unequal the distribution is, the better.[82] Even if one denies that a lesser inequality in the distribution of a certain value always overrides a greater amount of it, one could claim that some amount of the value should be "sacrificed" in order to reduce inequality.[83] This claim is in no way incompatible with claiming that autonomy is an intrinsic value.

---

[82] How "less unequal" or, rather, "less badly unequal" should be interpreted is a complex issue. See Temkin, 1993.

[83] Which is tantamount to saying that inequality is a negative value that is not lexically prior to other values (see III.3.3).

Another possibility is that the amounts of the goods in question should be weighted with regard to their value. That is, the relation between the amount of something that is of value and how valuable this amount is need not be one of 1:1. One such suggestion is that benefiting people matters more the worse of they are. This is sometimes called the doctrine of the priority of evil or, more recently, prioritarianism or the Priority View (Parfit, 1997, p 213). This view implies that the moral weight of improvements decline or, correspondingly, that it is of more value to improve the lot of someone who is worse off than someone else.[84] Prioritarianism expresses a strong intuition many have regarding well-being. One may, of course, have a similar intuition regarding autonomy.

A more commonly stated idea about the weight of value with regard to autonomy is that there is a level of autonomy above which further increases of autonomy is of little, or perhaps no, value or moral importance (Lindley, 1986, p 107). To stipulate such a level has several purposes. One purpose is to prevent the ideal of autonomy from being too demanding by always providing reasons for even further improvements of autonomy. Another related purpose is to make the ideal attainable for most people.

Another related possibility is to argue that autonomy only is valuable above a certain level. This idea is perhaps most plausible when combined with the claim that the autonomy of a person ought to be respected only when the person's capacity for autonomy is above a certain level. Below this level of autonomy there is not enough autonomy to command respect, since it lacks value, one may argue. We will return to ideals that consider autonomy primarily as a right to respect later on in this chapter (III.3.3).

As already mentioned (III.3.2), the reason to formulate all these norms is that any ideal of autonomy just stating that autonomy is a value, in this and that respect, is insufficient. In order to be action-guiding, any such ideal of autonomy has to say how the value should be promoted, i.e. it has to take a stand on the normative issue. Is autonomy to be maximised, weighted somehow (and, if so, how), or to be distributed equally (and, if so, to what

---

[84] Prioritarianism should be carefully distinguished from (the version of) egalitarianism, since the last position, as opposed to the first, states that a less unequal state is better than a more unequal state (at least if some other conditions are met, e.g. that no one deserves to be worse of than another), even if no one is better off with regard to e.g. well-being in the more unequal state. See Temkin, 1993, p 245-248.

extent)? And what is the weight of autonomy in comparison to other values? If no answers to these questions are provided, defences of practices on the basis of the value of autonomy will remain indeterminate, since the implications of the ideals will be as unclear as the ideal itself.

3.2.2 Autonomy and time

Another matter that a normative ideal of autonomy must address is questions of time. One such question is whether moral ideals in general, and ideals of autonomy in particular, should be neutral with regard to time, that is, should hold that the fact that a state of affairs with intrinsic value, A, occurs at a different time than another state of affairs with intrinsic value, B, cannot in itself affect the value of A relative to B, or conversely. In other words, temporal neutrality says that when something occurs does not make any direct evaluative or moral difference.

Applied to ideals of autonomy as a value, the idea of temporal neutrality states that a person being authentic with regard to a desire, and autonomous with regard to the realization of the desire and/or in fact, realizing an authentic desire, is, ceteris paribus, good for the person, regardless of when it happens. The ceteris paribus clause is important to emphasise in order to avoid confusion. As a matter of fact, it may make all the difference in the world when something occurs. For instance, consider an ideal of capacity claiming that having authentic desires is of value in itself. As previously argued, authenticity is a matter of degree (see III.2.1 – III.2.4.2), so one desire can be more or less authentic than another, and one and the same desire can be more or less authentic over time. It may even be the case that a desire can become more authentic over time (partly) *because* it is located at a different point of time (if, e.g., time is connected to the maturity of a person and the maturity of the person makes her more prone to authenticity). To accept the possibility of this is not to deny temporal neutrality. In order to deny this idea in the present context one would have to affirm the possibility that two desires (or the same desire at two different points of time) that are equal regarding their degree of authenticity (and strength) nonetheless are different regarding their intrinsic value, only because they are located differently in time. This seems strange indeed.

As I said earlier, the primary task here is to say what kind of questions a practically useful ideal of autonomy has to answer, not to defend any particular answers to these questions. Having said that, neutralism regarding time must

nevertheless be the default position. In order to give this position up, strong reasons indeed would be needed and I, for my part, know of no such reasons. On top of this, one argument that supports neutralism regarding time has already been given: the implications would otherwise be strange. Of course, it should not be denied that time often matters in practical decision-making. Perhaps the most important fact regarding time to practical decision-making is the epistemological one: very often, the more distant in the future a certain possible state of affair is, the more uncertain it is. For instance, it would certainly be foolish to reject a certain 100€ today in order to preserve a 50% chance of getting the same amount of money tomorrow.[85] Thus, since future events regularly are more uncertain than present one's, we are surely rational to act with more consideration to the present. This is no violation of temporal neutrality. It only shows that we should not disregard time in our practical decision-making.[86] So, even if temporal neutrality is plausible, it may be rather inconsequential for practical purposes.

Another question of time that ideals of autonomy must address is when there is a difference in time between a desire, and the realization of that desire.[87] The question becomes most pressing when one does not hold the desire that is realized anymore. Is it still of value for the person that this desire is realized? Answering no to this question implies that if you act as to spoil a project of mine that I have fought hard for in the past but no longer care about, you will not have made my life worse. Nevertheless, the most intuitively appealing answer seems to be no: if realizing desires is of value, then how can realizing something make my life better if I no longer desire it?

---

[85] Unless, of course, one likes to gamble, there is a danger with possessing the money today, and so forth.

[86] In fact, the most influential arguments against temporal neutrality (Williams, 1981) only remain forceful if directed against temporal neutrality as a practical guide of conduct or decision-making rather than against the principle itself. I am thinking about the kind of arguments that tries to establish that trying to take all one's life into equal consideration (and in that sense *being* neutral regarding time) will inevitably make one fail to do so. This is the idea of neutrality as indirectly self-defeating, i.e., that trying to accomplish something will make this accomplishment impossible. This question has been thoroughly discussed elsewhere (Parfit, 1984, p 3-52, 149-186), also specifically regarding autonomy (Lindley, 1986, p 88-93), so I will not dwell upon it further.

[87] This question only concerns ideals of self-realization, since these ideals, unlike ideals of capacity, regards realization of desires.

But if we are to ignore past desires in this way, should we not also ignore future ones? But to ignore future desires does not seem to be intuitively appealing.

This problem is well known in the discussion of preferentialism.[88] I think the theoretical solution to the problem is to be found in this discussion. Once again, this is another problem that an ideal of autonomy must tackle and my primary motive is to point it out but, just like the general question of time bias, there seems to be a plausible solution. The solution is to preserve the central idea of temporal neutrality: there should be no time bias, while at the same time recognize that the only preference-realization that is of value is the realization of preferences that are held when they can be satisfied. Thus, from the point of view of autonomy, my life does not fare any better if I realize some desire while not having it anymore, and my future desires are relevant insofar as I can realize them whilst having them.[89] Symmetrically, my life does not fare any worse if I do not have a desire anymore and someone else acts to frustrate that past desire now.[90] Furthermore, if you perform an action now with delayed effects that prevents the realization of my desires in the future when I still have them, you have made my life worse off regarding autonomy. This preserves the intuitions regarding time and value just mentioned above.

3.2.3 Comparisons of autonomy

In order for an ideal of autonomy to be practically useful, we need to be able to *compare* different state of affairs regarding (the morally relevant parts of) autonomy. This is so, since conflicts are possible: conflicts between respecting autonomy and promoting autonomy, conflicts between promoting autonomy now versus later, or conflicts between promoting the autonomy of one person

---

88 However, it should be noted that the problem of how past and future desires should be accounted for is somewhat less from the point of view of autonomy compared to preferentialism, since an agent is unlikely to try to realize some desire she does no longer hold and thus is unlikely to succeed in doing so (remember that autonomy presupposes not just satisfaction but also the person realizing the desire in question). So even if one claims that realizing desires before or after one has them is of value (contrary to what is argued here), this will probably seldom be a realized value.

89 This is what Hare, 1981, p 102-106, has called preferences 'now-for-now' and 'then-for-then' and what have elsewhere been called "the theory of simultaneous satisfaction of preferences" (Tännsjö, 1998, p 83).

90 Unless that person can act so as to frustrate my desire when I had it, which would require backward causation or a time machine.

versus another. Sometimes, conflicts with other ethical considerations arise too. For instance, we may have to choose between respecting someone's autonomy and promoting her well-being or avoiding harm to her. This means that we sometimes will need some idea of how to compare autonomy to other values as well. Whenever conflicts such as these arise, we have to compare pros and cons in order to try to take a stand on what to do.

In this subsection, I will disregard the very important question of how autonomy should be compared to other values. The reason that I disregard this question is that, although very important, it is very difficult, and to start to tackle that question would require, at least, a book of its own. Furthermore, in order to compare autonomy to other ethical considerations, we must first have some idea of how to perform comparisons of autonomy. I will thus focus on this question.

Really, the question of comparisons of autonomy is not one, but two. First, there is the theoretical question of whether or not such comparisons are meaningful at all, that is, the question of whether or not a measurement of autonomy can be created. Second, there is the practical question of whether or not this measurement can be used to settle conflicts in practice. In order to use a measurement in practice, it has to be meaningful to start with. So, the possibility of answering the practical question depends on a positive answer to the theoretical one.

However, the need for comparisons and measurement depends on the normative theory of autonomy. In a normative theory of autonomy that holds autonomy to be an absolute right and nothing more, and thus that autonomy should never be violated, the comparisons needed will be rather straightforward, since we only need a binary scale to determine whether an action was wrong: either it violated autonomy, in which case the action was wrong, or it did not, in which case it may be permissible, due to other normative considerations. However, even on such an uncomplicated normative theory of autonomy, we will need to determine who is autonomous enough to fall under the principle of an absolute right to autonomy. The more factors one thinks are relevant to determine that limit and the more these factors are matters of degree, the more complicated becomes the problem of measurability.

By making the normative theory of autonomy more complicated, more complex kinds of comparisons and, thus, measures will be needed. If rights to autonomy are thought to be prima facie, one will have to specify under what

circumstances such rights are overridden.[91] If the theory says that only certain qualitative states override the right to autonomy, for instance if someone will die as a result of respecting the right, then comparisons will be easier than if one claims that amounts of something, for instance well-being or autonomy, can override autonomy.

This brings us to *quantitative normative theories*, that is, theories that claim that amounts of a value matter. To this group not only utilitarianism and other kind of consequentialistic theories belong, but also prioritarianism, and theories that claim that equality matters, since one may distribute a good more or less equal (Temkin, 1993). If autonomy is a matter of degree, which I have argued that it is, and autonomy is to be thought of as a value to promote, then we can promote this value to different degrees. This calls for some way of measuring degrees of autonomy. Since I will deal with ideas of rights to autonomy later in this chapter (III.3.3.), and since the problem of measurement regarding such theories is partly less serious, I will in the following focus on normative theories that claim that amounts matter, like theories that holds that autonomy is a value to promote.

In the following, I will first say something about what measurability is. Then I will try to show why different practical problems calls for different kinds of measurement. I will then try to argue that theories that consider autonomy to be a value that should be promoted will have difficulties solving the theoretical problem of measurement. However, given some simplifying assumptions, we may at times be able to compare outcomes with regard to autonomy, which can be sufficient for practical purposes.

What is, then, measurability? Some kinds of "things" (objects or states of affairs) are measurable if they can be assigned values according to some rule. According to this definition, it may seem as if we can measure anything. For instance, we could create a measure of love through applying the method of electric shock and the rule that the more electric shock a person, A, is prepared to endure to see another person, B, the more A loves B. However, measurements should ideally be both (sufficiently) *valid*, i.e. be an adequate measure of the objects or states of affairs it is measuring, and *reliable*, i.e. be exact and unambiguous.[92] So, even if the proposed measure of love is

---

[91] I will give a closer account of prima facie-rights in III.3.3 and IV.1.1.1.

[92] Both validity and reliability are matter of degrees.

relatively reliable (will generate determinate answers on how much different persons "loves" other persons), it will probably not be valid at all. This is the case since the measurement will not measure that which most of us call love but rather, among other things, how a person manages physical pain. It is thus desirable with a measure that is both (sufficiently) valid and reliable.

Different practical problems call for different kinds or degrees of measurability. The simplest case is if the goal is to enhance the autonomy of a particular person. Then we only need *intrapersonal* measurability, i.e. we only need a scale on which we can compare the autonomy of a particular individual.[93] Furthermore, in order to determine only whether the autonomy of the individual has been enhanced or not, we need only to be able to compare the autonomy with regard to more or less, i.e., on an *ordinal* scale.

However, this is hardly sufficient in the context of evaluating medical practices, such as presymptomatic genetic testing, and the institutions surrounding them, if an important goal of these practices is to promote autonomy. These practices do not only concern one individual. An action, which is a part of such a practice, which is favourable to the autonomy of one person, may be unfavourable to the autonomy of another. At least, we cannot presuppose that this is not the case. Thus, one will need *interpersonal* comparisons of autonomy in order to evaluate the introduction and regulation of a medical practice such as presymptomatic genetic testing.

Furthermore, there are often more than two alternatives, both regarding choices of courses of action within a practice and regarding choices of practices. Of course, the general question of whether a certain practice should be introduced at all can be answered with a "yes" or a "no", leaving us with only two alternatives. However, when it comes to questions of *how* a practice should be introduced and what regulations it should be subjected to, there are many alternatives. Since different people may benefit to different degrees given different practices, we will need a measurement that tells us how much more these different people will benefit from a certain practice in comparison to others in terms of autonomy. This requires a scale that enables us to

[93] It may be possible to do such comparisons *intertemporally*, (at different points of time) or, perhaps, only *intratemporally* (at the same point of time).

compare differences or intervals between the objects or state of affairs, i.e., an *interval* scale.[94]

To complicate matters further, presymptomatic genetic testing is often used to make reproductive decisions and, thus, will affect not only the autonomy of existing people, but also who will exist. If the goal of presymptomatic genetic testing is autonomy promotion in general, one will have to take these "potential", non-existing persons into account. This requires a scale with some natural zero point, like scales of height and weight, since we will have to be able to determine, for instance, whether a certain life will increase overall autonomy in comparison with no life at all. These kinds of scale are called *ratio* scales.

To this last complication, it may be retorted that the goal of presymptomatic genetic testing in reproductive decisions is not to promote autonomy in general, but only to promote the autonomy of the parents. This could be defended by claiming that the concern of the health care professionals should be the client/patient at hand and not someone else. But taken to an extreme, this claim is surely false. Even if it is plausible to claim that the *primary* concern of health care professionals should be for the patient at hand (see VI.3.1.2), this cannot be their *only* concern. If devastating consequences would result from only caring about the patient at hand, it is hard to see why health care professionals should be allowed to ignore this just by pointing to their position as health care professionals. For instance, a doctor has *some* duties also to third parties. It is by no means obvious that e.g. a geneticist should pay no consideration to the unborn child (e.g. by allowing parents to choose a fertilized egg with Krabbe's syndrome (see I.4.1) to be implanted after PGD). Some kind of an idea of a life not worth living, and thus a ratio scale defining a zero point, is thereby plausibly required.

All this means that some scales allow for "more" measurability than others. If autonomy can be ordered on a ratio scale, one can also settle the intervals, but the possibility of settling intervals is insufficient for a ratio scale. A ratio scale is necessary in order to use the scale arithmetically, a precondition for it being meaningful to say that something is, e.g., twice or three times as much as something else, something an interval scale does not allow. A similar point relates to interval and ordinal scales. If we can determine differences in interval regarding autonomy, we can also settle whether someone is more or

[94] Of course, the same goes if the goal is to minimize the inequality of autonomy.

less autonomous, but not the other way around. Furthermore, each of these scales may be *partial*, ordering just some objects or states of affairs of some kind, or *complete*, ordering all objects or states of affairs of some kind. As we have seen, for practical purposes, sometimes nothing short of an, at least partial, ratio scale would do.

Can we, then, construe such a measure for autonomy, even theoretically? Or, more precisely, is there a (sufficiently) valid and reliable way of comparing different degrees of autonomy? What kind of such a measurement can we create? An interpersonal or only an intrapersonal? Is it possible to construe a ratio scale of autonomy or only an interval scale or, perhaps, only an ordinal scale? Or is it implausible to claim that there is any valid and reliable scale at all?

I will start with considering the creations of *complete* such scales and my conclusion will be rather negative. For various reasons, it is not likely that even an ordinal intrapersonal scale can be construed, and, thus, much less likely that stronger kinds of measurements can be construed.

Consider the ideal of self-realization that claims that the more "important" (strong) and "self-governed" (authentic) desires that the person succeeds in achieving of the desires she has, the more autonomous the person is (and in virtue of that, the better off she is, ceteris paribus). According to this ideal, we will need a measurement of the strength and authenticity of (realized) desires in order to determine the level of a person's autonomy. Furthermore, we will need a measurement that determines the relative weight of the authenticity and the strength of desires.

When it comes to the measurement of strength of desires, there are some answers to be had in classic decision theory. Given that desires can be analysed in terms of preferences, so that someone's, P's, desire X is stronger than P's desire Y if, and only if, P prefers X to Y, and given that we can ignore "irrational" desires,[95] then intrapersonal-intratemporal ordinal scales of strength of desires can be construed (Resnik, 1987, p 22-25). That is, we can order all desires that a certain person has at a certain time on a scale that tells us

[95] According to classic decision theory, a set of preferences are rationally ordered if they are asymmetrical (so that the person does not prefer X to Y and Y to X at the same time), transitive (so that if the person prefers X to Y and Y to Z, she also prefers X to Z) and connected (so that the person prefers X to Y, or prefers Y to X or is indifferent between X and Y for all relevant outcomes X and Y (she "knows what she wants")). Otherwise, they can be said to be irrational.

which state of affairs the person prefers to other state of affairs and which state of affairs the person is indifferent to. Furthermore, if a person can take a stand on some hypothetical lotteries according to the principle of maximised utility, then intrapersonal-intratemporal interval scales of strength of desires can be construed (Resnik, 1987, p 88-100).[96] Perhaps, it is even plausible to talk about a natural zero point, and thus a ratio scale, of strength of desires. This may be plausible if it is reasonable to assume that there are states of affairs to which someone is genuinely indifferent, that is, it does not matter at all for the person whether the possible state of affairs is a fact or not (Brülde, 2003, p 154-155). I see no reason to deny this possibility.[97]

However, despite these theoretical possibilities of comparing strengths of desires intrapersonally, things looks much more gloomy when it comes to interpersonal comparisons of strength of desires.[98] The reason for this is the following. In the case of one person, the person herself can compare one desire to other desires and thus determine the strength of the desire in question. However, regarding different persons, there is no common person whose ordering of the preference-orderings of different people we may use as a basis for comparing the strength of the desires of different people. I can compare the strength of my desire to learn Russian to my desire to learn Greek by pondering what I prefer to the other. But I cannot compare my desire to learn Russian to your desire to learn Russian. The only thing I can ponder is whether *I* prefer that I learn Russian to you learning Russian. But this is once again to compare two desires of *mine*, rather than your desire *to* mine. To state the case differently, there is no "overindividual super-subject" that has both the desires directly accessible for comparison (Brülde, 2003, p 156). This is not to say that one cannot create an interpersonal measure of strength of desires, but only that there is no reason to believe that such a measure will be valid, since we have no reason to believe that the estimation of

---

[96] The basic idea is that if you have (at least) three alternative "outcomes" or states of affairs and you can order them on an ordinal scale, the "utility" of the middle alternative is determined by how great a chance you would need to get the most preferred alternative in a lottery between the most preferred and the least preferred alternative in order to be indifferent between the lottery and getting the middle alternative for sure.

[97] If desires are above the point of zero, aversions can be said to be below it (i.e. state of affairs that the person prefers not to be the case).

[98] I will ignore the case of intrapersonal-intertemporal comparisons, since this kind of comparisons are vulnerable to very much the same arguments as those directed at interpersonal comparisons.

the strength of different person's desires will be adequate.[99] The problem is, thus, an epistemological or methodological one.

The problems of measurability are even larger regarding authenticity. On my account of authenticity, at least two factors determine the level of authenticity of a desire: level of (hypothetical)[100] knowledge of why one has the desire and level of approval (or disapproval) of the desire.[101] If a desire is approved of to a certain degree given a certain level of knowledge of why one has it, it is more authentic than if it is less approved of at this level of knowledge. If the level of approval remains given more knowledge, the desire is more authentic than if the approval decreases given this increase in knowledge. So, degree of authenticity is in this way a function of level of approval and level of knowledge. Where does this leave us regarding measurability of authenticity?

If "approval of" can be construed as a pro-attitude in the same way as desires (which I assume it could), measurement of "approval of" can be construed in the same way as measurement of strength of desires. As we have seen, this will probably mean that there is no valid way of comparing "approval of" interpersonally.

Furthermore, and to make things worse, it is hard to see how a valid measure of the level of knowledge can be construed at all. Of course, one could stipulate a scale, such that each true statement[102] that the person is holding about the relevant subject matter constitutes a "natural unit of knowledge".[103] Unfortunately, this is hardly plausible. First, the received idea of (propositional) knowledge is not only about holding true beliefs, but rather

---

[99] Attempts to avoid this difficulty of interpersonal comparisons have been proposed through ideas of sympathy or "putting oneself in someone else's shoes" (Hare, 1981, p 128). However, these kind of proposals has epistemological complications of their own: we will only know if we have succeeded in putting ourselves in someone else's shoes if we already can make the relevant comparisons (Bergström, 1982).

[100] I will implicitly assume this qualification in the following.

[101] Measurement will naturally become even more complicated if the idea of authenticity becomes so, e.g., if one argues that actually engaging in criticism of the desire makes it even more authentic.

[102] Of course, we would need to have a theory of statements that make it illegitimate for two different statements that describe the same state of affairs in different ways to be counted twice, for instance by individuating statements according to prepositional content, and which also rules out that the conjunction of two statements counts as a third. Let us disregard these complications, since there are plenty of others anyway.

[103] Thus giving a ratio scale.

about holding *well-founded* true beliefs (perhaps because they are well-founded). In order to make the measurement valid one would thus have to settle the very complicated epistemological matter of (degree of) well-foundedness. Second, and more importantly in this context, some knowledge is probably more relevant to the authenticity of a desire than other knowledge.[104] For instance, one fact that is part of the explanation of why I have a certain desire is that I have a brain. It is hard to see why knowledge of this fact with remaining approval of a certain desire would make it more authentic. That is, we will probably need a measurement or criterion of the *relevance* of certain knowledge to the authenticity of desires. One cannot dismiss the possibility of creating such a measurement a priori, but I cannot even imagine how this measurement would look.

Regarding ideals of capacity, the prospect of creating any kind of complete measurability is even bleaker, since they would also require a way of assigning values to decision competence and efficiency in a way that makes measurement (sufficiently) valid and reliable. Moreover, such ideals would also need some way of weighing together these factors with the factor of authenticity to determine the level of autonomy of a person.

Consider decision competence, to start with. It seems plausible to claim that the capacity to reach a decision from one's desires by considering alternatives, relating relevant beliefs and desires and reaching a judgement on what to do on the basis of this, is a matter of degree. For instance, more information may make this psychological process easier for the person. However, it is very hard to imagine how one could assign numerical values to such a complicated psychological process in a non-arbitrary way.

Very much the same point applies to efficiency. It seems plausible indeed to claim that one more or less has the capacity (and the actual condition fulfilled) to realize one's decisions. In other words, the extent to which one controls the circumstances necessary to realize one's decisions certainly seems to be a matter of degree. For instance, a hearing aid can improve the capacity of a partially deaf person to complete a course in history, or cognitive behaviour therapy can improve a neurotic person's ability to abstain from going back to check the stove three times a day. Nonetheless, it is difficult to see how this could be measured in any valid and reliable way, partly, of course, since so many factors influence the capacity for efficiency.

---

[104] This is, of course, a general problem for my idea of authenticity that needs to tackled.

The conclusion must thus be that there is little hope of achieving a complete measurement of autonomy, not even an intrapersonal and ordinal one. However, this conclusion should not make us despair altogether regarding the possibility of *partially comparing* different outcomes with regard to autonomy. In a particular case, it may be meaningful to say that a certain line of conduct will improve autonomy more than another and one may even plausibly argue that this is in fact so.

However, for this move to be credible, we probably have to make some rather controversial assumptions. One such assumption is that the persons involved are authentic roughly to the same extent throughout the practical situation we want to evaluate, since arguing in favour of someone being more authentic than another seems especially hard. Furthermore, we have to assume that there is at least a way in principle to measure the strength of desires, competence and efficiency of persons, since this is necessary for the practical comparison to be meaningful at all. However, in the light of the fact that the major problems with the measuring all these things are epistemological and methodological, as we have seen, the assumption that there is a true answer to which desire is stronger, and who is more competent and efficient may seem less controversial. The assumption seems even less controversial in the light of the fact that most people seem to think that we, in fact, are more or less of these things, even if it can be hard to find the answer out.

Consider once again the example of the partially deaf person's hearing aid. It seems reasonable to claim that this facility makes this person more autonomous and that, if she manages the course partly because of this facility, she is thereby living a more autonomous life. It even seems reasonable to hold that one could argue that a much better hearing aid makes her even more autonomous and, perhaps, that the difference between no hearing aid and the worse is less than the difference between the worse one and the better one (or the other way around), even if one cannot quantify the comparisons in numerical terms. One can thus argue in favour of interval comparisons, although vague, in particular cases.[105] One can even argue, even if one cannot prove or quantify it, that a certain policy will be more conducive to general autonomy than another. For instance, one may argue, with reference to various

[105] One has then found what Griffin, 1986, calls "pockets of cardinality", i.e., limited ranges where objects or state of affairs of a certain kind are comparable on an interval scale.

empirical indications, that spending a certain amount of money on hearing aids will improve the autonomy of those who need such facilities more than spending the same amount of money on higher salaries for directors in public office will improve these directors autonomy.

If this is plausible, there may then be *partial* measurability of autonomy. Even if *numerical* assignments may be quite arbitrary, one can thus sometimes meaningfully talk about more or less autonomy, and perhaps even more or less to different extents and for different persons. And sometimes, this is sufficient for practical purposes. For instance, in the examples just mentioned, comparisons of autonomy will be action-guiding if the goal is to promote autonomy. It should also be kept in mind that the difficulty of measuring autonomy is irrelevant to the question of the value of autonomy. Autonomy may be a good thing, even if it is impossible to measure. We have no independent reason to believe that the elements of a good life are easily detectable.

3.3 Autonomy as a right

There is a widespread discourse on the right to autonomy, (right to) respect for autonomy (or autonomous decisions) and (the right to) being treated as an autonomous person. This seems to be the dominant way to conceive of autonomy in the normative discussion of autonomy in biomedical ethics (Beauchamp & Childress, 2001, chapter 3). There is disagreement on the nature of these rights, what it is that should be respected more precisely and the scope of the rights. However, there are some characteristic ideas about rights in the context of claims to a right to autonomy in biomedical ethics. As I said earlier, there is a difference between considering autonomy as a value that should be promoted and a right that should be respected. A way of characterizing the idea of a right to autonomy is to investigate this difference.

As previously stated, something of value is something we have a pro tanto reason to promote (see III.3.1). Thus, values can give rise to obligations (the most obvious case being when a person can act in a certain way to realize a value and there are no other reasons not to act in this way). In this way, values and rights can be put upon a par. However, rights, unlike values, are essentially about obligations to others: what we are allowed to do to other individuals.[106]

---

[106] This is not necessarily true of rights-talk in general, since a right to do something, X, may be conceived of just as an option to do X, i.e., it is both morally permissible to do and to abstain

Rights thus give reasons to act (or to abstain from acting) towards others in certain ways: values *may* do so, but rights *must* do so in order to be rights in the context of the right to autonomy.[107] To make a long story short: if P has a negative right to X (e.g. life), everyone else has a reason not to prevent P from having X, and if P has a positive right to X, (at least) someone else has a reason to see to it that P has X. So, if autonomy only is a value, Robinson Crusoe, alone on his island, has a reason to promote it. But if autonomy only is something there is a right to, reasons to act from that right becomes a practical concern when Friday enters the stage.

The most common way to conceive of the right to autonomy in the context of biomedical ethics is as a negative right not to be prevented from deciding on medical measures (see below). However, it is of course possible to defend a *positive* right to autonomy: a right to be helped to become a more autonomous person and/or to live a more autonomous life (Räikkä, 1998, p 54-56). However, this amounts to saying that we have a pro tanto reason to make others more autonomous, i.e. that autonomy is a positive value.[108] Thus, everything that can be said about autonomy as a positive right can be cast in terms of autonomy as a positive value, which I put forward earlier. I will stick to this terminology.

This last remark about the possibility of positive rights to autonomy highlights the fact that there are basically two ways to account for rights. One is to say that rights are founded on values. The other is to say that rights are based on certain features of the person that in themselves give rise to constraints on what we are allowed to do in order to promote the good (or intrinsic values). The second way of accounting for rights is perhaps the most common and

---

from doing X (see IV.1.1.1). But in the context of the right to autonomy in biomedical ethics, which is our concern here, the received way of interpreting rights is to conceive of them as corresponding to obligations to others (Beauchamp & Childress, 2001, chap. 3).

[107] Recall the disclaimer in the previous note. I am here talking about injunctions (the "heart of rights-talk"). This concept in particular and the concept of right in general will be given a much more thorough investigation when discussing the right to know (see IV.1.1.1). The present concern is merely to make the distinction between rights and values in the context of the right to autonomy in biomedical ethics.

[108] It might be claimed that autonomy as a positive right, rather than a value, gives every person a reason to promote the autonomy of everyone else, but not their own autonomy. Even though this is a possible position, it is hard to see why one should endorse it: why should the person herself be excluded?

straightforward (Kagan, 1998, p 172-173), especially in biomedical ethics regarding the right to autonomy (Beauchamp & Childress, 2001, p 177). The basic idea is that one ought not to be prevented from autonomously deciding what to do and to act upon one's decision (at least if one does not seriously harm anyone else and is at least minimally rational), even if a greater amount of value would have resulted had one been prevented from doing so (i.e., if one's autonomy was not respected). That is, there is a moral constraint on the prevention of P from deciding and/or acting upon his autonomous decision, even if the value that would result from preventing P were greater than the value of not preventing P.

This does not have to mean that no amount of value can justify not respecting P's decision. The right may be *prima facie*, i.e. overridden by stronger considerations, e.g. if the amount of value is great enough.[109] That is, constraints may have *thresholds*: limits above which the rights are overridden by competing reasons, such as values at stake in the situation. The value may be well-being, but may also be autonomy conceived of as a value. Sometimes considerations that may override a right are competing rights, conflicting with the right in question in a certain situation. If some right does not have a threshold, and it is always wrong to infringe the constraint no matter what the cost is in terms of value, the right is *absolute* (see also IV.1.1.1).

However, if rights are founded on values, things get more complicated. Perhaps the most noteworthy feature of such rights is that they can be designated to produce a normative theory with the exact same content in terms of what is morally forbidden, allowed and prescribed as rights construed as constraints on the promotion of value. For instance, consider the idea that autonomy is a value to be promoted as well as a right to be respected (see e.g. Beauchamp & Childress, 2001, p 64). One way to make this idea intelligible is to claim, in line with the idea of rights as constraints, that autonomy is valuable and, thus, ought to be promoted, but that there is a constraint against preventing others to decide and act autonomously. So even if an act, A, would better promote autonomy than another act, B, it may be morally wrong to

---

[109] I am here using prima facie concerning rights as synonymous with pro tanto regarding values, i.e. as a reason that is always there, although it may be overridden. Sometimes it is used to designate reasons that apply in some circumstances but not all (Kagan, 1989, p 17). However, this use would collapse the difference between prima facie and absolute rights, on the one hand and special and general rights, on the other (see IV.1.1.1).

perform A, because A consists of preventing someone from deciding and acting autonomously.[110]

Another way to reach the same conclusion is to say that autonomy is a value that ought to be promoted, but that not respecting autonomous decisions, besides being an instance of less autonomy-promotion, has a (considerable) negative value of its own. This is tantamount to saying that there is a constraint on promoting autonomy through not respecting autonomy, even if more autonomy is realized overall. And if the negative value of not respecting autonomy is lexically prior to all other values, this is tantamount to saying that there is an absolute right to have one's autonomy respected.

Thus, since "constraint-based" and "value-based"[111] foundations of rights may result in the exact same normative theories, I will to a large degree ignore the difference between them in this context. Henceforth, for reasons of simplicity I will use the 'constraint'-vocabulary when talking about the right to have one's autonomy respected. However, it should be kept in mind that this could be reformulated in terms of values. Nonetheless, the distinction between autonomy as a value that should be promoted and a right that should be respected is an important one. It provides us with alternative (but not incompatible) ideals of autonomy. The idea of autonomy as a right to be respected sets constraints on what we are allowed to do in order to promote autonomy and other values.[112] It is this idea will be examined in this section.

All ideals that consider autonomy as a right in some way have to demarcate a sphere around the individual where this right is valid. Otherwise individuals would have a right to decide on matters that do not concern them or could damage others, which seems implausible. This is the background of the talk of the ideal of *personal autonomy* (Feinberg, 1986, p 27; Tännsjö, 1998a, p 115): a private sphere where the individual should be allowed to make and live according to her decisions (Mill, 1859). This idea has been expressed in various

---

[110] The act, A, might, for instance, be the act of manipulating someone to undergo an autonomy-enhancing psychiatric treatment.

[111] Value-based is not the same as derived rights, that is, rights that ought to be recognized due to the recognition being conducive to some value (see IV.1.1.2), since value-based rights regards the nature of rights, while derived rights regards the justification of rights.

[112] As I said, these constraints can be formulated in terms of values, but it is nonetheless a moral "block" against e.g. promoting self-realization by not respecting an autonomous decision (even if not necessarily an absolute one).

ways, e.g. "she determines herself, i.e., makes by herself decisions which concerns *only herself*, or more precisely, which concerns others only in such a way that in *normal circumstances* they cannot have any justified claim against the decision." (Räikkä, 1998, p 51)[113] This, of course, gives rise to questions about what should be counted as concerning only oneself, damage to others, normal circumstances, when others have justified claims, and so forth. A rights-ideal of autonomy should say something about these questions in order to serve as a guidance of action. This will not be done here, however, since my primary purpose is merely to point out the type of questions that an ideal must try to answer.

Besides setting a limit on what decisions are self-regarding enough to fall under the scope of the right to respect for one's personal autonomy, an ideal of this kind must set a limit for how autonomous a person must be in order for the right to be applicable.[114] This is a normative issue, since it is one about how we should treat people – at what level of autonomy their decisions *should* be respected. This normative issue should be carefully distinguished from the empirical question of how autonomous someone is in a situation, i.e., how authentic, decision competent, and efficient someone is regarding a desire, decision and action. The normative issue is about whether any given degree of autonomy should give rise to moral reasons and must thus be settled within a normative framework, i.e., when arguing in favour of an ideal of autonomy.

It may seem strange to let the questions of the right to autonomy and the actual level of autonomy part altogether, however, since respecting someone's autonomy may seem to presuppose that the person in question at least has one desire, and at least some capacity to reach a decision from it. However, it is at least theoretically possible to say that we should treat someone *as if* she is autonomous, i.e. let her go on in her "doings" without prevention, even though she is not deciding on how to act at all (she is just "behaving"). Taken

---

[113] In this quotation, as in the article as a whole, Räikkä gives the impression that he considers this condition to be a part of the conception of autonomy. Conditions on when autonomy *should* be respected are here taken to be a question of the ideal of autonomy.

[114] It is important to make a distinction between the generally autonomous person, who may be non-autonomous regarding some decision (e.g. the normal adult who decides on a treatment without any prior knowledge of its likely effects) and the generally non-autonomous person, who may be autonomous regarding some decision (e.g. the mentally disabled who decides on what shirt to wear).

to an extreme, such an ideal is surely absurd,[115] but if qualified, it has proponents (Rhodes, 2000, p 115). The idea is then that we should apply a kind of principle of charity, saying that people who we can assume have a general capacity to be autonomous get the benefit of a doubt. That is, even if we are unsure whether they are autonomous regarding some particular decision, we should treat them as if they are and, thus, respect their decision, in the sense that we should not try to prevent them from going through with their doings.

Nevertheless, even this idea presupposes that there is some normatively relevant limit on how autonomous someone must be in order for her to have a right to be treated as (if she were) autonomous. So any rights-ideal of autonomy must specify some, perhaps vague, level of actual autonomy over which the person's decision should be respected and under which this obligation is not applicable.

A couple more things should be mentioned with regard to the right to respect for one's personal autonomy that concerns the biomedical context in particular. The first is the emphasis on decision competence, which is a recurring theme in biomedical ethics, while questions of authenticity are often ignored.[116] A standard account of what competence is required for a principle of respect for autonomy to be applicable can be found in Beauchamp and Childress:

> Patients or subjects are competent to make a decision if they have the capacity to understand the material information, to make a judgement about the information in the light of their values, to intend a certain outcome, and to communicate freely their wishes to care givers or investigators. (Beauchamp & Childress, 2001, p 71)[117]

Of course, this account plausibly makes competence a matter of degree (e.g. since "capacity to understand material information" is), but Beauchamp and Childress, like many others, proposes a charitable interpretation, including at least all normal adults in most situations, as well as, at least in some situations,

---

[115] If e.g. applied on lethal viruses or collapsing houses.

[116] This is obvious in standard textbooks like Beauchamp & Childress, 2001, p 69-77, and Tännsjö, 1998a, p 112-114, 140-142.

[117] The first three conditions on competence are well in line with my characterisation (even if differently put), while the fourth and last regard efficiency rather than competence (see III.2.4.1).

the mentally retarded, children, and those suffering from psychiatric disease (Ibid). As already mentioned (see III.2.3), the central idea is to be rather generous in applying the principle of the right to respect for one's personal autonomy in order not to invite to the type of paternalism in medicine that the principle was originally designed to avoid. Thus, if one favours this mainstream conception of autonomy in health care, situations in which one may legitimately disregard someone's desires, due to lack of competence, are rare. Respect for autonomy is the default position.

A related feature of standard accounts of respect for autonomy in biomedical ethics is the emphasis on decisions rather than acts. The standard situation discussed with regard to the right to respect for autonomy is the health care professional offering a medical test or treatment, explaining what it amounts to and asking for affirmation or rejection from the patient. The central act of the patient is thus a "speech-act", consisting of the expression of the patient's decision. This explains the predominant vocabulary of respecting *decisions*: it is seldom respecting autonomy by not preventing the actions of the patient that concerns health care, but taking heed to what the patient has decided.[118]

One further point regarding ideas of respecting autonomy in the context of biomedical ethics is the focus on exercising such respect primarily by avoiding coercion or manipulation. The typical example of coercion in care is the administering of medical tests or treatments against the desire of the patient by physical force or by threats of sanctions. Coercion disrupts the connection between decision and action and thus prevents the individual from exercising her autonomy. The standard case of manipulation is when health care professionals knowingly abstain from disclosing information that is relevant to the decision of the individual about the medical intervention in order to have the individual make a certain decision. Rather than disrupting the connection between the patient's decisions and attempts to act on this, health care staff is here interfering with the individual's process of decision-making and causing the decision not to be the result of the desire of the individual (even if she thinks it is), but the result of the health care professional's opinion on what should be done. This, thus, also clearly prevents the individual from

[118] Take e.g. the standard case of respecting someone's desire not to prolong her life (i.e. euthanasia). See III.2.4.1.

exercising her autonomy. Thus, both coercion and manipulation constitute failures to respect the autonomy of the individual.

However, even though coercion and manipulation are important, probably the most important, ways of not respecting the autonomy of someone, there is another way of restricting autonomy that is sometimes brought to stand in the general debate on autonomy in moral philosophy, but which is seldom mentioned in the context of medical ethics. The following characterisation this kind of autonomy restriction is pertinent.

> Consider the way parents might violate the autonomy of, say, their adolescent child by constantly pre-empting her choices about clothes, a place to live, what car to buy, and the like, and buying these things for her secretly and surprising her with them. The parents violate the person's R-autonomy [right to be treated as autonomous].... by treating her as if she could not adequately do so herself. (Christman, 1988, p 110)

The idea is that one can restrict someone's autonomy by making decisions and acting on her behalf in matters that really ought to be decided by her, thus treating her as if she could not manage to decide on these matters herself. This way of not respecting the autonomy of someone does not neatly fall into the category of either coercion or manipulation (although some definition of the latter might be strained to include cases like Christman's). This is surprising, since one of the main concerns of autonomy is to avoid that someone else makes decisions on one's behalf, disregarding the desires and values of the person (or supposing one has better knowledge about what a person "really" wants more than herself). This idea will not be disregarded in the following (see IV.2.2.2).

3.3.1 Justifications of autonomy as a right

Thus far, we have concentrated on the nature of the right to respect for one's personal autonomy. I will now say something about the justification of such a right, which may basically proceed in two ways. First, one may claim that respecting people's autonomy constitutes a constraint on what we are allowed to do in order to promote the good (either of the person in question or all things considered). This constraint may be argued to be absolute, always making it morally impermissible to abstain from respecting someone's autonomy in order to promote the good. The constraint may also be argued to

be prima facie, i.e., overridden if the values or other competing moral considerations at stake are important enough. Secondly, one may claim that respecting people's autonomy is, in general, a good means to promote some value (e.g. well-being), i.e. that the right to respect for one's personal autonomy is of instrumental value. I will now say something about each of these ways of justifying the principle of right to respect for one's personal autonomy.

Generally, the task of determining which justification is the most plausible one is a difficult and controversial one. The method of a reflective equilibrium favoured in this book, roughly states that we should seek a coherent match between principles, thought experiments, particular judgements that are reasoned and considers our intuitions (see I.3). Needless to say, which of these justifications is the most plausible one cannot be settled in this context.

However, I will make some remarks that at least suggest that an *absolute* right to respect for one's personal autonomy is implausible. I say, carefully, *suggest*, since there is no neat knock down-argument to this effect.

First, there is a contra-proportionality between the scope and the plausibility of the principle of an absolute right to respect for one's personal autonomy. Recall that the principle of respect for autonomy requires a sphere around the individual where the right is valid; hence the talk of personal autonomy. The broader this sphere is construed, the wider the scope of the principle. For instance, take the classic idea that the principle applies whenever no on else is harmed by an action. If one interprets harm as "serious physical harm that is a direct consequence of the action", the scope of the principle becomes very wide. However, it also becomes very implausible, since it would imply that *no* amount of non-physical suffering that an autonomous action leads to can *ever* justify preventing it. On the other hand, if harm is construed so as to include every consequence of an action that makes someone somewhat worse off, it becomes much less controversial, especially if one includes omissions to perform actions one could have performed. However, to conceive of harm in such a broad way, would rob the principle of practical significance, since it is very difficult to think of actual situations where no one else is affected somewhat negatively by one's actions, at least in the sense that had one acted differently, at least someone else would have been somewhat less worse off. An action with the alternative of giving money to the Red Cross would then probably fall outside the scope of the principle. So what the

principle can gain in plausibility, it will loose in scope and, thus, practical interest.

Second, and more importantly, it seems outlandish to think that no amount of bad effects could ever make it morally permissible to violate a person's autonomy in a particular case,[119] even if the bad prevented only is bad for the person whose autonomy is violated. This seems especially obvious when the decision or action prevented is not one that the person herself considers important, e.g., when the desire not respected is less strong, a less permanent one for the person, or less authentic in some way. Moreover, it seems even easier to accept this possibility if the bad effects consist of the severe reduction of *autonomy* in the future. And if we add cases where the well-being or autonomy of others is at stake, regarding restrictions of autonomy as permissible seems even more plausible.

Thus, it is probably more reasonable to consider the right to respect for one's personal autonomy as a prima facie-right, i.e., as a right that can be overridden if enough value is at stake. As already mentioned, there are two ways of accounting for this idea: as a constraint (with a threshold) on what we are allowed to do to promote overall good or as a (considerable) negative value ascribed to the restriction of autonomy (III.3.3).[120] However, both these ways of accounting for the prima facie-right has the same implication: we should "sacrifice" some other values in order to respect autonomy. For instance, if an alternative action, A, generates more well-being than another alternative, B, B may nonetheless be the right thing to do, if A consists of the restriction of autonomy (given that these are the only alternatives). Since the right is prima facie, there is, however, an upper limit (although it may be vague) to what price in terms of well-being, other values or other morally relevant considerations we ought to pay in order to respect autonomy.

One interesting consequence in this context is that the same goes for autonomy as a positive value. The prima facie-right to respect for one's

---

[119] Examples that demonstrate this point have been construed, I think, convincingly elsewhere (Glover, 1977, p 82; Tännsjö, 1998a, p 100-102). These examples contain a violation of someone's autonomy, but the violation nonetheless is morally required or, at least, permissible (at least seemingly after careful consideration). *One* such example is enough to demonstrate that there is no *absolute* right to autonomy, i.e., that the violation of autonomy is *always* wrong.

[120] Another, though somewhat misleading, way to put the second idea is, of course, to say that the negative value founds the constraint in the promotion of other things of value (and the "un-promotion" of other things of negative value).

personal autonomy implies that there is a "moral price" to *preventing* someone from deciding and acting autonomously, even if the prevention would promote the individual's *overall* autonomy (by making him live a more autonomous life or being a more autonomous person). Therefore, the constraint on the violation of autonomy also regards the promotion of autonomy: according to the proponent of the prima facie-right, the fact that we cannot always trade a violation of someone's autonomy for more autonomy overall (for her or anyone else) is what makes the right a constraint. The prima facie-right to respect for one's personal autonomy thus has a built in time bias: it is having my autonomous will respected (in the sense that I ought not to be manipulated or otherwise prevented from deciding and acting from it) here and now that is of relevance.[121]

Finally, one may justify the right to respect for one's personal autonomy by arguing that general adherence to such a right promotes overall good. A traditional way of doing so is to use a Millian line of reasoning, arguing that respecting autonomy (in health care) promotes overall well-being (Tännsjö, 1999). However, even if such an argument is successful, it does not establish a right to respect for one's personal autonomy in the sense defined here. This is so, since this argument denies that there is a *principled* moral constraint on violating autonomy: whenever violating someone's autonomy produces more well-being, we ought to do so.[122] However, one could argue that general acceptance and/or observation[123] of the right to respect for one's personal autonomy has good consequences in terms of well-being (better than if there were less or no such acceptance and/or observation). One can thus, on general

---

[121] However, it is a time bias compatible with the idea of temporal neutrality (see III.3.2.2).

[122] An exception is rule utilitarianism, since it claims that we ought to act in accordance with the rule, general adherence to which produces more overall well-being than any alternative rule. If the rule of respecting the autonomy of others is such a rule, we ought to adhere to it, even if some action would produce more well-being by not adhering to it. However, I will disregard this possibility, since rule utilitarianism is neither plausible (see VII.6.2), nor a common position in biomedical ethics.

[123] The distinction I have in mind here is the one between consequentialistic arguments in favour of installing a disposition in individuals to act as if there is a right to respect for one's personal autonomy (with or without believing that there is such a right) and consequentialistic arguments in favour of implementing regulations in an institutional setting, demanding that the professionals in this setting act in accordance with the right to respect for one's personal autonomy. Of course, one could argue in favour of both.

consequentialistic grounds argue in favour of the *recognition* of the right to respect for one's personal autonomy, a recognition that perhaps should take the form of a policy.

It should be kept in mind that such an argument does not imply that health care professionals or state officials should try to find out or think about when the violation of someone's autonomy produces more well-being, since a firm disposition to confirm to or strict observance of the rule to respect the autonomy of others may produce more overall value than if these parties deliberate on when to respect autonomy and when not to. The Millian argument in favour of the right to respect for one's personal autonomy may therefore produce recommendations in practice that are identical to those of the position that claims that there is a moral prima facie-right to respect for one's personal autonomy.[124] Therefore, it may be difficult to decide on which of these justifications is the plausible one by just considering their practical implications. We may have to turn directly to our moral intuitions about these principles, for instance, through thought experiments. However, I will not do this, since, as already mentioned, the purpose here primarily is to point out the question that an ideal of respecting autonomy must address.

4. Concluding remarks

In the previous chapter, we noticed that in the context of presymptomatic genetic testing and genetic counselling, arguments are often made with reference to autonomy, where autonomy cannot be understood only as a right to respect, but also as a value to promote. Although this kind of argument is common, the idea of autonomy as a value to promote is seldom elaborated. An idea often used but seldom clarified calls for a more thorough exposition of the idea, as well as the concept it is formulated by. This is important, for instance so that the plausibility of arguments using the concept and the idea becomes more evident. This more thorough exposition of autonomy as a concept and the idea of autonomy as a value to promote has been the task of the present chapter.

The exposition rests on the distinction between conceptions of autonomy, stating what autonomy is, and ideals of autonomy, stating what is morally

---

[124] Of course, there is the theoretical possibility for the consequentialist to argue that it is in fact true, due to the way the world as a matter of fact works, that respecting autonomy *always* will produce more well-being than not respecting autonomy. However, this argument is hardly plausible.

relevant about autonomy. So the first task was to develop a conception of autonomy. Autonomy, generally characterised, says that to be autonomous is to govern oneself or to decide one's own way. To live autonomously is then to live in accordance with one's basic desires or values. From this it should be obvious that autonomy is a matter of degrees: a person can more or less lead the life she has chosen, more or less choose how to live, and her desires can be more or less her own. Against the background of this general characterisation, I used the following minimal definition of autonomy as my point of departure: a person is autonomous in a situation to the extent that she does that what she has decided to do, because she has decided to it and decides to do what she wants, because she wants it. Here three components are discernable: will (or desire, or value, i.e. pro-attitude), decision, and action. I then argued that how autonomous a person is, is determined by all these components and that all these components can vary in degree.

First, the will one acts from can be more or less authentic. Generally speaking, an authentic desire is a self-determined desire, or a desire that is truly the person's own. I rejected some suggestion on how this is to be understood, e.g. the idea that authenticity merely consists of consistency between desires, or consistency between different levels of desires, or that authentic desires are desires created from a "true I", free from social and other external influences, or that authentic desires are morally praiseworthy ones.

Instead I proposed an account of authenticity, according to which an authentic individual should be able to critically evaluate the basis from which she makes her decision: an authentic desire can be upheld in the light of knowledge about why one has it, so that knowledge of why one has it would not make one disapprove of it. The agent can, at least hypothetically, identify herself with the desire, willingly acknowledge that she has it and will not be inclined to abandon it just because she learns new things about herself. Inauthentic desires are desires that one would disapprove of if one were to find out why one has them. This idea connects the thought of identification and rationality as ideas of authenticity, and is in correspondence with our intuitive idea of an authentic individual, or so I argued. I then confessed my conviction that actual critical evaluation increases authenticity even more than just the ability of desires to withstand hypothetical critical evaluation, but left it to the reader to decide on the plausibility of this.

Another factor that determines the autonomy of an individual is the capacity to make decisions from one's desires, or decision competence.

Decision competence is also a matter of degrees, since a person can be more or less capable of successfully performing the task of deliberation.

The last component in the conception of autonomy, efficiency, is to, through action, realizing that what one has decided, or at least the ability to do so. A number of factors affect the efficiency of a person. An important factor for the arguments of this book is how well founded the beliefs that one acts upon are. This since ill founded believes are more likely to be false, and false beliefs about the consequences of one's decisions and actions probably will make one take a non-efficient route for the realization of one's ends. Thus, receiving information, including genetic information, can improve one's efficiency and, thus, autonomy. However, information can also affect information negatively, for instance by inducing emotional paralysis. These results of the discussion of conception are well in line with the findings of chapter II, that autonomy can be both promoted and reduced by genetic information.

A virtue of this conception is that it allows for the formulation of different, and sometimes competing, ideals of autonomy, both ideals that consider autonomy to be a value that should be promoted and as a right that should be respected. I presented two basic ideals of autonomy conceived of as a value to promote, cast in the terms of the conception: the ideal of self-realization and the ideal of capacity.

The ideal of self-realization says that the value of autonomy consists of living one's life in accordance with one's own basic authentic desires, through one's own decisions and actions. Crudely put, the more a person in fact succeeds in living according to her basic authentic desires, the more autonomous she is, the better off she is, ceteris paribus. This ideal captures the idea that the good thing about autonomy is to in fact succeed in living the life one wants to live. The decision competence and efficiency of the person causally determines the extent to which the person in fact succeeds in realizing her desires. However, decision competence and efficiency does not have to be ascribed a value of their own, according to this ideal. They can be taken solely as necessary presuppositions to realizing the desires autonomously.

The ideal of capacity says that the value of autonomy consists of being an *autonomous person*. This is a person with authentic desires, and enough decision competence and efficiency to implement these desires. The autonomous person, then, both has the capacity required and the actual conditions fulfilled

in order to independently consider her own basic projects and values, make decisions on the basis of them and realize them through her own action. This ideal is to a great extent an ideal of character. An autonomous person is not weak of will, self-deceiving, confused, phobic, and so on, since all these things tend to destroy autonomy in the sense defined here. Also this ideal makes autonomy a matter of degree: the more authentic, decision competent and efficient I am, the better for me, ceteris paribus. The value, then, is to be such a person that *can* realize her desires, that is, *if* the person has desires, it is better for her if they are authentic and she is capable of deciding and acting on them.

However, these ideals do not themselves imply any answers on what one ought to with respect to autonomy. Therefore, I pointed out what additional questions proponents of these ideals must tackle in order to render them action-guiding: questions of norms, time and comparisons. Regarding norms, I did not argue in favour of any specific one, but only presented some alternatives. Regarding time, I argued in favour of temporal neutrality and the relevance of now-for-now preferences. Regarding comparisons of autonomy, I argued in favour of a rather sceptical position on the possibility of measuring autonomy adequately, even in principle. However, I left open the possibility that one may in some circumstances use empirical indications to make some comparisons more credible, which may at times be sufficient for practical purposes.

Also ideals of autonomy conceived of as a right to respect were formulated, using the conception. Also regarding these ideals, I pointed out questions proponents of them must tackle in order for them to be practically useful: perhaps most notably the question of when one is autonomous enough to deserve treatment as autonomous and the question of how widely one should construe the personal sphere in which the right should be respected. In this context, I indicated why an absolute right to autonomy is implausible. I also explicated some implications of the traditional idea of respect for autonomy in biomedical ethics, and primarily the constraint on coercion and manipulation in health care. Finally, I presented two ways of justifying the right to autonomy, and rights in general, which will be of consequence in following chapters.

Just as chapter II, this chapter leaves us with further questions to be tackled in the future. Some questions seem to be of a more technical nature, for instance questions that arise from the discussion of authenticity, like "How should desires be individuated?" and "Which knowledge is relevant for the

authenticity of desires?" However, there are also questions of a more fundamental nature. Perhaps most noteworthy, I have said nothing, besides some hints, about the justification of ideals of autonomy conceived of as a value and even less about the justification of normative ideals based on these alleged values. However, one hint regarding the justification of the ideal of self-realization is that this ideal captures the intuition that it is of value to actually lead the life one considers to be good oneself. However, any attempts to a more full-fledged defence of these ideals are absent in this book, and I thus have to remain neutral on the question of whether autonomy really is valuable in itself or not. Nonetheless, that autonomy is a value to promote seems to be presupposed by many authors in the debate on the value of genetic testing, as we saw in the previous chapter, so the question certainly merits a more thorough investigation. I hope I have at least provided a useful framework for such an investigation. Moreover, if one accepts my sceptical conclusions regarding the possibilities of comparing amounts of autonomy, questions remain on what conclusions to draw from this: does this have only practical implication, or does it also have theoretical implications regarding the plausibility of autonomy conceived of as a value? Although, I think, this an intriguing question, I will leave it for now.

Chapter IV
The Individual's Right to Genetic Information

1. Introduction

"The ethical questions surrounding genetic information are often addressed in terms of rights." (Häyry & Takala, 2001, p 403) They are indeed, and particularly discussions of access to genetic information. More often than any other rights regarding genetic information, the individual's right to genetic information about herself[1] is often defended or, at least, claimed.[2] This right is often referred to as the *right to know* (about genetic information about oneself) (Chadwick et al, 1997; Hermerén, 1999). Of course, there may be other possessors of a right to (know) genetic information about a person: for instance, the family and relatives of a person or parties who have an interest in the information for various reasons may be claimed to have such a right. These latter types of parties will be discussed in later chapters (VI and VII). This chapter will examine the question of the individual's right to (know) genetic information about herself; how this right could, and should, be understood, and whether there indeed is any such right.

The question of the individual's right to genetic information is thus twofold. First, there is the question of how "P has a right to genetic information about herself" (or P has a right to know) is to be interpreted. Of course, if such a right is claimed, the proper interpretation of it cannot be made independent of the context in which it is claimed. However, as we will

---

[1] That is, about (some part of her) her own genetic constitution.

[2] This is so in both legal context (see e.g. Council of Europe's Convention on Human Rights and Biomedicine, Chapter III, article 10.2; UNESCO's Universal Declaration on the Human Genome and Human Rights, Paris, 1997-11-11, article 5.c; and WHO's Proposed International Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services, 1998, page 9) and philosophical context (Chadwick, 1997, p 14; Takala, 2000, 94-100). However, it should be mentioned that the Council of Europe writes more generally about an entitlement to know "any information collected about his or her own health." (Ibid.) For more on WHO's statement, see IV.3.

see, there are a great number of possible and non-trivial interpretations of what such a right may involve, and, it seems to me, many of them have been overlooked. In fact, it is often far from obvious which of these interpretations that is presupposed in discussions of the right to genetic information about oneself (see e.g. IV.1.2 and IV.3). A careful analysis of the notion of this type of right might thus help us in evaluating arguments for and against it.

Second, there is the question of whether there is such a right: does the individual (or index-person) have a right to genetic information about herself? Of course, the answer to this question will depend on the interpretation of the question. But given an interpretation that is clear enough, what reasons do we have to think that someone has the right in question? In order to determine this, we have to scrutinize the arguments for and against right-claims of this sort. In this chapter I will first tackle the question of interpretation and then the question of argumentation or justification.

1.1 The concept of a right

"P has a right to genetic information about herself" is an instance of the general claim A: "P has a right to X". An analysis of such rights-claims must answer the following questions:

(i) Who is P?
(ii) What is X?
(iii) What does A imply (logically and/or conceptually (in a certain moral theory))?
(iv) How is A to be justified?

Of course, these questions are related in various ways, both generally and within the framework of a particular ethical theory. To answer the question of whether some person, P, has a certain right to something, X, one has to say something about the justification of the right. And if one can provide a tentative answer to this question, it is hopefully possible to see or at least make plausible what implication the right has. Obviously, one point of ethical theories is to try to provide coherent and motivated answers to questions such as these. Nonetheless, even though interrelated, these are different questions.

As regards question (i), the person P that is the subject of this discussion is, of course, the index-person, i.e. the person having, or the person that could have, a (presymptomatic) genetic test. Of course, sometimes there are several

index-persons: when a whole family performs genetic testing simultaneously, for instance. This does not alter the fact that the test is performed on some individual and that this (or these) individual(s) may or may not have some kind of right to the information resulting from such a test. I will not have to say anything more than this about question (i) in this context.[3]

As regards question (ii) there are many ambiguities. What is the right in question in this context a right to? That is, how could "genetic information about oneself" be interpreted? This is the specific question to be discussed in this chapter and I will therefore return to it (see IV.1.2). Before that, however, there are some general things that should be said about rights, relating to question (iii) and (iv).

1.1.1 The implications of rights

When we say that someone, P, has a right to something, what does this imply (or presuppose)? In order to answer that, we have to make some distinctions. To start with, there is the distinction between the rightness or moral permissibility of an action and the right to perform an action. As will be clear in the following, different ethical theories have different ideas about the relationship between rightness and rights. These theories can be placed on a spectrum with extreme positions at the ends. On the one extreme, there are theories that claim that rights exhaust everything that can be said about moral rightness and wrongness (pure theories of rights à la Locke). On the other extreme, there are theories that claim rights to be totally irrelevant for the question of moral rightness or wrongness, at least on a basic level (e.g. pure consequentialist theories à la Bentham).

It is not unusual for ethical theories to position themselves somewhere in between these two extremes (e.g. Rawls). One such position is that if an action violates a right, this is in itself a very strong (often overriding) reason for the wrongness of the action, and if one has the right to perform an action X, it is almost always morally permissible (but not necessarily so) to perform X (see Dworkin, 1977). Furthermore, most theories of this type seem to agree on the opinion that rights do not exhaust the moral field – there are actions that are wrong due to other reasons than being violations of rights.

---

[3] In the context of other types of genetic testing, such as prenatal diagnosis of PGD, the question of who is the possible right-holder may however be the most problematic one.

The focus in the following will be rights rather than moral rightness, since this interpretation of "right" seems to be the most common with regard to the question of the right to genetic information. However, there are some writers who sometimes seem to interpret the phrase "The person P in situation S[4] has the right to genetic information" as "It is morally wrong of P in S not to have (access to or knowledge of) certain genetic information (about herself)". As will become evident, this interpretation seems to be the proper one when it comes to the authors who defend a duty of the individual to have genetic information about herself (see V.3).

Moreover, there is a distinction between absolute and prima facie rights.[5] Absolute rights are inviolable in the sense that it is always wrong to violate them. That is, there are no ethical considerations of any kind (including other rights) that can override the right in question. Prima facie rights, on the other hand, can be overridden (perhaps by other rights). If a right is prima facie, it is thus not enough to establish that a certain action is a violation of it in order to establish that the action is wrong. One also has to establish that there are no other ethical considerations that override the right in question in the situation.[6] As will be evident in the discussion of the right to genetic information, these rights, if there are any at all, are most plausibly defended as being of a prima facie kind. I have already argued that this is probably plausible for rights to have one's autonomy respected as well (III.3.3.1).

Furthermore, there is a very basic distinction between negative and positive rights. The distinction can be characterised in terms of the moral reasons for others to act or abstain from acting towards the right-holder in various ways they give rise to. Positive rights, then, correspond to at least one other person having a reason to provide the right-holder with, or to help her keep hold of, that to which she has a right. Negative rights correspond to others having a

---

[4] This component is necessary, since the right may be thought to be valid only given that certain conditions are fulfilled.

[5] Terminology differs regarding this distinction. This terminology is from Beauchamp & Childress, 2001, p 357-358. Räikkä, 1998, makes the same distinction, using the terminology of strong and weak rights, and Thomson, 1990, p 153-169, speaks of different stringency of rights, and calls absolute rights "maximally stringent" (Thomson, 1990, p 175). Of course, prima facie rights can be of different strength or stringency (see next footnote).

[6] Of course, different prima facie rights can differ in strength, so that one stronger, but overridable, prima facie right always overrides another weaker.

reason[7] not to deprive the right-holder of, or not to prevent her from acquiring, that to which she has a right. Negative rights are therefore sometimes described as the right not to be prevented from doing or having something, or the right to *non-interference.*

A common example to clarify the distinction is the right to life. If one has negative right to life, others have a reason to refrain from taking one's life. If one has a positive right to life, at least someone else has a reason to ensure that one keeps on living, even if it requires active measures being taken. Since genetic information is different from life in that the former is not something that one initially has, a more relevant example in this context may be a right to eat. A negative right to eat implies that other have reasons not to prevent me from eating, while a positive right implies reasons for actively assisting me in eating (e.g. by giving me some food).

Anyone familiar with the discussion about the distinction between acts and omissions – or between doing harm and allowing harm to occur - will see that the distinction is not as clear-cut as might be the first impression. In fact, the distinction between positive and negative rights characterised as above is founded on the distinction between acts and omissions, since the reason corresponding to a positive right is a reason to *do* something (i.e. *act*, e.g. by helping someone) and the reason corresponding to a negative right is a reason to abstain from doing something (i.e. an omission).[8]

Rights, thus, imply certain moral reasons of others.[9] More specifically, someone, Q, having a right with respect to something, A, is equivalent to P having a reason to act *in certain ways* towards Q with respect to A.

Another example perhaps will clarify. Take two persons, Jack and Jill, and the action of Jack giving Jill 100€. Let us assume that he owes her that amount of money due to a previous loan. Let us assume that this gives Jill a right to the money (that is, Jill has the right that Jack gives her 100€, or, she has a right to receive that amount if we grant that receiving something can be defined in terms of someone else giving it). Jack then has a corresponding reason to give Jill the money. So, Jill here has a positive right to receive 100€ from Jack. Assume further that Jane does not owe Jill any money, but is in a position to

---

[7] It is almost always presupposed that reasons connected to negative rights concern *all* others (see Häyry & Takala, 2001, p 404).

[8] I touch upon this distinction in several places in this book (see e.g. III.3.3 and V.3.2).

[9] Unless we are talking about "rights" as pure options, without injunctions or enforcement privileges (see this section below).

stop Jack from paying his debt. Obviously, Jill has a right that Jane does not do this. Thus, she has a negative right to receive the money from Jack with regard to Jane. However, she has no positive right that Jane gives her 100€.

In addition, the concept of negative and positive rights includes the possibility of "waiving". This means that a right-holder may always choose to abstain from that to which she has a right and thereby cancel the moral reasons of others to act in certain ways with regard to this. For instance, Jill may choose to cancel the Jack's debt, thus relieving him of the reason to provide her with the money.

Moreover, saying that people have rights to *things* (such as food or money), or state of affairs (such as being alive), is often an elliptical way of saying that people have rights to do things (eating or buying food, retrieving money that has been lent, go on living, etc). I will sometimes use this kind of elliptical way of speaking. However, it should not be presupposed that all rights are of this kind. For instance, it is possible that the right to have genetic information only means that others have reasons to not to prevent one of being in the state of knowledge of certain genetic facts about oneself.

Both positive and negative rights can be analysed into elements.[10] When a person, P, has a right to (do) X, one or more of these elements can be referred to or be presupposed. More precisely, in Kagan's terminology, the following three elements constitute a *full negative right* (for P to do X):

> (1) an *option* for the agent to do X (or not do X, as he chooses); (2) an *injunction* protecting the agent's decision – i.e., it is wrong for others to force the agent not to do X; (3) an *enforcement privilege*, giving the agent the right to enforce the injunction. (Kagan, 1989, p 219)[11]

---

[10] One such classic analysis is Hohfeld's account of different kinds of rights (Hohfeld, 1919; see also Lindahl, 1977, p 25-37 for an excellent summary of Hohfeld's analysis). I will disregard this analysis, primarily since it is more suitable for analysing legal than moral rights. See also footnote 16 in this chapter.

[11] Kagan's analysis, although illuminating, can come through as misleading, since he does not talk in terms of reasons. This might give the impression that he excludes the possibility of prima facie-rights. In order to avoid such possible misunderstandings, I will explain the elements of rights in terms of reasons, except regarding options, which I have never seen formulated in terms of reasons.

An option is most easily viewed as a guarantee that P is acting morally right, or at least morally permissible, when P does as she wants with regard to X.[12] Take for instance the right to some piece of property, like a car. A right to property normally means a right to sell the property in question.[13] If P has such a right regarding a car, in the sense that P has an option, then P does not do anything wrong morally when he sells the car and P neither does anything wrong if P abstains from selling it.

An injunction is most easily viewed as a restriction upon others to react in various ways towards P, given P's right to X. If P has a negative right to X, other people have a moral reason not to interfere with P's doing X.[14] To be sure, "force" and "interfere" are vague terms, but they are usually defined as to include more than only physical prevention. To punish P in various ways if P does X is usually included, as are threats and deceit. These details need not concern us anymore at this point. However, if one argues in favour of a particular negative right, one has to be precise about what kind and degree of force that others have reason to abstain from, and why.

An enforcement privilege is most easily viewed as a reason for the moral permissibility of reacting against anyone who tries to interfere with P's doing X, i.e. anyone who violates the injunction. As with injunctions, it is sometimes unclear what kinds and degrees of reaction are permissible. P may be allowed to use force of different kinds and to different degrees in order to ensure that P is not prevented from doing X. P may also be allowed to punish already performed violations of the injunction, perhaps with the aid of a third party, such as the state (which makes the enforcement privilege a positive right to aid with punishment).

A *full positive right* is constituted by the same elements: (1) an option to do X; (2) a positive injunction – providing reasons for others to help the agent's doing X in various ways; and (3) an enforcement privilege.

A full positive right to housing, e.g., would then presumably include the option to occupy and in various ways use a certain sheltered area with certain facilities. That is, one is morally permitted, but not obliged, to occupy and use

---

12 Options are sometimes called 'licences' (Häyry & Takala, 2001, p 404).

13 The right to property or ownership can be divided into several parts (or functions) of which one can have some, but not necessarily all, e.g. the right to use (in certain ways), sell, give away, destroy and so on. See Adler-Karlsson, 1969.

14 Whether the reason to non-interference is identical to, corresponds to or just explains the injunction is not of interest in this context.

it in these ways. Furthermore, at least someone else has a reason to act so as to make this possible, and if she or they do not, the right-holder has a right to take actions against the obliged party (for instance, by filing a complaint to a legal institution with the power to punish the obliged party).

These elements of rights can be separated and are in fact so. There can be injunctions without options.[15] This should not come through as very controversial, at least not on more common sense opinions of morality. Destroying some rare and antique piece of furniture that one owns, buying pornography, spending all one's money on liquor instead of sending even a dime to Tsunami-victims can all be considered to be blameworthy and/or wrong actions, but actions that others still are wrong to prevent one from performing. In any case, one cannot *infer* an option from an injunction.[16] One has to argue in favour of them separately.

Just as it is conceivable, and perhaps plausible, to have injunctions without options, options without injunctions are also conceivable (Dworkin, 1977, p 188-189).[17] For instance, an enemy may not have the negative injunction to

---

[15] Even such a radical theorist of rights as Nozick would agree to this (Nozick, 1981, p 498-504). He holds that an action a person has a right to perform can be blameworthy and even wrong. For instance, his theory of right does not imply that it is morally OK not to help people who will otherwise starve to death, even if they have no right to be helped. This seems to be overlooked by some standard accounts of Nozick (see Tännsjö, 2000, p 80-92). However, it is doubtful that Nozick would accept that the violation of a right ever is right, and he certainly argues that we have a right to enforce violation of rights (Wolff, 1991, p 24). So rights include injunctions and enforcement privileges, but not necessarily options, according to Nozick. Nevertheless, he does not hold that the moral field is exhausted by rights and is, then, not an extremist in the above-mentioned sense.

[16] In the discussion of rights to genetic information, Hohfeld's concept of *claim-rights*, in which rights include both options and injunctions, are often presupposed (See Häyry & Takala, 2001, p 404, and Rhodes, 1998, p 15). Of course, one may choose whichever terminology one sees fit, but one cannot, then, automatically assume that a right in the sense of an injunction includes a right in the sense of an option. At least this cannot be done in *moral* contexts, even if one does so in legal contexts (which is Hohfeld's area of discussion). This is why Kagan's analysis of rights should be preferred to Hohfeld's when discussing moral rights (and the *basis* of legal rights, which I assume to be morals).

[17] In fact, what Hohfeld calls privileges (in law) can be analysed as options without injunctions (in morals). According to Hohfeld, if someone, P, has a privilege regarding some action, A, this means that P has no obligation to abstain from doing A. However, from this we cannot conclude that Q does not have a privilege to prevent P from doing A. That is, P violates no one's right if she does A, but Q may still be free to prevent P from doing A. Thus, in Kagan's terms, a privilege is an option without an injunction (and an enforcement privilege). That is, if a person is (morally) free

escape from war-camp (we have a right to stop him), but it may not be wrong of him to escape (or to abstain from doing so). If we have a right to prevent him from escaping and he is morally permitted to escape or abstain from escaping, he has an option without an injunction or an enforcement privilege.

The reasons referred to in the explanation of these elements may vary in strength or stringency. This corresponds to the distinction between absolute and prima facie rights mentioned above. If the reasons are *conclusive*, i.e. guarantee the permissibility or impermissibility of the actions mentioned, the right in question is absolute. If they are not, the right is prima facie, and other reasons may thus override the reasons implied by the right in question. On the basis of this, it is easy to see how different prima facie rights may vary in strength: the more powerful reasons they imply, the stronger is the right, that is, the more powerful reasons are needed in order to override the reasons implied by the right. As mentioned in III.3.2.3, their strength may be taken to be determined either by qualitative or quantitative factors, or both. I will return to what determines the type and strength of reasons implied by various rights to genetic information.

Let us follow up on Kagan's analysis of rights and introduce the term *thin rights*. A thin right is an injunction. As Kagan remarks, thin rights are "the heart of right-talk" (p 221-222). This remark is easily validated. General characterisations of the distinction between positive and negative rights, like the one above, put emphasis on the reasons of others to provide for (or do) or abstain from doing certain things (see also e.g. Buchanan et al, 2000, p 380-381 and Wolff, 1991, p 19). Certainly, when someone claims that her right was violated when she was prevented from speaking her mind or had her property appropriated, she need not mean anything more than that there are reasons for it being wrong for someone else to prevent her from speaking her mind or for someone else to appropriate her property. The fact that injunctions are the core of rights is also clear in the debate on the right to genetic information (see this chapter below).[18] Thus, until discussing the duty to know (V.3), thin

---

to perform an action, she is permitted to do so (and permitted to abstain), but others may be allowed to prevent her from doing so.

[18] For instance, Räikkä's analysis of rights is obviously about injunctions: "On a reading of 'rights' that has no difficult ontological burdens, 'S has a right to live' is simply a short hand for 'there is a moral reason not to prevent S from living or a moral reason to help S to live'." (Räikkä, 1998, p 58) This definition of rights is weaker than Kagan's definition of injunctions, since Kagan terminology is about moral *constraints* (it is *wrong* for someone else to violate the right of S), while

rights, or injunctions, will be the focus of our attention. So, whenever I speak of negative and positive rights henceforth, I have these kinds of rights in mind, unless I explicitly state otherwise.

Finally, there is a distinction between general and special rights. General rights always holds, in all circumstances, whereas special rights holds only given certain circumstances. For instance, I guess many people would consider the (negative) right to life a general right. This means, then, that this right is not conditioned on something else being the case. This does not mean that the right is absolute: even though it holds regardless of circumstance, it may nonetheless be overridden by other morally relevant concerns. On the other hand, a special right may be the right to free speech. This right may not hold regardless of what you say and how and when you are saying it: it may not hold when you are slandering or stirring up a mutiny. Another example of a special right is the right of Jill in the example above to receive 100€ from Jack. This right holds only on the condition that Jack owes her this sum of money.

However, it is not always clear whether exceptions to a generally held right are due to it being special or prima facie. For instance, the right to free speech may be claimed to hold generally, and cases of slandering or instigation merely being cases of overriding ethical concerns (probably of an "risk of harm"-kind). And exceptions to the negative right to life (e.g. to prevent a mass-murderer going berserk in a kinder-garden) may be claimed to imply that this right is not general at all, but conditioned on certain (although normal) circumstances. It seems to be of little practical concern whether exceptions are due to the right being prima facie or special, as long as the circumstances in which the right does not hold are clear enough. However, it may be of concern in terms of motivation or justification of the right. My conjecture is that pure consequentialists would regard rights with exceptions as special rather than prima facie, since a right being overridden in a certain situation just shows that it should not be respected in this situation, and, thus, is no right (there are no special ethical considerations of rights according the pure consequentialist). On the other hand, someone who thinks that people have rights regardless of consequences would be more inclined to say that the

---

Räikkä writes that it is enough with a moral reason not to interfere or to help S with regard to some action or omission X in order to speak of S's right to X. In this regard Räikkä's analysis is to be preferred.

exception of a right (e.g. the negative right to life) is due to the right being overridden by other ethical concerns, while the right, nevertheless, still holds (but the violation, or rather infringement, of it is still permissible or even obligatory, because of the overridingness of the other ethical concerns). This relates to the basis or justification of rights, which I will address in the following.

1.1.2 The justifications of rights

Moral ideals expressed in terms of rights are often put in opposition to consequentialist ideals. However, this alleged conflict does not follow in any simple way from the kind of normative categories that make up rights, since also consequentialists can grant these categories. To be sure, even a pure consequentialist can grant the existence of options, injunctions and enforcement privileges. Regarding options, a person has an option between two alternative actions, which truthfully can be described as doing X and not doing X, if, and only if, it is true of both the actions that they are optimal, that is, there is nothing else the agent could do in the situation that has better consequences.[19] A person, P, has a negative thin right with regard to X if preventing P from doing X always, as a matter of fact, is a sub-optimal act (and a positive thin right if it is sub-optimal not to help P in doing X). And if enforcing an injunction is the optimal thing for P to do in a situation, P has an enforcement privilege in that situation. If all these conditions are fulfilled, a person has a full right in the sense defined above.

The difference between theories of rights and consequentialist theories thus lies on a more fundamental level, namely on the level of justification.[20] Consequentialism grants options when, and only when, two or more alternative actions are optimal, and *because* they are optimal. It will not accept moral reasons that do not refer to consequences. Theories of rights, on the other hand, grant that if an action violates a right this, in itself, is a reason to reject the action, even if the act is optimal. Theories of rights thus grant options in the sense that we are, at least sometimes, allowed to perform actions

---

[19] In order to make the point in a simple way, I am here presupposing the maximisation version of consequentialism. See II.4.2.

[20] I will disregard the type of theories of rights that are sometimes called "right-utilitarianism", according to which we should maximise the actual respecting of rights, since I know of no proponent of this kind of theory in biomedical ethics. I presuppose the standard assumption in theories of rights, that rights are, perhaps overridable, constraints (see III.3.3).

that are sub-optimal. They also grant constraints in the sense that we are, at least sometimes, wrong to perform actions that are optimal. Why? Well, since performing the action would be a violation of a right. So theories of rights hold that there is a moral reason to respect certain rights, regardless of the consequences of doing so. However, I will not assume that a theory of rights has to presuppose that rights exhaust everything that can be said about moral rightness and wrongness. So a theory of rights does not have to be extreme in the above-mentioned sense.

However, also theories of rights provide a justification or basis of the rights defended. The most common way of doing this is to refer to a property of the individual or a relationship the individual stands to something in virtue of which the right should be granted. Common suggestions of properties that are the basis of rights are being a human, being rational, being an end in oneself, having a free will or having (the potential of) certain capacities. Common suggestions of relations that are the basis of rights are being the relative of someone, or being promised something by someone. In order to investigate the plausibility of a proposed right to something in the following discussion, the proposed basis of the right has to be evaluated. In the context of the individual's right to her genetic information, the claim that the information is of a particularly sensitive and personal kind is particularly salient as a basis for a basic right to have the information. We will return to this (see IV.2.1).

This difference from consequentialistic theories with regard to the justification of rights can be cast in terms of *basic* versus *derived* rights. A basic right is, then justified with reference to a property of the individual or a relationship the individual has to something in virtue of which the right should be granted. If a right is basic, there is a moral reason to respect this right, regardless of the consequences of doing so. On the other hand, derived rights are rights that are justified on other grounds. Theories of rights are thus theories that defend at least some basic rights. Theories of rights can include derived rights, for instance rights that are derived from basic ones, but they also have to include basic ones. There is a moral reason to respect rights that are derived from basic rights regardless of consequences too, since they are derived directly from basic rights.

This means that pure theories of consequence do not include any basic rights. However, derived rights can also be defended on consequentialist

grounds in various ways.[21] One way is to argue that we have good reasons to believe that not respecting the right always will be sub-optimal, as a matter of fact. That is, our world is actually constituted in a way that always makes the respecting of a right better in terms of consequences than not doing so. Another way is to claim that there are consequentialist arguments in favour of a particular institutional setting that involves the recognition of some right, e.g. a regulation that recognize a right of someone to something. A consequentialist could, for instance, argue that we should implement regulations that protect the right to free speech, since the implication of such a regulation is conducive to general welfare. The right thus derived is then not a moral one (it may still be morally permissible to prevent someone from speaking), but a legal right, which we have alleged moral reasons to uphold.

It is important to emphasise this distinction between moral and *legal* rights. This also holds for theories of rights, since such theories may be open to societal regulations that do not perfectly mirror the moral rights recognized by such a theory. So even if there is a moral right to X, it does not follow that this right should be a legal right as well. It may seem natural, however, when it comes to basic injunctions. This is so, since a basic injunction claims that it is (at least prima facie) wrong to prevent someone or to fail to assist someone. It then seems tempting to think that these injunctions should be enforced. However, it is not self-evident that such rights should be legally enforced, that the violation of rights should be sanctioned by punishment, or that these rights in any other way acknowledged by societal institutions. It takes further argument to establish that a certain right should be recognized as a legal right.

From this we can conclude that arguing in favour of a right to genetic information does not imply arguing in favour of theories of right. We have to examine what kind of right and what kind of arguments that are presented. And what implications regarding the conduct of others the rights imply also depend on the basis of the rights-talk. For example, if it is a libertarian talking, we can infer the presence of enforcement privilege from an injunction (Wolff, 1991, p 22) while this inference is illegitimate if we are confronting a consequentialist.

---

[21] Some writers would be reluctant to call derived rights (in the sense defined here) rights at all, since they would require a firmer basis than consequences (see Dworkin, 1977, p 193).

1.2 The interpretations of the individual's right

The previous subsections were about possible interpretations of the general claim that P has a right to X. The different possible interpretations are due to the fact that this claim may have different implications and justifications. Now I will turn to the interpretation of the specific right of interest in this context: the right of the individual to genetic information about herself. Beside the possible interpretations of rights generally, how is this more specific right to be understood?

With having genetic information *about* oneself, I mean P having information about the genes of P. I will sometimes talk about this by saying that P has information about her genes or genetic information about herself. As has already been stated, the person P that is the subject of this discussion is, of course, the index-person, i.e. the person having the (presymptomatic) genetic test. Of course, not only persons that actually have tested themselves will be of interest. The right may (also) be a right to be informed about the possibility of testing or a right to take a test that one asks for. The relevant P is, thus, the person who can have the genetic test performed. The right to *test* oneself is not of much concern here, however. The central element is the result of the test: the information that can be derived by it. Nonetheless, testing may be necessary to gain certain information. So a right to information may imply a right to testing. The individual discussed here is thus anyone who may gain information about herself from presymptomatic genetic testing.[22]

Furthermore, there is the term 'genetic information'. What kind of genetic information are we talking about? We have already discussed the question of genes and genetic information (see I.4). The point that needs to be emphasised here, is that we are not interested in *any* kind of information about a person's genes, but certain facts about her genes that may be relevant to the person's decision-making. For example, the discussion is not about receiving a book containing the complete sequence of one's DNA (C, G, C, C, A, and so on). This will be of no interest to anyone, unless you are able to interpret this information. What is of interest is particular information, such as "being the carrier of a BRCA1 gene (see I.4.1), which increases the risk of breast cancer with this-and-this magnitude during this-and-this period of time".

---

[22] Of course, I am presupposing the limitations made in chapter I, i.e. that the focus of attention is competent, normal adults.

Given these specifications, what can it mean to have the right to one's genetic information? Besides the different possible interpretations of 'having a right' (see the previous section), I think we can discern three main interpretations: the right to *gain access to* genetic information, the right to *receive* genetic information and the right to *use* genetic information.[23] Let us look at these interpretations one at the time.

What does it mean for a person, P, to have or gain *access* to genetic information? A minimum requirement for this to hold is that there is "a method or procedure for obtaining the information, not necessarily that he or she actually obtains it." (Pörn, 1997, p 41) A stronger and more interesting, requirement is that P, in order to gain access to the genetic information, must acquire *knowledge* about the method or procedure for obtaining the information. One possible interpretation is thus to consider the right[24] as a right of others not to be prevented from informing P about how to obtain genetic information about P, and perhaps also a right of the individual not to be prevented from being informed. An example of an argument in favour of such a negative right may be a libertarian argument that the state should not intervene when private companies advertise home testing (see IV.2).

Another possibility is to interpret the right as a positive right to be informed about how to obtain this genetic information. This right would then imply reasons that others would act wrongly if they were to withhold such information from P. An example of arguments in favour of such a positive right could be consequentialist arguments in favour of genetic screening procedures (Munthe, 2002, p 91-94), i.e., arguments in favour of society's obligation to inform everybody that testing can be done.

What does it mean for a person, P, to *receive* genetic information? Perhaps the most natural interpretation of 'receiving genetic information' is to learn about or getting to know about genetic information. I suppose that most talk about

---

[23] These main interpretations can be further specified, as we will soon see. They can also be conditioned on various circumstances, i.e., whether or not the right holds could depend on the situation in various ways. That is, the right in question may be special rather than general (see IV.1.1.1). For instance, the right to receive genetic information may hold only given prior indication of increased risk (see IV.3.2.2).

[24] When I am talking about 'the right' in this context, it is, naturally, a shorthand expression for 'the individual's right to genetic information about oneself'.

"the right to know" should be interpreted in this way.[25] However, P's right to gain access to genetic information seems to be of mere academic importance, if P has no right whatsoever to learn about or getting to know about the information (and even more so if P has an obligation not to receive the information, i.e., if there is no element of option included in this right).

The reverse is not as obvious, however. One may argue that P has the right to learn about some genetic information about herself under certain circumstances, without P having the right to know about the possibility that she can learn about this information. For example, one may argue that a person has the positive right to learn about whether or not she is a carrier of the gene for Huntington's disease if she asks for this information from a genetic clinic that reliably can perform these tests; i.e. she has the right to take the genetic test and learn about the result from it (and the genetic clinician has a duty to perform the test and the counsellor has a duty to reveal the result). This is, of course, compatible with arguing that the very same person lacks a (thin) positive right to be informed about the possibility to do the test (because no one has an obligation to inform her of this possibility).

This position does not seem to be implausible (see IV.3.2.1-IV.3.2.2). Furthermore, it is an example of a position that is naturally described as both granting and not granting some person(s) the right to genetic information (granting a positive right to receive the information, under certain circumstances, and not granting a positive right to access to genetic information). Thus, it should be obvious that general talk about "the right to genetic information" or "the right to know" is not only an oversimplification, but also clouds the issue.

What does it mean to 'learn about' or 'getting to know about' genetic information about oneself? The terms are certainly vague in general. Perhaps the most salient vagueness in this context is the following: what degree of understanding should we demand in order to say that the individual has learnt about or gotten to know about certain genetic information about herself?

This question has been discussed previously (see II.2.3.2). I then reached the conclusion that the value of genetic information is conditioned on the proper understanding of it. We cannot exclude the possibility that the same goes for

---

[25] Even though one might also be talking about the right to know about how to gain access to genetic information. See e.g. Takala, 2000, p 87-105, where references are made to both the first and the second interpretation of 'know'.

rights – the right to genetic information may be conditioned on some degree of proper understanding of it, especially if the basis of rights is values (see IV.3.2.2).

We should continuously bear in mind that genetic information is often hard to understand. For example, it often involves or implies estimations of probabilities that are difficult to grasp, and even if one grasp them on some abstract level, it may be hard to grasp their relevance in relation to one's own situation. Do we have a right to know in the sense that we have a right to "full" understanding (and perhaps only full understanding), or do we have a right to receive information even if we barely understand it? Do we have some right to receive genetic information about ourselves even if we do not have the capacity or desire to understand it? We will of course return to these crucial questions. However, already now a hint will be dropped. To argue in favour of a right to receive genetic information without a corresponding obligation of others to ensure some level of understanding (or at least attempt to do so) may be very hard indeed, since using genetic information without understanding of it is at best pointless but is also more likely to lead to dire consequences than would receiving understood information (see II.2.3.2).

This brings us to the third interpretation of 'the right to genetic information', namely 'use'. As we have already seen, the individual can use genetic information in a great number of ways. It may be used to plan one's future career. It may be used in reproductive or health care decisions. Thus, questions of rights to implement these decisions, with or without the aid of others, here rise to the surface. For instance, should we be allowed to withhold information about a serious disease from our employer? Should we be allowed to abort a foetus on the basis of certain genetic information?

Obviously, the questions are legio, since the possible use a person can make of genetic information is vast. Therefore, these questions cannot be treated in a systematic and thorough matter. I will instead concentrate on the right to access to and the right to receive genetic information. What is important to note in this context is that the right to receive genetic information cannot be of much interest if there is no right whatsoever to use the information in any way at all. Thus, just as the right to gain access to genetic information only is of interest if there is at least some right to receive it, the right to receive it only is of interest if there is at least some right to use it. However, there may be rights to use genetic information in various ways,

given that one has it, without any right to receive it. But the fact remains, the right to know cannot plausibly be claimed only to be a right to have certain knowledge. The point to remember is thus that, even though a right to use certain genetic information in certain ways may not seem to be a reasonable interpretation of the right to 'know' of it, some such right must be presupposed if the right to know genetic information is to be interesting at all. We have to suppose some right of the index-person to use genetic information if the discussion of gaining access to or receiving the information is to be of any concern.

We now have the required tools to analyse the individual's right to have genetic information about herself. The easiest way to illustrate the possible interpretations is perhaps to use a matrix (see Table III).

Table III: P's (the index-person's) right to genetic information (about herself)

	Gain access to	*Receive*	*Use*
Option to	It is morally permissible for P to gain access to genetic information or to abstain from doing so	It is morally permissible for P to receive genetic information or to abstain from doing so	It is morally permissible for P to use genetic information or to abstain from doing so
Negative injunction	There is a reason for others not to prevent P from gaining access to genetic information	There is a reason for others not to prevent P from receiving genetic information	There is a reason for others not to prevent P from using genetic information
Positive injunction	There is a reason for others to help P to gain access to genetic information	There is a reason for others to help P to receive genetic information	There is a reason for others to help P to use genetic information
Regulated negative right	There is a reason for the negative injunction to be implemented in regulation	There is a reason for the negative injunction to be implemented in regulation	There is a reason for the negative injunction to be implemented in regulation
Regulated positive right	There is a reason for the positive injunction to be implemented in regulation	There is a reason for the positive injunction to be implemented in regulation	There is a reason for the positive injunction to be implemented in regulation

The row enlists different interpretations of 'right' and the columns different interpretations of 'genetic information about oneself'. We thus have 15 different interpretations of the individual's right to genetic information about

herself. However, even this is an oversimplification, to say the least. For instance, the three main interpretations can be made more precise, as we have seen. 'Gain access to' can be interpreted (at least) as either the existence or the knowledge of the existence of a procedure from which one can receive genetic information. 'Receive' can be interpreted differently, e.g. depending on the conditions one has for learning about or knowing of the information. And there are separate interpretations of 'use' for every possible use of genetic information.

Furthermore, the interpretation of rights can be further specified. Every one of these rights can be general or special, absolute or prima facie and basic or derived, adding up to 120 possible interpretations, regardless of the other complications. And to this it might be added the possible variations regarding the strength of prima facie rights. Moreover, for every injunction there might or might not be a right to enforce the injunction, i.e. an enforcement privilege.

What is more, some may want to defend several of these rights. This is possible since, of course, the interpretations can be combined in various ways. That is, some of the statements in the matrix are compatible and can thus be defended without contradiction. In fact, logically, it is true that one can combine affirming or denying any one of the statements with affirming or denying any one of the other statements, as long as one does not affirm and deny the very same statement. If we concentrate on the 15 interpretations of the matrix, which, then, is a simplification, this gives 32.768 different possible combinations.[26] And if we add the possibilities of further specifications, this number grows exponentially.

Needless to say, all these possible combinations will not be explored, one by one. Luckily enough, there are some very plausible simplifying assumptions that can, and should, be made. For instance, while there indeed may be options without injunctions and the other way around, I will aim at the heart of "right-talk" and concentrate on injunctions. This will not mean that I will ignore the question of whether there are options without injunctions or injunctions without options. The distinction between rights as options and injunctions is an important one, the conflation of which gives rise to much confusion.

---

[26] This is so, since every statement can be affirmed and denied, i.e., have the truth-value truth or false (but not both). One statement thus can have two combinations, two can have two times two, and so on: add one statement and the possible combinations are doubled. So 2^s, where s=number of statements.

Nevertheless, I will focus on injunctions, discussing options mostly to avoid misunderstandings. The exception is the discussion of a duty to know, a discussion that concerns the plausibility of an option to know (see V.3).

Another simplifying assumption is that if one can establish, or at least make a strong case in favour of, an injunction, this, in turn, is a powerful argument in favour of regulation in order to enforce or promote the injunction. Once again, the distinction between (moral) injunctions and (legal) regulations is of utmost importance and should be separated in order to avoid confusion. However, if one can establish an injunction, it requires special reasons to claim that it should not be enforced by regulation (such reasons may consist of values or rights of enough importance being threatened by the regulation). Or at least, so I will assume.

Furthermore, some combinations are of no practical interest whatsoever, and may thus legitimately be ignored. As we saw above, there is no interest in having a right to access to genetic information if there is no right whatsoever to receive it, and no interest in a right to receive it if there is no right whatsoever to use it. If this claim is granted (and I will assume it is) the following conclusion is valid. If there is no right to use genetic information, there is no right to receive it, and if there is no right to receive it, there is no right to gain access to it. However, the conclusion is not valid the other way around: there may be a right to use the information even if there is no right to receive it, and there may be a right to receive the information even if there is no right to gain access to it.

Moreover, as I just argued, some right to use genetic information has to be presupposed in order for the right to receive and have access to genetic information is to be of any interest. However, such a right will be presupposed rather than argued for, since genetic information can be used in innumerable ways, making the number of rights verge on infinite. The focus will therefore be the right to gain access to or receiving genetic information on the assumption that some subsequent uses may be justified. However, some especially controversial uses will be explored in later chapters (e.g. the use of genetic information for purchasing insurance under favourable terms in chapter VII).

2. Negative rights

As we have seen, the negative (thin) right (or injunction) to have genetic information about oneself can be interpreted in (at least) three ways: the

negative right to gain access to, the negative right to receive, and the negative right to use genetic information. As previously stated, the focus here is the right to gain access to or receiving genetic information, while at least *some* right to use genetic information is only presupposed. This leaves us with two negative rights-claims: (i) there is a reason that it would be morally wrong of others to prevent P from gaining access to genetic information, and (ii) there is a reason that it would be morally wrong of others to prevent P from receiving genetic information. The aim in this section is to see whether and to what extent such negative rights to have genetic information about oneself can be defended and justified. When doing this, we will find use for the previous theoretical discussion of rights (section IV.1).

Of course, the boldest claim in this context would be to say that it is *always* wrong to prevent someone from gaining access to or receiving genetic information about herself. However, this position is a straw-man. No one has ever defended that position. So, instead of trying to fight that straw-man I will take a look at the most extensive system of negative rights that actually has been defended or, at least, indicated (the Radical Libertarian, see below) and see whether this defence is, or can be made, sound. If this position can be argued to be too extensive, which I will argue, the straw-man will also have been successfully defeated.

As noted in the previous chapter, rights are often defended within the framework of an ethical theory. The most salient defences of extensive negative rights can be found in liberal and libertarian theories.[27] These theories emphasises non-interference of the state. This makes the tie between moral rights and regulated legal rights indissoluble, since the right not to be prevented explicitly includes the right not to be prevented by regulations.

This liberal framework is the background of the actual discussions of the negative right to know. Since the discussion will be more interesting if we investigate some actual defence, I will as a point of departure consider the argument developed by Tuija Takala, 2000, p 85-105,[28] who is one of the most outspoken defenders of negative rights to know, and, then primarily, of not being prevented from gaining access to or receiving genetic information by

---

[27] In Nozick's libertarian theory, the only *positive* rights there can be are either rights that are the result of voluntary agreements and the right to be assisted by the state in making sure that negative rights are respected (or to be compensated when they are not). See IV.3.1.1.

[28] This text was originally written as an article with Matti Häyry as a co-author.

regulation. She writes: "The 'right to know' normally implies that the information individuals want must not be withheld from them." (Takala, 2000, p 97)

A natural interpretation of this quote is that it states that if individuals have a right to know, then they should not be prevented from gathering (genetic) information about themselves.[29] If there indeed is such a right to genetic information it is thus a negative right: other agents (including societal institutions such as the government in particular) should not force the agent not to get genetic information about herself (it would be wrong of them to do so) or, at least, they have a reason not to do so. What is being stated is then a negative thin right (an injunction) to gain access to and receiving this information.

Takala defends this injunction, at least with regard to societal institutions, since she also claims that, as a consequence of the right to know, "not many regulations seem justifiable in the context of genetic testing." (Takala, 2000, p 101) She is thus not only claiming that the injunction should be legally enforced, she also hints that the injunction implies difficulties in justifying any type of regulation that would impede the individual from gaining access to or receiving genetic information, for example pre-test counselling requirements (see II.3.4.2).[30]

How can the (alleged) right of the individual not to be prevented from gaining access to and receiving genetic information of herself be violated by regulation? One way, which has been the focus of discussion, is by being denied the possibility of freely acquiring such information on the market. The discussion is thus about commercial genetic testing. Commercial genetic testing is here defined as genetic testing performed by commercial enterprises, i.e., enterprises that have economic profit as a motive.[31]

---

[29] As it stands, the quote seems to presuppose that someone already has the information in question with the possibility of withholding it from the individual the information is about. This is not primarily the kind of situation that Takala wants to discuss, which is obvious from the rest of the text.

[30] We are probably entitled to assume that the right in this context includes a right to get help from society if anyone tries to force the right-holder (e.g. by physical violence or threat of such) into not getting the genetic information, i.e. an enforcement privilege of some sort. There is hardly any point in society's granting rights if it does not have any ways of ensuring that the right is respected or that violations of it are compensated.

[31] It is not necessary that profit is the only or primary motive of the enterprise. It is sufficient that profit is one of its motives. Enterprises run by a government with partially economic motives

Commercial enterprises can offer genetic testing services to medical professionals (who then send samples from their patients for analysis) or to the general public directly. I will not discuss commercial enterprises selling genetic testing to medical professionals, although this is obviously an interesting question in its own right. However, it is not a question that has been discussed in terms of the individual's rights to her own genetic information, which is the focus of our interest here. This discussion will thus be about commercial genetic testing that is offered directly to the individual being tested, i.e. the index-person, by the commercial enterprise. The ultimate version of this is complete testing kits, which the individual may use at home without the assistance of medical or laboratory personnel. Therefore, although commercial genetic testing may also involve people sending blood-samples to laboratories, I will henceforth call this type of tests 'home tests'.

Home tests are already on the market in parts of the world. In the United States home tests for BCRA1 can be ordered by mail, and in London, genetic tests that reveal sensitivity to certain diets can be bought directly in shops.[32]

Takala is thus discussing genetic home testing in terms of the right to genetic knowledge or information about oneself (Takala, 2000, p 85-105). She is claiming that individuals should have the right not to be prevented from receiving such information by buying genetic home testing or, at least, challenging those who claim otherwise to state their case (Takala, 2000, p 101). Furthermore, a similar right of the commercial enterprises is being defended: they should not be prevented (by regulation) from selling genetic tests.[33] Society thus has a corresponding reason not to interfere with the selling of the test.[34] She is also questioning all kinds of regulation that can circumscribe the way in which the information is purchased (Takala, 2000, p 92-93, 100-101). One

---

(such as the Swedish monopoly on the selling of liquor: Systembolaget) are therefore commercial in the sense defined here. A more narrow definition could exclude examples of what this really is about: the marketing and selling of genetic testing on a market.

[32] In the United States the tests are provided by Myriard Genetics in Salt Lake City (Capron, 2000) and in the United Kingdom by Sconia (www.genewatch.org).

[33] It is, of course, conceivable to have a prohibition against selling while allowing buying, or the other way around, as is the case with prostitution in Sweden: it is a punishable offence to buy, but not to sell, sex.

[34] However, perfectly in line with standard liberal ideas, other commercial enterprises are allowed to "prevent" some commercial enterprise, C, from selling a test by competing with them on a market, making it unprofitable for C to offer genetic testing. Towards them C only has a privilege in the Hofheldian sense, then.

such proposed regulation is the demand that selling genetic testing should be accompanied by genetic counselling (Hoedemaekers & ten Have, 1998, p 223; Takala, 2000, p 92).[35] Another is to have quality controls of genetic testing or of the commercials for them (Ibid).

However, Takala is not proposing a right to have home tests in the sense of a moral option. Takala is explicitly claiming that she does not intend to defend the view that individuals who purchase and use home tests are always doing something that is morally permissible.[36] So, the right at stake in this context is a right not to be prevented from gaining access to and receiving genetic information, but not a guarantee that one is acting morally right or blameless if one does so.

If we sum up Takala's position, it can be described in the following way. Marketing and selling genetic testing directly to the index-person should be allowed and that this practice should not be regulated, *in any way different from other free exchanges on the market.* This last clause means that prohibitions against pure coercion or deceit should be enforced on this market (by the state),[37] in the manner libertarians think that they should.[38] For instance, it should be prohibited to sell a pregnancy test, claiming it to be a genetic test or to sell it while threatening the potential buyer's family with a gun. Let us call this position the Radical Libertarian.[39]

However, I will not presuppose that the Radical Libertarian regarding genetic testing has to defend libertarianism regarding society as a whole.[40] For instance, libertarianism as commonly conceived, usually is taken to include a prohibition against taxes on transactions (at least for other purposes than to

---

35 As we shall see, this could be said to be a positive right of the consumer: if an individual purchases a home test, she also has the right to be counselled about it. This corresponds to a reason for the company to provide for the counselling.

36 Takala writes: "people can be *morally* criticised by others for purchasing genetic information which it is, nevertheless, their legal right to purchase." (2000, p 99)

37 As we will see, upon closer scrutiny, it is unclear how "deceit" should be interpreted. From this it may follow that libertarians have to defend a larger degree of regulation than commonly thought. See IV.2.2.1.

38 This is not to claim that Takala herself is a libertarian in general.

39 Since the Radical Libertarian is in favour of regulating against coercion and deceit, it is in a way misleading to say that a Radical Libertarian in particular and libertarians in general, are arguing against regulations of the market. Really, they are arguing against certain forms of regulations.

40 Although libertarianism in general may be though useful to defend the Radical Libertarian view adumbrated here. See IV.2.2.1.

finance the minimal state). The Radical Libertarian's position in this context is thus compatible with a general tax on market transactions, including the selling of genetic tests. The position I am interested in is the one that denies that the marketing and selling of genetic testing should be regulated in any particular way, e.g. by societal demands on the commercial enterprise to offer genetic counselling whenever offering genetic testing or by governmental bodies supervising the quality of the tests. In other words, the Radical Libertarian claims that there should be no constraints on the marketing of genetic testing that is not also a constraint on the selling of shoes, that is, no regulation at all (except against coercion and deceit and perhaps some tax on transaction common to all goods and services).

As previously indicated, it is not obvious that this is the position Takala herself holds. Rather, it seems as though she wants to challenge those who favour regulation to provide arguments for this.[41] Furthermore, it is not unequivocal from her text whether or not she is advocating that tests should not be the subject of the same type of regulations that surrounds other medical goods and services (for instance pharmaceuticals), e.g. official quality controls.[42] If she does not, I have much less quarrel with her argument than the following text indicates. In any case, her arguments can be used to adumbrate the Radical Libertarian's position, which is the target of my criticism in the following.

The position of the Radical Libertarian can be contrasted against two other positions that will be useful in the discussion to come: the Moderate Liberal and the Total Prohibitionist. These three positions answers the following questions: 1) Should home tests be allowed? 2) If home testing is allowed, should it still be regulated in some way? 3) If it should be regulated in some way, in what way should it be regulated? They are thus all about the scope and strength of a negative right to genetic information.

The position of the Moderate Liberal says that marketing and selling of genetic testing should be allowed but regulated (over and above the minimal amount of regulation on coercion and deceit that should hold for any form of

---

41 Foremost, Takala is asking for arguments in favour of a relevant difference between genetic testing and astrologer's advice, which is subject to very sparse regulation (Takala, 2000, p 101). I will return to this (IV.2.4).

42 Even though quite a few remarks indicates that she is (see quotes in IV.2.3.1, IV.2.3.2, and IV.2.4).

transaction. I will implicitly assume this qualification in the following.) Of course, this is not really *one* position. Rather, it is a common designation for all the positions that defend some kind of regulation but do not propose a complete ban. As already noticed, there are different possible regulations that can surround commercial enterprises selling and marketing genetic testing:[43] (governmental) control of the quality of tests and/or information about them and advertisement for them, and regulations requiring (access to) genetic counselling when performing genetic testing. The Moderate Liberal may also defend that commercial enterprises should be banned from doing *some* genetic tests altogether. They could either defend that these tests should be banned throughout the society in question or that only public health care should be allowed to perform them. Similarly, a Moderate Liberal can argue that some types of tests should not be regulated at all. What are reasonable regulations of very reliable tests may not be reasonable regulations of less reliable ones, and what are reasonable regulations of genetic testing on very serious monogenetic diseases may not be reasonable regulations of more complex or less serious diseases, and so on. However, there are some *general* arguments in the debate implying that these differences are of no concern to how one should regulate (see e.g. IV.2.1). We shall address these arguments also.

The position of the Total Prohibitionist says that there should be a ban on all marketing and selling of genetic testing. As should be clear, the Moderate Liberal could come very close to the Total Prohibitionist (for instance, if she argues that all but one tests should be banned). However, the Total Prohibitionist probably has some argument based on principle against genetic testing that justifies a general rejection of allowing them. However, this position has never been defended and is just characterised as a limiting possibility.

In the following, I will argue against the Radical Libertarian's position. For most purposes, the distinction between the right to gain access to and receive genetic information need not to be upheld, since most arguments are directed towards both these rights. However, some arguments are directed towards one of the two rights, in which case they will be separated (see IV.2.3.1 and VI.3.2.1-IV.3.2.2). In this context, the negative right to *gain access to* genetic information is most naturally interpreted as the right not to be prevented from being

[43] See Takala, 2000, p 92-93 and Hoedemaekers and ten Have, 1998, p 223.

informed about the possibility of genetic testing by state intervention in advertisements for commercial genetic testing. In contrast, the negative right to receive genetic information is most naturally interpreted as the right not to be prevented from buying genetic testing in the way one sees fit. These are obviously different rights, and they should therefore be distinguished, even if the distinction is sometimes irrelevant.

In order to reject the Radical Libertarian, I will first argue that there is no basic negative right either to gain access to or receive genetic information about oneself (see IV.2.1). I will then argue that basic libertarian principles do not support the Radical Libertarian (see IV.2.2.1). I will then argue against an attempt to derive the Radical Libertarian position from a Kantian ideal of autonomy (see IV.2.2.2). The attempt to argue that the rights in question can be derived from autonomy conceived as a value and consequentialistic considerations of well-being are then being scrutinized (see IV.2.3). It is then argued that these ethical considerations speak in favour of some regulations, i.e. some limitations on the negative right to know. Lastly, I will look into some casuistic arguments that try to argue in favour of a Radical Libertarian position by analogy to relevantly similar cases (see IV.2.4). It is argued that also this attempt fails. If my argument succeeds, we will be able to draw some more general conclusions about the scope and strength of a negative right to know (see IV.2.5).

2.1 Basic rights

Is there a basic right to gain access to and receive genetic information about oneself? Remember that if there is such a basic right, there is a moral reason to respect this right, regardless of the consequences of doing so. So if there is such a right, the case of the Radical Libertarian is certainly strengthened.

However, also basic rights must be justified somehow. As I said, this is commonly done by pointing to some property of or relation to the individual that is the right-holder (IV.1.1.2). In the case of genetic information, the most predominant foundation of a basic right is the following (in fact, I know of no other): "genetic information is particularly sensitive, or more profoundly personal than other types of knowledge, because it describes the deepest, immutable level of human biology." (Takala, 2000, p 96)[44] The fact that is

[44] Takala herself does not hold this argument valid, but only discusses its possible relevance for making a morally relevant distinction between genetic and other kinds of information (Takala,

supposed to ultimately support the right to genetic information is thus the property of the object of the right, namely genetic information, standing in a certain relation to oneself, being about one's deepest nature (or something of the like). Let us accept that genetic information is personal and sensitive due to its nature. How is this supposed to found a basic right to genetic information?

The line of reasoning can be construed as follows. If this information is about my very nature or the essence of me, it may be thought that I have a special entitlement to gain access to and learn about this information. This, it might be claimed, includes a negative right not to be prevented from purchasing the information. The right is basic in the sense defined above: it should be respected, not because general respect of the right would promote overall good or being necessary in order to respect some other right, but because the violation of the right would be wrong in itself, at least prima facie (see IV.1.1.2). This argument will be called the *sensitivity-argument.*

Many authors, including Takala, have argued that genetic information is not especially sensitive or personal (as opposed to other kinds of information), at least not in any normatively relevant way (Holm, 1999; Launis, 2000; Takala, 2000). With this I concur (see I.4.3). However, this is not enough to reject the sensitivity-argument. This is the case since it may be concluded from the arguments against genetic information being *especially* sensitive that this only shows that other kinds of information also are personal and sensitive enough to found rights.[45] Of course, this conclusion denies that genetic information is *more* profoundly personal and sensitive than other kinds of information, but it may still be thought to be personal and sensitive *enough* to found a right to it.

However, even if this is granted, the sensitivity-argument is still problematic. Even though genetic information is profoundly personal and sensitive, it is also essentially about others, namely about those with whom one share one's genes. Consider the following example. The young man John knows that his grandfather had Huntington's disease. John takes a test in order to find out whether he is a carrier of the gene. The test, alas, turns out to be positive. Due to the nature of the heredity of this disease, John's father *must* be

---

2000, p 96-97). However, since the quotation captures the thought I am interested in concisely, I use it.

[45] As we shall see, a consequentialist could claim that genetic information should be *treated as if it is* especially personal and sensitive, since it is considered to be so (this claim may be doubted, however). See VII.4.1.

a carrier of the gene.[46] John is familiar with this and reaches the valid conclusion that his father is a carrier. This example is not atypical, but concerns the vary nature of genes often emphasised – they are hereditary. Thus, gaining knowledge about (a part of) the genetic constitution of one person is sometimes to gain knowledge about (a part of the) the genetic constitution of another (given the proper background knowledge).

Now, according to the sensitivity-argument, certain rights are based on the (alleged) fact that genetic information is personal and sensitive (if not uniquely or especially so, then at least very personal and sensitive). More specifically, the right to gain access to and receive information about one's own genes is founded in this way. However, it does not seem to be implausible to claim that if a certain piece of information is very personal and sensitive, then one has a right to control this information from the access of others.[47] Anyway, why claim that the sensitive nature of the information is the foundation of the first right but not the second? That is, if the foundation of the basic right to have the information is that it is very personal and sensitive, it is hard to see why it cannot also be the foundation of the right to protect the information from spreading to others.

But if this holds, we have a collision of rights due to the hereditary nature of genes. Let us assume that John's father does not want anyone else (including his son) to find out whether or not he is the carrier of the gene for Huntington's disease. If John then exercises his right to find out about his genetic susceptibility he is violating his father's right to prevent others from finding out whether or not he is a carrier, since John will *know* that his father is a carrier if he finds out that he himself is a carrier. In effect, the exercise of one right will lead to the violation of another. And a foundation that supports conflicting rights must be flawed, it may be argued.

This may not be a problem, if one grants that these rights, although basic, are only prima facie, that is, they may be overridden. Then one could claim

---

[46] I am here disregarding the very remote possibility that John's father is not a carrier and the exact same mutation that the grandfather has recurs in John due to a random mutation.

[47] This is how the sensitivity-argument of genetic privacy goes and it is a common way to argue in favour of the right to keep some things from others, e.g. information about one's sexual orientation from one's employer (see VII.4.1).

that one right overrides another.[48] But it is not clear at all, only on the basis of genetic information being very personal and sensitive, which right should override which. The problem is a general one for the sensitivity-argument: it is not obvious what the fact that some piece of information can be considered to be very sensitive in relation to one individual entails, since it may be equally sensitive in relation to another individual. The implications of the argument are thus unclear, to say the least. In itself, it is not obvious what practical moral implications it supports, if any. Since there are no other arguments to support a basic negative right to gain access to or receiving genetic information (at least that I know of), the claim that there is such a basic right seems to be a dead end (at least until someone comes up with another argument).

Let me clarify what this argument against the sensitivity-argument says. It does not say that any rights are implied by genetic information (allegedly) being especially sensitive. Rather, it points to the vagueness of the argument by saying that it is very unclear which rights, if any, the argument supports. As we will see, it might as well be used to argue in favour of privacy-rights (see VII.4.1), which, then, would come into conflict with the right to know for the reasons stated. Why, then, one might ask somewhat rhetorically, think that it supports one of these rights over the other? Since the argument does not give any clue to an answer to this question, it remains true that *if* the argument founds rights, it founds conflicting rights (or the argument itself present no reasons to the contrary, at least).

Furthermore, even if one grants a basic right to genetic information about oneself, founded on the sensitivity of genetic information, it is not clear what *kind* of right is supported by this foundation and, thus, that it rules out regulation of commercial genetic home testing. For what the sensitivity-argument may found is a right to gain access to and learn about one's genetic constitution, not a right to gain access to and learn about one's genetic constitution *in any way one pleases*. For instance, all reasonable accounts of rights would agree that it would be wrong of a person to learn about her genetic information by threatening a geneticist with a gun into performing a test, and that such a threat may legitimately be prevented.[49] Thus, the alleged right does

---

[48] One might claim that one right always overrides the other, or that they have different weights, depending on the situation, so that sometimes one override the other and other times it is the other way around. See IV.1.1.2.

[49] Extreme and fanciful situations, e.g. if lives could be saved, may of course be exceptions.

not necessarily rule out surrounding regulation designed to protect the interests of others, of society or even of oneself.

One way of respecting a general unspecified "right to know" is to offer genetic testing in the public health care setting. Another is to allow people to use commercial genetic testing, given that they are also offered genetic counselling. If both these rights are granted, a wide range of rights of individuals is, in effect, granted: the negative right not to be prevented from getting genetic testing from public health care, for instance, and the positive right of tested individuals to have access to counselling whenever tested. Yet another way to respect an unspecified right to know is, of course, to allow people to purchase genetic testing under whatever terms they see fit. But it does not follow from the sensitivity-argument that it is *this* right to know that should be respected. And that is what is required of the sensitivity-argument to support the Radical Libertarian.

2.2 Rights derived from basic rights

2.2.1 Libertarianism

One could resort to arguing in favour of a right to gain access to and receive genetic information about oneself on the ground that these rights can be derived from other basic rights. One general and principled way of doing this is to defend the Radical Libertarian's position regarding genetic testing with reference to libertarianism in general. I will present the basic tenets of libertarianism closer when discussing justice (see VII.5.2.2).[50] However, for now it is enough to be acquainted with the core of libertarianism: that normal adult persons whose capacity and competence to make decisions is not in any serious way diminished, should be allowed to (i.e. should not be prevented from) consent to whatever arrangements they themselves want and act accordingly, at least as long as they do not violate the rights of others.

Applied to the question of home testing, the reasoning that tries to take us from general libertarianism to the Radical Libertarian's position may be adumbrated as follows. Voluntary, i.e. mutually consented, transactions on the market should not be prevented. For instance, P may not legitimately be interfered with if P voluntarily establishes a contract that gives P a genetic test in exchange for economic compensation and another person (or a group of voluntarily cooperating people in a company) may not legitimately be

[50] We are here primarily concerned with Nozick's brand of libertarianism.

interfered with if they offer P this test, given the terms of the contract she and they voluntarily consent to. To by force or threat of force (or other sanctions that are not the result of normal market competition) interfere with P is to violate P's right to engage in voluntary transactions. This is wrong, according to libertarianism. Thus, the state should allow the selling and buying of genetic testing, and the marketing of these tests. Furthermore, given libertarian premises, it seems illegitimate for the state to limit this right to establish contracts, e.g. by demanding that the contracts have a certain content (for instance, by requiring genetic counselling). It also seems illegitimate to interfere with companies advertising about these services.

If one accepts this line of reasoning, it seems as though one has to accept that it is wrong (at least of the state) to prevent people from gaining access to genetic testing, since it is wrong to prevent them from gaining knowledge of the procedure to obtain genetic information by banning advertisement for genetic testing. It also seems as though one has to accept that it is wrong to prevent people from receiving genetic information, since it is wrong to prevent people from buying genetic tests in any way they seem fit and it is equally wrong to prevent companies from selling them in any way they seem fit (at least as long as no rights are violated). That is, there is no *direct* basic right to gain access to and receive genetic information about oneself, but it is generally wrong of the state to prevent transactions resulting in the gaining and receiving of genetic information. So libertarian grounds seem to support derived negative rights to genetic information in the way advocated by Radical Libertarianism.

The basic tenet of libertarianism is, then, that normal adult persons whose capacity and competence to make decisions is not in any serious way diminished, should be allowed to (i.e. should not be prevented from) consent to whatever they themselves want, at least as long as they do not violate the rights of others. As we will we see later, libertarianism can be criticised on moral grounds (see VII.5.2.2). Furthermore, it is doubtful whether the conclusions about free markets can be inferred from the moral premises of (Nozick's brand of) libertarianism (see VII.5.2.2). However, regardless of this, there are problems with the argument from libertarianism to the Radical Libertarian's position. Surprisingly enough, the latter position is perhaps not a self-evident implication of the former. This is due to the vagueness of the term "consent". Let me elaborate this point.

According to libertarianism, in order for any transaction to be legitimate, i.e. in order for the justice of the situation before the transaction to be preserved to the situation after the transaction, the parties of the transaction must consent to the transaction. This is a basis for libertarianism and one of the characteristics of it that gives it some of its intuitive appeal ("what can be wrong with whatever consenting adults voluntarily agree to do?"). However, in order for a person, P, to truly consent to X (whatever X is), P has to know what X is about. Otherwise, mutual consent could be the case even though one of the parties was gravely deceiving the other – something that evidently runs counter to the basic tenet of libertarianism. More specifically, there are two ways in which the condition of consent may fail to be fulfilled: 1) If P thinks that what she has expressed consent to is something else than it actually is, 2) If P has no or not enough knowledge about what she has expressed consent to in order to be able to comprehend what it is. So *expressed* consent is not sufficient for *actual* or *valid* consent. This is why the widely accepted requirement in biomedical ethics is not consent but *informed* consent (Wilkinson, 2003, p 76-77).

One exception to 1) and 2) may be if one consents to X "whatever X is". But even this may be doubted. Let us take an example. Jill asks Jack if he wants to participate in a game of mensur. Mensur is a kind of fencing game, the aim of which is to scar the opponent's face. Let us assume that Jack says: "Yes, that will be fun!" Can we thus conclude that Jack has consented to playing the game? It seems that we cannot if, for instance, Jack thinks that mensur is the same thing as a friendly game of poker. Whatever one feels about Jack having a reason to enter the game given what he has expressed, we cannot conclude that he has *consented to playing mensur*. What he really has consented to is a friendly game of poker and nothing else. The situation is similar if Jack has no idea about what mensur is or if he only has very vague ideas about it, in which case he has consented to nothing in particular or to something equally indeterminate, as are his ideas about mensur. Once again, this means that consent has to be informed in order to be valid consent at all.

The question of consent has bearing upon the question of deceit and manipulation. If Jill knows that Jack thinks that mensur is the same thing as a friendly game of poker, she is taking advantage of this fact to get "consent" for something that Jack really is not consenting to at all (let us, plausibly, assume that Jack would not consent to mensur if he really knew what it was). This is, at least, manipulation and maybe also deceit. According to libertarianism,

transactions based on deceit are illegitimate, and plausibly so. The problem is that the notion of deceit, like consent, is rather vague. Let us assume that Jack has a crush on Jill and would express consent to almost anything she proposed. Let us furthermore assume that 2) is the case, i.e. Jack has (almost) no idea about what mensur is. Is this deceit, manipulation or what? Is the consent illegitimate or are there good reasons that Jill may scar his face without him explicitly saying that he is willing to risk such an outcome?

We may, of course, argue that Jack should not really have expressed his consent without proper knowledge about what he was consenting to. We may, furthermore, argue that once he did, he is forced to face the consequence that Jill is morally permitted to disfigure his face. But it is doubtful, to say the least, whether Jack has *consented* to mensur. And if consent is the basis of the morality we are appealing to, it is doubtful if there is any reason why Jill may slice his face up. And it is neither obvious that someone saying "propose any transaction, I am consenting to it whatever it is" makes the proposed transaction legitimate. One may think that this leaves too much moral manoeuvre to exploit emotionally or otherwise dependant persons.

The lingering question, that is the reason for the vagueness of the notion of consent, is how much knowledge about a transaction is required in order for the transaction to be legitimate. One proposal is "all the knowledge the potentially consenting parties have (or easily can find out) that would affect the other party's decision of whether or not to consent to the transaction". This proposal has the advantage of usefulness when it comes to defining manipulation. To manipulate is to withhold information that the other party would consider relevant in order to decide whether or not to engage in the transaction. Furthermore, it is hard to see how any more limited demand on consent would preserve the intuitive appeal of the basic moral tenet of libertarianism.

However, this demand makes the duties of commercial enterprises that are selling genetic tests rather far-reaching. The discussion is thus about the scope and strength of commercial enterprises duty to offer "accurate" (Takala, 2000, p 97) or "adequate" (Hoedemaekers and ten Have, 1998, p 217) genetic testing and information. How much information should the seller provide to the buyer?

If the moral basis of the practice is to be found in libertarianism, the seller should provide enough information in order to meet the demands of valid

consent. That is, then, all information that the seller has (or easily can find out) that is of relevance to the buyer. What does this mean, besides the obvious consequence that the seller must not lie or communicate the information in an outright deceitful way?

Well, different buyers will want different information and different amounts of information, and they may need yet other pieces of information in order to decide what use to make of the test result. As a consequence, the seller must find out what the buyer wants to know about the product and what they need to know in light of what they are striving for. In the case of such a complicated product as genetic testing this will likely require genetic counselling. The general point is that sellers must anticipate what buyers may want and need to know, in order to be able to provide for that information.[51]

This leads to the rather surprising conclusion that even libertarians may have to welcome certain regulations (over and above the regulations accepted by the Radical Libertarian). The minimal state has an obligation to preserve the justice of transactions and to compensate for the violations of just transactions. In order to safeguard consent (which is the basis of just transactions) the state would have to supervise the quality of tests and the truthfulness and completeness of the information provided by the companies. Maybe they have to legislate in order to guarantee that counselling is provided whenever genetic testing is done, if this particular good is of such a complex kind that careful disclosing of information is required in order to guarantee proper consent. Given the complexity of the results of many genetic tests this may very well be the case.

However, this may seem to run counter to the spirit of liberty of libertarianism. Should not the individual herself be able to determine how much information she wants? Should she really be forced to receive "accurate" knowledge?[52] That would seem plausible only if she is obliged to have such knowledge – and that seems implausible indeed.

This way of putting it is to misconceive the basis of the regulations, however. The question is not one about individuals' obligation to know, but about individuals' right to the information she considers relevant for deciding

---

[51] Hoedemaekers and ten Have, 1998, p 223, makes a related point: "Free choice requires adequate information about the product."

[52] Takala makes these points (2000, p 97).

on whether or not to engage in a transaction. In order to see to it that she gets that information, regulation of the party *providing* the information (the commercial enterprise selling genetic testing) is necessary. The regulation is necessary, not in order to ensure that the buyer knows this-and-that, but in order to ensure that the seller provides the information that is relevant to the buyer. This may, for instance, be information about the uncertainty of the test (that it only gives an indication of a higher probability of some condition and not a prediction and what this means), about the possibility of false positives and negatives and so on. The commercial enterprise cannot presuppose that this information is irrelevant. Either they ask if the person wants it, or they presuppose (on the basis of normal psychology) that this is the kind of information that probably is relevant for the buyer and inform her. In order to try to ensure that rights are respected, the minimal state should implement regulations to this effect.[53] The most obvious candidate is maybe a governmental board inspecting the quality of the marketing of genetic testing and the tests that actually are offered. But if that is too preventive for the libertarian spirit, at the very least, rights to retroactive compensation in cases where the requirement of informed consent have not been met must be enforced by society.

To conclude, it is not obvious that libertarianism implies the position of the Radical Libertarian. Rather, if libertarianism takes seriously its own basic commitments to consent, some Moderate Liberal position seems to be warranted.

2.2.2 Kantian autonomy

Another foundation for a general defence of Radical Libertarianism may be sought in a Kantian notion of autonomy. In the debate about the right to know, there is a widespread understanding of this notion, according to which one can argue from autonomy to a duty to make rational choices and from this to a duty to know, e.g. about genetic information (Harris & Keywood, 2001; Laurie, 1999, Rhodes 1998).[54]

Takala (2000, p 98) suggests that this line of reasoning may be thought to support some kind of regulation of commercial genetic testing, since rational

---

[53] Or at least see to it that those whose rights are not respected are duly compensated. It is unclear, on libertarian premises, whether the role of the state is to prevent rights from being violated or just help those whose rights has been violated with receiving compensation.

[54] I will question both this interpretation of Kant and this line of reasoning (see V.3.1).

decision-making requires *accurate* information, and this may be promoted by regulation (e.g. an official board that controls the adequacy of the tests that are being marketed). However, Takala questions this line of reasoning. Her main complaint is that the Kantian argument in favour of a duty to know, even if valid, is irrelevant to the question of regulation. This is the case since "Kant's philosophy deals primarily with the morality of individuals" rather than "the legitimacy of the social regulation of people's lives" (Takala, 2000, p 98). Questions of regulation should rather be settled by a Millian account of autonomy "which maintains that we are allowed to make uninformed and even self-destructive choices as long as we do not significantly harm others by doing so." (Ibid)

These remarks can be questioned on several accounts. Firstly, it is based on a misinterpretation of Kant, who quite explicitly defended that his account of morals (resting on his concept of autonomy) should be the basis of laws – namely legal perfect duties.[55] Secondly, it is highly controversial whether or not the potential harm presented by commercial genetic testing is significant enough to warrant regulation. I will return to this latter question (see IV.2.3.2).

However, Takala invokes further considerations of Kantian autonomy against prohibition and regulation of commercial home testing:

> If individuals have a duty to make their own decisions, then they must not be legally forced into acting in accordance with the opinions of others... Rational, autonomous individuals can have a moral duty to seek the best possible information concerning their health status. But they must decide for themselves where and how to find this information, otherwise they would be acting 'heteronomously' – following somebody else's law. (Takala, 2000, p 99)

This could be interpreted as stating that the Kantian conception of autonomy is incompatible with regulating duties by law. However, as already mentioned, this is not the case. What Kant claims is that acting *out of* duty (out of reverence for the moral law or autonomously) cannot be legislated, and that a person who acts *in accordance* with the moral law *only* because she wants to avoid

---

[55] See e.g. Kant, 1797 Part I, Chapter II, Section I about property rights. See Nell, 1975, p 44-51 for an exposition of legal rights based on the Categorical Imperative. It may of course be questioned whether the duty to have knowledge of one's genetic constitution is a legal perfect duty.

punishment, is acting heteronomously. That is, legislation cannot guarantee that people will act with the proper motives. This is not to say that (Kantian) autonomy cannot and should not be the basis of regulation and legislation of external behaviour (including, perhaps, genetic data-collecting behaviour). According to Kant, autonomy could and should. What Takala would need to claim is that a Kantian cannot validly infer from the fact that something is a duty that it should also be enforced by regulation. But in order to demonstrate that, she needs to provide further arguments.

However, Takala's argument can be reformulated, so that it may be thought to support the Radical Libertarian. One way of conceiving of autonomy inspired by Kant is that we (normal, decision competent adults) should be treated as autonomous or, to put it differently, should have our autonomy respected. This can be understood in different ways. A Millian way to understand it is that we should be allowed to make whatever decisions we want to and to be allowed to act on these decisions, at least as long as we do not (seriously) harm others. A more Kantian version of this is that we should be allowed to make our own decisions and act on them, since this is a way of others to treat us as worthy. Let me elaborate this last point.

If a benevolent person, P, is coercing or manipulating another individual, Q, into making a decision this must be due to the fact that P does not think that Q realises that this is the decision he ought to reach (according to P:s opinion). This is equivalent to P saying to Q: "You are unable to deal with this issue in an appropriate manner, in contrast to me, who therefore should handle this". This is to treat Q as non-autonomous - as unable to govern herself duly. This is to treat Q in a condescending or patronizing way, as if she were no better than a child we have to take care of in order for her not to get herself or others into trouble.[56] This may reasonably be said to be not to respect Q, or to treat Q as unworthy.

It is perhaps something like this that Takala is expressing in the last sentence of the quote. Not to trust the individual herself to decide if and how she should gain genetic knowledge is to treat her non-autonomously or without respect for her autonomy. To forbid the individual from gaining access to genetic information about herself is to say to the individual that she cannot deal with this information as she sees fit herself. Why? Presumably

[56] This is Kantian in spirit: see Kant 1797, Part II, Duties of Virtues to Others, Section II, §§37-41.

because the individual is not considered to be able to handle this appropriately herself. For instance, to make it compulsory for the individual to take genetic counselling in order to be tested is to say that the individual is not capable of deciding herself whether or not she should take the counselling – this society must order her to do so for her own sake.

Some Moderate Liberals seem to be able to answer this line of reasoning. They can once again make the point made above concerning libertarianism: regulation does not have to enforce an (alleged) obligation on the individual to get certain information (in a certain way). Some regulation is directed towards companies to enforce their duty to provide accurate information or adequate testing if that is what is sought after. However, this can be used only to argue in favour of some regulation, e.g. governmental control of the quality of tests and/or information about them and advertising for them, and maybe even regulated demand for genetic counselling when performing genetic testing (with the proviso that individuals should be free to decline such counselling). It cannot be used to argue in favour of total prohibition, or even partial prohibition of genetic testing. It can neither be used to argue in favour of banning individuals from getting unsupervised information, if that is what they want.

But there is a more general weakness with this Kantian argument of treating persons as autonomous. The problem is that it always applies. Whatever regulation of whatever line of conduct is saying: "this is not up to you to decide – it is forbidden to do this and this". And it is not hard at all to think of situations where individual's right to be treated as autonomous seems to be overridden by other ethical concerns. For one, we have the right to be protected from harm. In a falling scale, legislation of murder, fraud, false marketing, smoking, and wearing a seatbelt when driving have been considered to be justified in order to avoid harm to others (and, sometimes, to the individual herself). If one considers this and other ethical factors as relevant for justifying regulations, it is thus not enough to state that a certain regulations fails to treat some individuals as autonomous in some respects.

Furthermore, the Kantian conception of autonomy is far from unambiguous (see e.g. V.3.1). It may, and indeed has, been interpreted in other ways, so as to form the basis of a defence of regulation (Hoedemaekers and ten Have, 1988, p 222-223). The interpretation I have in mind takes the second formula of Kant's Categorical Imperative as its point of departure, namely the Formula of Humanity: "Act in such a way that you always treat humanity,

whether in your own person or in the person of any other, never simply as a means, but always at the same time as an end." (Kant, 1785, p 429)[57] If emphasis is put on the formula's parts about the treatment of others, the following reading does not seem to be farfetched: "[T]his means especially to respect the capacity of other people to act freely, to respect other people as beings with their own life-projects, interests and values, and as people who can engage in purposeful action to achieve their various ends." (Hoedemaekers and ten Have, 1988, p 222)

Hoedemaekers and ten Have do not flesh out in any detail how this reading of Kant can form the basis of any regulation, but I think that their line of reasoning is something along the following lines (Hoedemaekers and ten Have, 1988, p 222-223). If commercial enterprises provide information about their testing that is false, one-sided, biased or plays on the anxiety of the consumer in order to get her to purchase genetic testing, the consumer is not making that decision in a manner she would have if she had not been thus influenced. This, it may be argued, damages the autonomy of the individual (see IV.2.3.1). Another more direct interpretation is that when commercial agents try to sell genetic testing to buyers without disclosing relevant information, they are treating them as a means only for their financial aims, i.e. for reasons of making a buck, they omit to providing relevant information. In order to try to ensure that this will not happen, an independent body supervising the quality of advertising is needed. This is, of course, a kind of regulation more intrusive than the one the Radical Libertarian would concur to.

2.3 Rights derived from values

2.3.1 Consequences of autonomy

One can try to derive negative rights to genetic information from considerations of autonomy, not by claiming that such a rights can be derived from a basic right to have one's autonomy respected, but on the basis that the recognition of such rights are conducive to autonomy conceived of as a value to promote. This idea can be formulated in different ways and the aspects of autonomy emphasised may vary. In the discussion of the negative right to home testing, Takala, 2000, refers to "the freedom of commercial testing"

---

[57] According to Kant there is a very close link between autonomy and morally praiseworthy behaviour (see also V.3.1.2): the formula of autonomy is said to be derived from the Categorical Imperative (Kant, 1789, p 431-434).

(Takala, 2000, p 99), and claims that a defence of regulations in this area is a defence of "policies which would curtail the freedom of choice of the [...] clientele" (Takala, 2000, p 100).[58] She is thus emphasising the importance of not being prevented from trying to obtain genetic information about oneself in the way one seems fit, on the grounds that this would reduce something that is to be cherished: the "freedom of choice". This can be interpreted in line with the idea discussed above of cherishing a right to home tests from the negative right to have one's autonomy respected. However, it may as well be interpreted as the idea that a negative right to home tests would promote the autonomy of people. Since the former idea has already been rejected, the latter interpretation is the more charitable one.

However, considerations of autonomy as a value to promote are ambiguous regarding the question of regulation of commercial genetic home testing. It has been claimed that the practice of unregulated commercial genetic testing may reduce the autonomy of some parties in some regards (Hoedemaekers & ten Have, 1998).

The question, then, is what system of negative rights, and thus what system of regulation, that such considerations of autonomy speak in favour of. Let us start by looking into the negative right to gain access to genetic information, in the sense of getting to know about a method for obtaining the information. Various ways of regulating the possibility of advertising about genetic testing are examples of circumscriptions of this right. We will then move on to investigate the question of the relevance of autonomy to the idea of a negative right to receive genetic information.

The right to gain access

Would a system of uncontrolled advertising for commercial genetic home testing pose a threat to individuals' autonomy? And is this threat serious enough to warrant regulation? Both those who are inclined to defend and oppose unregulated commercial genetic testing seem to agree that the answer to the first question is yes. Uncontrolled advertisement for commercial genetic home testing may do this by being "manipulative" (Hoedemaekers & ten Have,

---

[58] The last quote is picked from a line of reasoning about the responsibilities of medical professionals towards their clientele. According to Takala, such a responsibility may justify warnings from the professionals against commercial genetic testing, but not regulations of it (p 99-100).

1998, p 222; Takala, 2000, p 91) or "deceptive" (Hoedemaekers & ten Have, 1998, p 223).

When is advertising deceptive? Hoedemaekers and ten Have use the following definition of deception (regarding advertising): "deception occurs when a false belief, which an advertisement either creates or takes advantage of, substantially interferes with the ability of people to make rational consumer choices" (1998, p 223).[59] It should be added that the advertiser must believe that the belief she is trying to convey is false and intend to convey the belief in order for it to be deception. As previously argued, consent is incompatible with deception. Therefore, even a libertarian should agree that transactions based on deception are illegitimate. And rightly so: to be deceived into choosing something X, is not to choose X freely, since the thing that one would choose is not the thing that one gets. Thus, even the Radical Libertarian should accept minimal regulation against deceptive advertising. The question is if one should go further. Should we also regulate advertising that, although not outright deceptive, may be seen as manipulative?

When is advertising manipulative? Hoedemaekers and ten Have suggest that this is the case when it "impair[s] people's capacity for critical evaluation of arguments offered" (1998, p 223).[60] For instance, this is the case when advertisement "exploit[s] consumers' emotions or anxieties" (Ibid).[61] Even though the definition leaves room for reasonable disagreement on its scope of application (e.g. due to the vagueness of "critical evaluation"), I think that the following example would qualify as manipulative.

> An image of the future. As the news is about to start on TV, there is a commercial and you get out of the sofa to make some coffee. Half-way there, your attention is caught by a deep, confident, and trustworthy voice: "Each person carries 8 to 10 genetic predispositions for serious and lethal genetic disease. Research has shown that many cases of cancer and cardiac diseases are inherited". The speaker – a white haired, stately man in a white coat with wise and calm eyes – wanders through impressive laboratories. The image fades to colourful, animated DNA-

---

[59] Hoedemaekers and ten Have, 1998, p223, are quoting this definition from Boatright.

[60] It could be claimed that a definition of manipulation should also include the intention of the sender to impair the receiver's capacity in this way. I will disregard this component, however, since it will be of no consequence for the argument to follow.

[61] See Takala, 2000, p 91, for a similar account of manipulation.

models and then to dark interiors of ordinary homes, where people with hollow eyes gaze through rainy windows. The children by their side all have the same concerned expressions in their faces when looking at the adults. A new voice enters: " To put one's worries to rest. To secure the future of oneself and the loved ones. It is now possible for you too! BioKit 3000 is easy to use and gives you knowledge within a few minutes. BioKit 3000 is sold at your local pharmacy and supermarket. BioKit 3000. *Your* future in *your* hands!" In the meanwhile, the image shift to bright summer's scenes in beautiful, affluent surroundings. Happy, well-dressed people turn their attention towards a colourful plastic box, holding it in their hands. In the final scene, a happy family with the children in the middle is gathered around the little box, glowing with joy. The camera is closing in until you see that the box has a little glass window, where the picture of cheerful face is shown next to the word "HEALTHY" and "BioKit 3000™". (Munthe, 1998, p 11-12. My translation)

Naturally, whether the commercial in this example is manipulative according to the definition of manipulation mentioned above will be relative to an individual. Some people's capacity to critically evaluate the commodity in question may not be affected, since they know very much about genetic testing beforehand and are not easily worried. However, this imagined commercial gives the impression that a person's health is positively affected by genetic testing. This is not so. It may be the case that some health risks can be reduced to some extent. So the commercial is not lying. But someone unfamiliar with genetics may easily get the wrong impression of the potential of the test. Furthermore, the commercial suggests that untested people lead an insecure life, worried and scared of their future. However, people who have taken presymptomatic genetic testing may become more worried about the future than those who have not (see II.2.2.2). In order to cut a long story short, this commercial is probably manipulative, since it would give the impression that the benefits of genetic testing are bigger than they are and that they pose no risk of harm.

Does manipulative advertising impair the autonomy of individuals? It may very well do so, in several respects. First, manipulative advertising may have a negative impact on the authenticity of a person. As we have seen, manipulation is typically the kind of cause of a desire that would make a person be inclined

to disapprove of having the desire if she knew that she had been manipulated (see II.2.2.3). For instance, if one were to find out that one desires to take a genetic test only because a TV-commercial had played on an unfounded fear one has, one probably would be inclined to disapprove of that desire. Second, manipulation may make it more difficult to reach a decision if it plays on one's anxieties and fears (see II.2.3.2 and III.2.3.2). And third, the advertisement may have a negative impact on the extent to which one lives the life that one wants to live. It is not implausible to assume that manipulative advertisement will make some persons purchase tests that they would not have purchased if they had known more about the test. That is, they will purchase tests on poor grounds and without proper knowledge about how to interpret the test. This may, for instance, lead to misinterpretation of the tests, leading to unnecessary anxiety and depression. And a troubled mind will generally have a harder time to realise her basic desires (see e.g. II.2.3.2).

However, this may not warrant regulation. Generally, in Western societies, advertisements that play on people's anxieties (e.g. for their physical appearance) are allowed, as are advertisement that are one-sided and biased in omitting to announce information about the product that most people would consider relevant for purchasing it.[62]

What it boils down to is a conflict between two sorts of freedom (or autonomy): the freedom to act on a market without interference through societal regulation and the freedom of individuals to live and to be able to live the lives they want without being manipulated. It is far from self-evident which freedom is most important.

However, it is obvious that both kinds of freedoms are granted some importance in our society. Generally, the more important a kind of choice is considered to be in our society for people's possibility to live the lives that they want to live, the more inclined we are to regulate in order to avoid manipulation. For instance, housing is considered so important that only regulated and authorised house brokers are allowed to inform private persons about the standard of the housing. And similarly, the more potential a commodity has to harm people's possibility to live the lives that they want to live, the more inclined we are to regulate in order to avoid manipulation. For

---

[62] As we have seen, it is not obvious whether a libertarian should agree to allow this, since manipulation also seems to undermine legitimate consent.

instance, many countries have regulation surrounding the marketing and selling of alcohol or pharmaceuticals. On the other hand, advertising for soaps, golf equipment and napkins is not that regulated.

Generally, the relevance of *some* genetic testing to important life-choices is high. For instance, testing for Huntington's disease or BRCA1 often is a life-changing experience with drastic consequences for the person's life (Marteau & Richards, 1996, p 4-38). These kinds of tests (for very serious late onset disorders) also have the potentiality of creating much incapacitating psychological harm (see II.2.2.2). Other tests probably are less important for life choices and probably have less potential to cause harm. For instance, the test mentioned at the outset of this section, which reveals a certain sensitivity for certain diets might be an example.

To conclude, in order to determine whether or not certain regulations should be implemented with reference to autonomy or "freedom" as a value to promote, it is not sufficient to establish that the regulation prevents some acting parties from doing certain things on a market. One also has to determine whether the freedom of others and freedom in other normatively important senses are affected. Freedom is never freedom, period. Freedom is the freedom to something in relation to somebody else (in this regard freedom is like rights and, indeed, correlative to them). Also free (in one sense) commercial acting parties can circumscribe the freedom of others, e.g. by manipulation. If this circumscription is serious enough, regulation may be warranted. And, as we have seen, at least some cases of advertising for commercial genetic testing seem to fall in this category.

The right to receive

Even if considerations of autonomy as a value to promote do not support a negative right to gain access to genetic information unequivocally, it may support a right to receive such knowledge. However, this has been questioned: Hoedemaekers and ten Have, 1998, have claimed that unregulated commercial genetic testing may have negative consequences in terms of positive liberty or autonomy. These authors emphasise two ways in which this may happen: by giving rise to social pressure to use genetic testing and by allowing the advertisement of testing that has not been the subject of quality control. We discussed the last question above, and will now turn to the first.

Hoedemaekers and ten Have expresses concern for the social pressure commercial genetic testing may give rise to:

> Individual autonomous decision-making may be compromised if widespread availability of commercial genetic tests leads to forms of social pressure to also use them. If genetic tests are easy available the tendency to make individuals accountable for not using them may become stronger. Commercialisation can also intensify another, circular process: marketing of tests increases their use, increased use may lead to enhanced social pressure, enhanced social pressure may lead to further creation of demand and this to a further increase in sales. (Hoedemaekers and ten Have, 1998, p 219)

Naturally, it is an empirical question as to how likely this scenario is. Some studies may nonetheless be taken to show that it is not unlikely (Hoedemaekers & ten Have, 1998, p 219). Furthermore, there are analogous examples in society. For instance, commerce has reinforced a social pressure to have cellular phones and e-mail and people are held accountable for not always being available by these means.

The remaining question is how and to what extent this compromises the autonomy of people. Even if there will be a social pressure on people to use various genetic tests, individuals can still refrain from doing so.[63] However, Hoedemaekers and ten Have are not claiming that autonomous choices are made impossible by social pressure, only that "autonomous decision-making may be compromised".

Hoedemaekers and Ten Have do not flesh out this idea, but here is an attempt. If there is social pressure to do something, it may be psychologically difficult to refrain from doing it (for most people), for instance because most people do not want to risk alienation from the community and because most people have a tendency to internalise social norms and patterns of behaviour. The case is then somewhat similar to the case of coercion by threat. A threat always leaves room for choice (you choose your life over your money), but still make it difficult for you to choose what you want the most. The difference is only that, in the case of social pressure, one is not threatened by someone in particular, but by one's social circumstances. So even if it is possible for any single individual to refrain from genetic testing it may be

[63] This is a minimal sense of autonomy – it is true that if one chooses to do so, one can refrain from doing so.

difficult for her to do so, even if she wants to. This can reasonably be considered to be a compromising of the autonomy of the individual, especially according to the ideal of self-realization presented earlier (see III.2.4.2).

However, it is far from obvious that this mechanism is undesirable, all things considered. Whether or not social pressure is something bad must depend on what kind of norms and patterns of behaviour it is pressing for. The social pressures not to resort to physical violence or to go to work despite that you do not feel like it are presumably desirable. So the fact that a practice gives rise to a social pressure working for its own maintenance (as maybe commercial genetic testing does for genetic testing) can not in itself be a sufficient ground for deeming the practice undesirable. Furthermore, I would guess that few people would be prepared to defend that the fact that commercial genetic testing creates a social pressure to use genetic tests (if that is a fact) is, in itself, a reason to forbid or regulate it (compare with cellular phones). What may make people hold such a view would rather be considerations of well-being – the fact that social pressure to conduct genetic testing pressures the individual to do something that is potentially harmful (especially if she would most have preferred to refrain from testing).

So, on reflection, the fact that unregulated home tests can threaten the autonomy of individuals can be an argument in favour of regulating *the marketing* of the commodity, even if one might be reluctant to forbid it. If a widespread use of genetic testing is of questionable value, the pressure to use it that may be the result of unregulated commercial testing is certainly questionable too. And in the next subsection, I will try to show why one can reasonably question the value of unregulated commercial genetic testing.

2.3.2 Consequences of well-being

One way to argue in favour of a certain right is to refer to the consequences in terms of well-being of respecting such a right. This can be done by arguing that respecting the right always is likely to lead to better consequences than not doing so. However, in general this move is unlikely to succeed, since one can almost always think of a situation when not respecting the right in question would have better consequences. A more promising way is thus to argue that the societal recognition of a right, i.e. by implementing it as a legal right, is conducive to general well-being. That is, one can argue that a certain institutional setting has better consequences than alternative institutional

settings. If such an argument is successful, one has argued in favour of a derived legal right from consequentialist premises. This kind of arguments will be scrutinized in this section.

So, are there consequentialist arguments in favour of recognizing some negative rights to gain access to and receive genetic information about oneself? As we will see, some such arguments have been proposed. The Radical Libertarian defends the most extensive system of negative rights, by claiming that any interference in the marketing and selling of genetic testing is unjustified. First, I will discuss and reject some consequentialist arguments in favour of the Radical Libertarian position. I will then argue that the benefits of genetic testing are more likely to be realised to a greater extent given certain regulations. However, this does not speak in favour of prohibiting commercial genetic testing altogether, i.e. the Total Prohibitionist's position. Rather, it speaks in favour of some Moderate Liberal position. However, in some cases of genetic testing, arguments may support a more prohibitionist position. The arguments are of a general kind, both relevant to the right to gain access to and receive genetic information through genetic home testing.

What consequentialist arguments might there be in favour of the Radical Libertarian position? Takala, 2000, has a few suggestions of this kind that can be used to argue in favour of the "free production and distribution of genetic services.... to the members of the general public" (Takala, 2000, p 89), i.e., unregulated selling and marketing of genetic testing, i.e. the Radical Libertarian's position.

"The commercialisation of genetic testing can make the tests accessible to larger groups of people." (Takala, 2000, p 89) Of course, commercial genetic testing *can* make genetic tests accessible to more people, but this can also be accomplished in other ways. One obvious candidate besides commercial enterprises is public health care. So, even if it is a good thing that genetic tests are accessible to a greater number, this in itself does not speak in favour of *commercial* genetic testing.

However, to this it may be replied that *more* tests will be performed if commercial enterprises are allowed to offer genetic home testing. Public health care may deny testing, e.g. if they think that there are no reasons to suspect that a person is a carrier of the gene tested for. These people may then resort to home testing if that is available.

However, this argument, if sound (which must be an empirical question), is at most incompatible with banning genetic testing, not with regulating them, e.g. by quality controls. Furthermore, it may be questioned whether these extra tests really are a good thing. In order for the line of reasoning to support the Radical Libertarian on consequentialistic grounds, one has to argue that these extra tests outside public health care increases total welfare. If we confine ourselves to the index-persons, it is highly unlikely that this will be the case when it comes to serious monogenetic diseases, like Huntington's disease. If there are no suspicions in the form of family history or symptoms, the risk of being a carrier of these genes is negligible. On the other hand, there is potential harm in the form of false positives, unnecessary anxiety while waiting for the result, misinterpretation of the results leading to more anxiety, etc (see e.g. II.2.4). A related point can be made regarding testing for multifactorial diseases, in which case testing will have low predictive value, which is problematic from the point of view of well-being and autonomy (II.2.2.2 and II.2.3.2).

Of course, one might feel that the individual should be free to expose herself to these potential harms if they choose to do so. But then the basis is not in consequentialistic terms of welfare, but rather in terms of liberty. And, as we have seen, it is not clear that considerations of liberty speak unequivocally against certain regulation (IV.2.3.1).

"Commercial genetic testing can increase well-being, reduce suffering, and enhance individual freedom and autonomy." (Takala, 2000, p 89) Of course, genetic testing *can, given the proper circumstances* realise these values for the index-person (see chapter II, passim). However, this goes for genetic testing in general and not for *commercial* genetic testing in particular. On the contrary, there are good reasons to believe that the circumstances favourable for these values to be realised are not present given unregulated home testing. The proper understanding that promotes autonomy and well-being is promoted by genetic counselling. Unregulated home testing does not have to provide this. The reliability of tests that is necessary for proper medical treatment or palliation (if there is any) is not guaranteed if there is no official body ensuring the quality of the test. To the contrary, much unnecessary suffering in the form of anxiety and other psychological damage may follow upon unregulated home testing. From this it does not follow that commercial genetic testing should be banned. However, it does indicate that the alleged advantages of testing may require some monitoring.

Takala also refers to the potential economic benefits that unrestricted commercial genetic testing may produce: "the production and marketing of genetic tests... generate profit and create employment" (2000, p 89) First, this may only be a weak form of ceteris paribus argument - other types of commodities are heavy regulated or even forbidden, despite their potential of huge economic profits.[64] Second, different types of regulation probably will have different effects on the profitability of commercial genetic testing. For instance, there is likely to be very different market effects between total prohibition and quality controls of some testing. As always, potential harms and benefits of different regulations have to be weighed against each other. Third, there may be economic disadvantages with commercial genetic testing, especially for public health care (see this subsection below). Finally, profit and employment may also be generated by other means than the production, marketing and selling of home tests – means that do not pose any of the risks produced by genetic tests.

So much for the consequentialist arguments in favour of the Radical Libertarian. However, further arguments can be added in favour of restricting the negative right to gain access to and receive genetic information from home testing. There are adverse consequences of home testing to first parties (the index-person), second parties (genetic and other relatives) and third parties (e.g. other commercial enterprises, such as insurance companies).

The tested individual may suffer the following adverse consequences of genetic testing. First, there are concerns of errors in the results of the tests, primarily false positives and false negatives (Andrews et al., 1994; Hoedemaekers and ten Have, 1998, p 219). As already discussed (see II.2.2.1), such erroneous results are of course problematic from the point of view of the index-person, since they may lead to unnecessary anxiety and unnecessary but risky medical interventions (in the case of false positives) or omission of needed treatment (in the case of false negatives).

However, this problem is a general one for genetic and other medical testing. In general genetic testing should be reliable (that is, avoid false results) in order to avoid harm. In the case of commercial genetic testing the problem

---

[64] Most obviously, examples are drugs, weapons and such, but also cars, housing and food are regulated and controlled in various, probably profit-reducing, ways in most Western societies (e.g. the limits on the environmental impact of cars).

may be particularly pressing, since commercial interests in profit maximising may encourage marketing of less reliable tests. There may be profitability without reliability. If it is generally a good idea to offer only reliable tests, this should also hold for commercial tests. Of course, this does not speak in favour of banning home testing. But it does speak in favour of controlling their reliability. Since it cannot be ensured that the commercial enterprises selling the tests have sufficient interest in guaranteeing the reliability of the tests, regulations ensuring the reliability should be implemented.

Second, even if a test is correct, it may be misinterpreted. As frequently stated, results of genetic testing are, as a rule, cast in probability estimations (e.g. the risk of breast cancer caused by BRCA1). These may be over- or underestimated, also leading to the same type of detrimental consequences as false positives and negatives. It may also be hard for the individual to see the relevance of a statement about the relative frequency of disease in a population to her own situation (see II.2.3.2).

Furthermore, some test results can be so vague as to defy any useful interpretation. What, for instance, of a test that says that you have an increased probability of 10-20% of contracting diabetes within the next 20 years? How can this result be the basis of decision and the feeling of certainty often sought after when testing? This goes to show that the predictive value of a test can be negatively affected by several factors: low risk number, non-definite risk number, high probability of being false, or by being about diseases with very varying penetrance and expressivity (I.4.1). In all these cases, the value of the test for the individual is highly dubious.

These problems of misinterpretation are intimately connected to commercial home testing. Home tests can be performed without any contact with health care professionals that can aid the person in interpreting the tests. Commercial enterprises have no direct interest in giving this aid. In fact, in the cases of marketed genetic testing, there have been varied interests from the commercial firms to provide information about the tests (Hoedemaekers and ten Have, 1998, p 219), so there are empirical indications to this effect.

Once again, this does not in itself speak in favour of banning commercial home testing. But it does speak in favour of regulating the practice in order to avoid these negative consequences. One proposed way is to demand that also commercial firms selling genetic testing offer genetic counselling whenever testing is performed (Hoedemaekers and ten Have, 1998, p 223).

There are further positive arguments in terms of positive consequences of requiring counselling. There are well-founded worries about the psychological damage of genetic testing (Hoedemaekers and ten Have, 1998, p 222, see also II.2.2.2). Genetic counsellors are trained to give support and recommend further help in order to avoid this. Genetic counsellors can also give information about medical treatment and palliation, if available. This increases the possibility for the individual of getting the care she needs and to avoid or ameliorate disease, thus increasing welfare.[65]

However, as mentioned, some tests give information that may be difficult to use (like the diabetes example above). It seems hard to defend that these tests can realise any value for the index-person (see also II.2.2.1 and II.2.3.2). Maybe these tests should be banned altogether then.

If we grant that the onus probandi lies with the prohibitionist, obvious adverse effects of the test have to be demonstrated. As we just have seen, generally, the less predictive the test is, the less likely it is to realise any of the positive values and the more likely it is to realise negative values. Thus, a stricter prohibitionist stance seems reasonable regarding tests with very little predictive value. The case in favour of prohibition is strengthened if there are no preventive measures whatsoever against the condition tested for.

Commercial genetic home testing may also harm relatives, especially if they do not want to have the test result. However, this is not a particular problem for commercial tests, but a general problem of genetic testing (like the problem of reliability). Nevertheless, the risk of harm to relatives may be greater in relation to home testing than it is in relation to testing performed by health care. The reason is that the problems attached to not properly understanding the test in question are spread to relatives. As argued, the risk of erroneous or misinterpreted results is greater in the absence of safeguarding mechanisms of adequate information (as e.g. official quality controls of the tests and information about it and counselling about the test and its results). Furthermore, in the counselling situation, the index-person is given opportunity to reflect about the proper way to disclose the information to relatives with the support of a professional with insights in the possible

[65] This last point can also be used to argue that public health care should perform these tests. However, this is not necessary, if commercial firms are legally obliged to give the same information and the market develops so that all who can benefit from testing can also afford purchasing home tests.

adverse effects of disclosure. This will help the index-person to disclose the information in a manner that is not traumatising for the relatives and their relations.

Once again, this is no argument in favour of banning home testing, but in favour of regulating it. There is, of course, no direct conclusion that can be drawn about the extent of the counselling that should be required. The matter must be settled in a piecemeal manner, looking at the expected adverse consequences of not having counselling. Different tests will probably require different amounts of counselling, depending e.g. on the seriousness of the disease, the predictive value of the test, and the presence or non-presence of preventive measures. In some cases, it may be enough to get a pamphlet with information; in other cases more extensive counselling may be required.

Also third parties may suffer from adverse consequences of commercial genetic home testing. Insurance companies are sometimes mentioned (Hoedemaekers & ten Have, 1998, p 220; Takala, 2000, p 91). Insurance companies may suffer from the consequences of the fact that people know about their genetic constitution without having this on any record available to the insurance company. The problem becomes most acute if partial regulation concerning insurance companies' access to genetic information is implemented. Partial regulation means that insurance companies are allowed to gain access to genetic information that the individual herself has (at least under some circumstances), but not to demand that a previously untested individual should be tested.[66] Home testing will make it hard for insurance companies to control that the individual does not withhold genetic risk information from them. Since they, given partial regulation, cannot demand that new tests be made, the individual may use the risk information to purchase more favourable insurance policies than the companies would have accepted, had they had access to the same information. However, this may be resolved by implementing a regulation, which says that commercial firms that perform genetic testing should send the result to the insurance company (or something like this).[67]

Even if the adverse consequences for insurance companies may be sidestepped by regulation, other third parties may suffer significantly from

---

[66] I will present this type of regulation later (see VII.1).

[67] If the test is actually performed at home, there can be law requiring the commercial enterprise to get the result and then to forward it to the insurance company.

commercial genetic home testing. I am primarily thinking of public health care. Unregulated supply of genetic home testing may lead to an excessive financial burden on public health care systems. If there are no impediments on the marketing or selling of home tests and public health care abstains from doing all the tests that can be done, an increase in demand of these tests will probably be the result. This tendency will be reinforced the more different kinds of genetic tests are available. This will mean that a lot of recently self-tested and concerned people will turn to the national health services with questions about the result of the tests and demands for further physical investigation (Brower, 1997).

Of course, public health care is not some self-sufficient abstract agent that carries this burden. Ultimately, the people of the society are the ones bearing the cost. So the potential adverse consequences of unregulated commercial consequences eventually affects all these individuals. If public health care is desirable,[68] and if the public (i.e. the individuals of society) has decided to implement such a system, then they ought to be able to protect themselves from excessive financial burdens on such a system and, thus, ultimately themselves.

Whether burdens will be excessive is partly an empirical question, depending on the extent to which the scenario of increased demands on public health care actually will be realised, given that unregulated home tests are allowed. The question is partly normative as well: "too much" is an implicature of "excessive" and the cost might, after all, be acceptable. For instance, some people that would not have discovered their susceptibility to preventable diseases might do so, and if they get in touch with public health care because of their home testing, this is, ceteris paribus, a good thing.

However, given that very sparse quality controls are made on genetic home testing, there is a risk that many tests are unreliable. Then public health care may have to confirm the tests themselves. And given that no demands on genetic counselling are made, many needlessly worried people will burden public health care. Let us simply call these kinds of costs for the public health care systems for excessive costs. Then the following should hold: the more excessive costs unregulated genetic home testing results in, the more reason it is to regulate the practice in order to reduce the cost. Obviously, this cost has

---

[68] I will argue later that are good reasons indeed in favour of a collectively financed system of health care insurance, primarily reasons of consequence and justice (see chapter VII).

to be compared with the benefits, but, as we have seen, there is little reason to believe that unregulated genetic testing will result in much benefit in terms of welfare.

This argument in favour of regulation is quite general. It says that we have a reason to regulate those tests that will lead to excessive costs. However, the argument does not tell us *which* tests that will lead to excessive costs (this is an empirical question). Neither does the argument tell us *how* they should be regulated more precisely. Of course, "in a way as to most efficiently reduce or eliminate the excessive costs" is a good general answer. And I have been suggesting that quality controls and obligatory counselling (financed by the firm and, thus ultimately, the buyer) are two ways of reducing unnecessary costs. But prohibition may be needed in some cases. The cost to the public of allowing a certain test must then be compared with the benefits of it. It is not obvious that the moral calculation will fall out in favour of the Radical Libertarian. Probably it will not.

2.4 Casuistic arguments

As we have seen, it is far from obvious that normal adult people always should be allowed to establish contracts and engage in transactions in any way they see fit. Regulations, and thus circumscribing negative rights, may sometimes be justified. Nevertheless, freedom should be the rule and societal interference should be the exception, one might think. That is, everything that is not regulated should be allowed, and regulation must only be implemented if it is based on very good reasons.

Of course, there is no unanimity on what constitutes good reasons for regulations. Some (like Locke and Nozick) thinks that only the violations of rights call for societal interference, while others (like Mill) seek their foundation in serious enough harm (or risk thereof) to others. These proposals may be combined and other ethical considerations may enter as well (like equality or autonomy).

However, instead of scanning every possible, or even plausible, ethical consideration, the following strategy might help us to settle the question of regulation. Let us consider relevantly similar cases and see how they in fact are regulated. If there is no obvious reason to doubt that the regulation is flawed, we should apply the general standard to the case at hand.

Takala also applies this strategy to the present question of home testing. Since she argues that "other... practices are not subject to constraints, although

their aim and features are similar to the aim and features of genetic testing" (p 87), her conclusion comes close to the Radical Libertarian: "not many regulations seem justifiable in the context of genetic testing." (p 101) Of course, eventually this kind of defence can only be conditional on the justifiability of the actual regulation. In order to finally assess it, one has to evaluate whether or not the present regulation of the relevantly similar practices are, in fact, reasonable or justified (Takala, 2000, p 100). Nevertheless, our judgement may be informed by considering the regulations of relevantly similar cases.

What are, then, the relevantly similar cases that speak in favour of very limited regulations, if any at all, in the area of commercial genetic testing? Takala puts forward the following four:

> Ann would like to be tested for her HIV status. Bob wants to get his head examined. Carol wishes to buy a pregnancy test kit. David wants an astrologer to tell him if the position of the celestial bodies is favourable to international peace negotiations. (2000, p 94)

These cases are compared with Emma, who wants to purchase a genetic test in order to find whether or not she has an "increased inherited risk to develop breast cancer" (Takala, 2000, p 88). Let us assume that it is the test for BRCA1, which we are already familiar with (see I.4.1) and which is in fact already being marketed.

There are similarities between the cases. We can suppose that the reasons for these persons to find out the information in question, is best known to themselves (Takala, 2000, p 88). We can furthermore suppose that the information provided would affect future decision-making that may concern other people than the index-person.[69] However, regarding regulations, there are differences. As Takala remarks, most countries have regulations demanding that the tests of Ann and Bob should be performed "only by qualified physicians" (Takala, 2000, p 95). This is different from Carol's pregnancy test, which "in many countries...can be purchased without any intervention from physicians, nurses or social workers" (Takala, 2000, p 101). And regarding astrologers, there are hardly any regulations at all. They are "allowed to market

[69] Takala make these suppositions and I will, for the sake of the argument, accept them.

their services in whichever way they wish, and there are no quality controls in their work." (Takala, 2000, p 100)

Takala's aim of criticism seems to be the Moderate Liberal and the Total Prohibitionist. Why should Emma's case be like Ann's and Bob's and not Carol's (Takala, 2000, p 101)? That is, why should we demand that the test is performed by a professional and not at home? And why should not Emma's case be treated like David's (Takala, 2000, p 101)? That is, why demand quality controls and other sorts of interference at all?

Let us start with comparing the cases of Ann and Bob with the case of Carol. There is a very strong reason for treating the case of Ann differently than the case of Carol. HIV regularly leads to an infectious and lethal disease, unlike pregnancy. Society ought to protect itself from the spreading of the disease, since successful prevention of the disease will save lives and avoid serious harm. If people are in contact with public health care when testing themselves for HIV, the public health care can provide proper care and information about how to prevent further spreading of the virus. Since the interest of third parties are so vital in this case, it may even be justified with quarantine if there is well-founded suspicion that the tested person will not comply to the measures necessary for prevention of further spreading. This interest is not present in the case of Carol. I will return to the question of what relevance this may have for the case of Emma after having considered Bob's case.

In the case of Bob, the reason for treating this differently than the case of Carol is another one. In the case of Bob, a person needs much knowledge in order to properly perform a head examination. The signs may be hard to interpret and it takes training to avoid making the wrong diagnosis on the basis of the signs. Moreover, the question of the presence of signs of pathology is of tremendous relevance for Bob's life and health. On the other hand, a pregnancy test is easy to interpret and very reliable and, although being pregnant or not is an important issue for most people, it does not carry with it potential threats of the same kind and calibre as a head injury.

That is the reason why we think that an officially qualified physician should perform the head examination – only such a person can do it properly and give proper guidance to the patient in light of its potential consequences. This does not mean that any individual lacks any right to take the "test" and find out the result. But in order to get accurate information, which presumably is what the patient is looking for, society has implemented regulations in order to

ensure the quality of the test. In most countries, the same is done for pregnancy test. Before they are permitted for marketing, their quality has to be approved by a governmental body.

So in comparison, there is nothing about Emma's genetic testing for BRCA1 that excludes official quality control. Furthermore, the genetic test in question is much like the head examination. The test may easily be misunderstood, since we are dealing with complicated estimations of probability (see II.2.3.2). As we have seen repeatedly, this may lead to over- or underestimation of the significance of the test, which may lead to serious harm (such as unnecessary anxiety or omission of well-needed treatment). So genetic testing of this kind seems more relevantly similar to Bob's case than Carol's. If demand for testing in a public setting is well founded in the case of Bob, it should thus be so in the case of Emma. To this it might be added that there is also relevant similarity between Emma's case and Ann's, which strengthens the case for regulation: since the potential harms threatening Emma may spread to her relatives, there is a third party interest to be protected also in this case. So far, then, comparisons with relevantly similar cases seem to support regulations that the Radical Libertarian would reject.

But the case of David seems to be somewhat of an anomaly:

> Astrologers are allowed to market their services in whichever way they wish, and there are no quality controls in their work. This is puzzling in view of the fact that their predictions are even more ambiguous and more open to interpretation than genetic test results. Should it be inferred from this that even quality control and marketing regulation are excessive and illegitimate hindrances on acquiring information in western societies? Or should astrologers be required to submit their methods and predictions to an independent review board for inspection? (Takala, 2000, p 100-101)

If one grants that the important commodity in all the cases is information, why regulate the exchange of some information but not others? Takala assumes that David is married to the president of a powerful nation and under this assumption we may, not implausibly, assume that the information that David will receive will influence important decisions that may affect the lives of many people, maybe in a harmful way (let us assume that the information he

gets makes his wife cancel the peace negotiations, with the result that a messy war continues). We are still generally inclined to reject societal interference with regard to this example of free exchange of information. Why not apply the same reasoning to the case of Emma, indeed, to all of the cases mentioned above? If not, what difference is there between the case of David and the other cases that makes regulation illegitimate in this case but not the others?

There is at least one important difference between the case David and the other cases that make regulation called for in the last cases. There is a generally recognized need to protect public's trust in health care institutions. This is one (perhaps the most important) basis of the confidentiality between the doctor and the patient (Beauchamp & Childress, 2001, p 306-308). It can also be argued to be the basis of standard bans on the marketing and prescription of medical products that have not been carefully scrutinised. If medical products (like genetic testing) are being sold without being quality controlled, there is, of course some risk that their quality will be poor. This may contribute to an undermining of general trust in medical products and medicine in general. This, in turn, may cause widespread reluctance to turn to the institutions of medicine, with grave potential harm on general health and welfare as the result. All the steps of this line of reasoning are, of course, based on empirical hypotheses. But they are generally recognized; probably since the consequences of not taking them seriously may be so grave. However, there seem to be no parallel societal need to protect the credibility of and trust in the institution of astrology.

In addition, there seem to be another crucial similarity between the cases of Ann, Bob and Emma: they are about maladies that can be ameliorated if the person is properly guided. This calls for an institutional setting around these cases not called for in the case of David.

Finally, it is not obvious that David should not be prevented. If David's use of an astrologer's advice leads, or has a high risk of leading, to grave harm and death of other people, this seems to be a reasonable ground for interference. Maybe it is not the free exchange of "information" that should be prevented and maybe it should not, or cannot effectively, be prevented by regulation. But generally, if one grants that avoiding harm is ethically relevant, avoidance of serious enough harm is a legitimate ground for prevention. Thus, if regulating home testing can prevent serious enough harm, it should be regulated. As we have seen, there are reasons to believe that this may very well be so.

2.5 Concluding remarks

What should we make of all this? Well, first, it should be noted that the fact that a test is a *genetic* test is of little relevance in order to determine what kind of regulation is called for. A defence of some regulations on some genetic home testing does not have to and should not rest on the premise that there is something special or unique about genetic information. Rather, arguments for and against regulation should, as always, be cast in normatively relevant terms, e.g. terms of welfare, harm, rights, justice, and autonomy.

Second, there seems to be some normatively relevant arguments in favour of some regulation (and maybe even prohibition in some cases), *pace* the Radical Libertarian. What kinds of tests that should be regulated and how they should be regulated have to be determined in a piecemeal manner, referring to the mentioned ethical considerations.

More specifically, I have argued that the following features of genetic testing may make regulations of different kinds justified. Commercial genetic home testing should be permitted, given that (and to the extent that) 1) it does not undermine general trust in medicine and health care, 2) it does not excessively burden public health care financially, and 3) regulations that avoids harm and reducing of autonomy are implemented. Regarding 3), I have argued that harm and reduction of autonomy can be avoided (or at least ameliorated) by (i) controlling the quality of the tests, (ii) controlling the accuracy of the advertisement for them, (iii) demanding genetic counselling when testing is made, and (iv) prohibiting commercial genetic testing for some conditions altogether (maybe by allowing only public health care to make the tests). The kinds, degrees, and proper instances of regulation, again, have to be determined in a piecemeal manner. However, generally speaking, the more serious the disease tested for is, the more unreliable the test is, the more difficult it is to interpret the result of the test, the less the predictive value of the test, and the less preventive measures are available, the more reason to regulate the marketing and selling of the tests.

The following should also be emphasised. To argue that commercial enterprises should be regulated in order to ensure a certain level of quality of information or testing is not to bluntly deny the individual's right to know (as Takala suggests, 2000, p 87), but foremost to impose certain duties on the commercial enterprise of home testing. To be sure, it is to restrict the negative right of some parties: commercial enterprises may not sell genetic tests in any

way they choose without being prevented, and this also limits the opportunities of the buyer. But in another way, some regulations increase the rights of individuals regarding genetic testing and information in some way – they do not only have a right to require this information, they also have a right to require adequate information presented in a useful way and support to deal with the consequences of this information when it is required. These are positive rights. One can ask what important rights of the individual have been lost in this process.

How does the question of regulation relate to the general question of a negative right to know? Well, as already pointed out, some regulations *do* circumscribe such a right. Even if quality controls primarily interferes with commercial enterprises, to demand that counselling should be offered when buying genetic testing is to limit the way in which individuals can buy genetic testing: even if they are free to reject the offer, they cannot buy the testing without paying for the counselling. And to ban some testing on the ground that the quality of the testing is too poor in some way is obviously to circumscribe the individuals right to receive (inferior) genetic information.

How does this discussion relate to the theoretical right-discussion? Well, we have settled some issues regarding the negative right to know. There is no such general right, since all reasonable justifications of a negative right to know support some system of regulations circumscribing this right. There is probably neither any basic negative right, since the arguments to this effect fails. If one accepts this, there is no absolute negative right to genetic knowledge.[70] This is so, since rights derived from values can always be overridden by the ethical premises from which they are derived: if rights are based on autonomy as a value or well-being, enough autonomy and well-being gained by violating the right can justify the violation. The only way to reject this possibility is by arguing that respecting the right in question always leads to more value, and I have argued that more values probably will be realized by recognizing a less extensive system of negative rights to know than the one advocated by the Radical Libertarian. So, if one accepts my arguments, one will be inclined to accept that there are some derived, legal, special, and prima facie

---

[70] Even if one accepts libertarianism or any other way to found the basic right to know, I think one should reject an absolute right to gain access to or receive genetic knowledge about oneself. Does anyone really think that such rights are so important that no amount of suffering or autonomy-reduction (or whatever one takes to be valuable) can ever override the moral importance of respecting such rights? This seems highly counter-intuitive.

rights not to be prevented to gain access to and receive genetic information about oneself, but nothing further. However, the scope and strengths of these rights have to be settled in a piecemeal manner, referring ultimately to the values that is the basis of the rights in question.

3. Positive rights

As mentioned at the outset of this chapter, the right to genetic information is often claimed. For instance, in the WHO Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services (Wertz et al, 1995, Preface) states: "All individuals should have a right to know their genetic risks and risk to their potential offspring; to be educated about these risks".

However, it is far from clear what kind of right, positive or negative, the authors have in mind, which is commonplace for statements regarding rights in this context.[71] Nevertheless, the addition that there is a right "to be educated about these risks" could be interpreted as a claim that there is not only a right not to be prevented to know, but also a reason of someone else to educate the individual whether or not she is at genetic risk (of some medical condition), and thus assist her in learning genetic information about herself. That is, the quote could be interpreted as claiming that there is some *positive* right of the individual to genetic information about herself.

Moreover, the WHO Proposed International Guidelines on Ethical Issues in Medical Genetics and Genetic Services (1998), partly based on Wertz et al (1995, Preface), states: "Presymptomatic testing should be available for adults at risk who want it, even in the absence of treatment, after proper counselling and informed consent..." (WHO, 1998, p 9) Even if this statement does not mention any rights explicitly, it expresses that a right to get presymptomatic genetic testing should be recognized, at least if there is some initial (suspicion of) risk (of genetic disorder).

More explicitly, Häyry and Takala claim that there *could* be such a right:

> In the context of genetics, the state could have a contractual duty to promote the health, and to protect the privacy, of its citizens. These duties, where they can be sanctioned, would then give rise to positive

[71] For references to other examples, see footnote 2, this chapter.

claim-rights both to knowledge and to ignorance. (Häyry & Takala, 2001, p 405)[72]

It is clear from this quote that the authors have *legal* rights in mind, since they write about a sanctioned contractual duty of the state. This seems to presuppose some kind of moral basis to the legal rights, i.e. that there are some arguments for why these rights should be sanctioned by the state. Here promotion of health and privacy are mentioned as possible grounds for legislation.

Moreover, the authors also mention a positive right to ignorance, i.e. a right not to know. I will return to this in the next chapter. Nonetheless, one may ask what the relationship between the right to know and not to know is. In modern liberal societies, it seems to be commonplace to assume that there is a right to know, as well as a right not to know, and that these rights are compatible. This may initially seem strange, since positive (and negative) rights correspond to reasons, and it would seem as though the positive right of P to know gives rise to a reason to see to it that P knows and a negative right of P not to know gives rise to a reason to see to it that P does not know. Since these reasons pull in the opposite direction,[73] it seems that the rights gives rise to a moral conflict. But this conflict arises only if three conditions are met: the rights hold under the exact same circumstances, with the exact same strength and the exact same persons have the corresponding reasons to aid. And those who claim that there is a right to know *and* a right not to know would (probably) deny at least the first of these conditions.

One obvious candidate for a circumstance necessary for the rights is the attitudes of (or the actions of, or consequences for) the individual about knowing: for the right to know to actually give rise to moral reasons, the individual must want (or ask for, or would want, or be benefited by) the genetic information in question, and for the right not to know to have the same moral bearing, the individual must want (or would want, etc) to avoid the information. This would give the person a right to know and a right not to know, but under different circumstances. Of course, the circumstances can be

---

[72] It seems as though Häyry and Takala presuppose that a positive right includes a negative one (Häyry & Takala, 2001, p 404). However, as we will see, this presumption seems justified only regarding basic rights (see IV.3.1).

[73] In the sense that they suggest two actions that cannot be jointly performed by one and the same acting party.

combined, and further items can be added to the list of circumstances that has to be in place in order for the right to give rise to actual moral reasons. However, the claim that there is a positive right to know that corresponds to everyone having a reason in all circumstances to see to it that one gets to know is in conflict with the claim that there is a positive right not to know that corresponds to everyone having a reason in all circumstances to see to it that one does not get to know. This means that if one is claiming that there is both a right to know and a right not to know, one has to specify the circumstances in which the respective rights hold. Another way to resolve the conflict is to claim that rights to know and not to know can be waived by the right-holder (IV.1.1.1).

Perhaps surprisingly, a general positive right to know, i.e. a right to know that holds regardless of circumstances, does not imply an obligation to know. Even if everyone acted wrongly, if they failed to see to it that I know, it does not follow that I do anything wrong if I choose to remain ignorant. Compare with the case of a positive right to life. Even if everyone else acted wrongly were they to abstain from helping me to go on living, I may not do anything wrong by ending my life. This means that the question of a right to know should be kept separate from the question of duty to know, an issue to which I will return (see V.3).

Despite the fact that a positive right to genetic information sometimes seems to be claimed, or at least presupposed or indicated, explicit argument in favour of such rights are hard to come by. This is so since the distinction between positive and negative rights are seldom made in this context. More often, possible arguments for more unspecified rights to know are presented (Chadwick, 1997, p 14; Hermerén, 1999, p 145-152).[74] These arguments generally refer to advantages of knowing for the individual, that is, positive values actualised due to the possession of knowledge about one's own genetic constitution. If this is the correct basis for the individual's positive right to have genetic information about herself, which I will argue that it is, there are no basic or absolute positive rights to genetic information. However, this "if" obviously needs to be substantiated. After having thus rejected the idea of a

[74] Many such arguments concern the alleged right of relatives to be informed about genetic risk from the index-person (Hermerén, 1999, p 145-152). I will ignore these arguments here, since they will be discussed in chapter VI.

positive basic right to know (IV.3.1), or a right derived from such basic rights (IV.3.1.1), I will move on to the possibility of such right being derived from values, which will prove to be a more promising line of reasoning (IV.3.2).

3.1 Basic rights

Against the background of the previous section, it should come as no surprise that basic *positive* rights to have genetic information about oneself are hard to defend. And to argue that there are no such rights may be considered to be as much an attack on a straw-man as in the case of negative rights, since explicit arguments that there are such rights are hard to come by (in fact, I know of none). However, in order to see to it that the straw-man does not come to life, it can be worthwhile to try to show why there most likely are no basic positive rights to genetic information about oneself.

There is a general argument to this effect, resting on two premises: 1) There are no basic negative rights to genetic information (about oneself). 2) If there is no basic negative right to something, X, there can be no basic positive right to X.

The success of the argument is thus dependent on the validity of these premises. If my argument from the previous section, that there probably are no negative basic rights to genetic information, is accepted, one will have no problem of accepting premise 1). Premise 2) can be defended in the following way. Positive and negative rights are always rights towards someone else. Negative rights correspond to moral reasons for abstaining from doing some things (to the right-holder), while positive rights correspond to moral reasons for doing some specific things (to the right-holder). From this it seems natural to conclude that if there are no such reasons for abstaining from certain courses of action with regard to something, there certainly are no such reasons to undertake certain courses of action regarding this. Take the example of a basic right to life. If it can be argued that there is no such negative right, i.e., others have no reasons to abstain from taking my life that holds independently of other moral considerations, then it seems farfetched to claim that others have moral reasons of this kind to take active measures to keep me from dying.

Note that this second premise only regards basic rights (and rights derived from them). This is so, since if a right is derived from the positive consequences of recognizing the right, then it depends on the consequences whether the right in question should be recognized or not. And it could very

well be that the consequences of recognizing a positive right to X will be good, but the consequences of recognizing a negative right to X will not.

If one accepts premise 1) and 2) the case against positive basic rights to genetic information will be settled. But in order to convince those who do not, further elaboration may be needed.

Recall the argument for a basic negative right to genetic information about oneself: the sensitivity-argument (see IV.2.1). This argument claims that (some) individuals have a basic negative right to genetic information about themselves due to the (alleged) fact that this information is very personal and sensitive. As demonstrated, the problem with the sensitivity-argument, besides resting on a highly doubtful premise that genetic information is necessarily very sensitive, is that the implications of the premise are so unclear that it can be used to argue in favour of conflicting rights. And an argument supporting conflicting rights must be flawed, unless it provides some way of solving the conflict, which it does not. This last line of reasoning holds regardless of whether the alleged rights supported by the sensitivity-argument are positive or negative. This is easily seen if one reformulates the argument to explicitly be about positive rights: just as the sensitive nature of genetic information can be thought to support some index-person's positive right to have genetic information about herself (and then a positive reason of someone else to help the index-person with this) it can be thought to support the positive right of others to prevent the index-person from acquiring genetic information about them. But then one sometimes can respect the rights of one of the right-holders only by violating the rights of another (i.e. a conflict of rights), since it is sometimes true that letting the index-person have genetic information about herself is to give this index-person genetic information about someone else. And since there is no independent reason to say the (alleged) fact that genetic information is very sensitive supports one of the rights more than the other, the basis seems flawed. This problem is perhaps even more obvious regarding positive rights, since it is natural to think that it is the health care institutions that have the corresponding moral reasons, in which case a conflict of reasons follows as well.

3.1.1 Rights derived from basic rights

There neither seems to be any good grounds for claiming that there are positive rights to genetic information (about oneself), which can be derived

from other basic rights. In fact, the basis for such rights seems to be even weaker than in the case of negative rights. Let us see why. First, one can refer to the basis of libertarianism. But libertarianism only acknowledges positive rights if they are the result of a voluntary agreement, for instance a contract (Wolff, 1991, p 19-20).[75] That is, only if you consent to a voluntary agreement, the content of which is to give me some genetic information about myself, I have a positive right to this information. Thus, the scope of such a right would be very limited, holding only in cases where such binding agreements have been established. More extensive positive rights, as those mentioned by Häyry and Takala at the outset of this section and (probably) favoured by the WHO (see IV.3) would lack any foundation on a libertarian basis.

Second, one can refer to the basis of Kantian autonomy that can be used to argue against (a sort of) paternalism: preventing the individual from making her decision by making the decision for the individual in her best interest (see IV.2.2.2). Even if one accepts this basis,[76] it cannot be used to found positive rights. This is so, since denying that anyone has a moral reason to help some individual to have genetic information about herself, and thus denying the positive right of the individual to have this information, is compatible with not preventing the individual from decision-making by making a decision for the individual. Of course, with some genetic information, a person could become more autonomous in various ways (see e.g. II.2.3.1), and this may give someone a reason to assist the individual in getting that information. But this is an argument referring to the beneficial consequences in terms of autonomy for the individual of having that information, not to refer to the basis of Kantian autonomy at stake here. That is, even if (the value of) autonomy can be used to argue in favour of a derived right (something we will return to shortly, see 3.2), a basic negative right to have one's autonomy respected cannot be used to derive a positive right to genetic information about oneself.

If there are no basic rights to genetic information, not even rights derived from such basic rights, which I have argued that there are not, the only possibility that remains to argue in favour of positive rights to genetic information is to argue in favour of such rights derived from the value realized by recognizing them. As argued in the previous section (see IV.2.5), if

---

[75] At least Nozick's brand of libertarianism, which we are concerned with here.

[76] I argued that this basis cannot be the only one of obligations and rights (see IV.2.2.2). It may be overruled e.g. by considerations of preventing harm.

there only are such derived rights to genetic knowledge, there are no absolute such rights, since derived rights can always be overridden by the ethical concerns from which they are derived. The only way to reject this possibility is by arguing that respecting the right in question always leads to more value, and we have already seen that giving someone genetic information about herself can lead to less value (see e.g. II.2.4). So there are no basic or absolute positive rights to genetic information.

3.2 Rights derived from values

As already mentioned, most arguments for a right to know refer to advantages of knowing (see IV.3). Since there are few, or perhaps no, explicit arguments in favour of a basic positive right or such a right that may be derived from some other basic rights, it is natural to look for a defence of a positive right to have genetic information about oneself in the mentioned advantages. And since referring to the advantages of the individual of knowing is to refer to some value for the individual of knowing, such defence will, then, be defences in favour of rights to know that are derived from considerations of value. If one accepts my argument that the predominant values of genetic information are well-being and autonomy (see chapter II), the question becomes if these values for the individual can be used to argue in favour of positive rights to genetic information, and then which positive rights can be defended on this ground.

The limited scope of this kind of argument must be kept in mind. Given that one accepts that it is not always valuable (in terms of well-being or autonomy) to have genetic information (about oneself), which certainly seems reasonable (see e.g. II.2.2.2), there cannot be any *general* value-derived right to this information. Of course, one can argue that someone, P, has a moral reason to help another individual, Q, to gain such information, due to the value for Q of having such information, and the lack of reasons to the contrary (e.g. there are no negative values realized for Q or anybody else, P can do this without any significant sacrifice on his own part, etc). In the sense that it, for these reasons, may be wrong of P not to inform Q, Q can be said to have a right towards P to have the information in question. But this argument would, then, establish only this: that one particular person should see to it that another particular person has genetic information about herself. This right cannot automatically be extended to other persons, since the consequences in terms of value may then be different.

A more interesting way of arguing in favour of some derived positive right is to argue that the general *recognition* of a right, e.g. by implementing it as a legal right, is conducive to general well-being and autonomy. That is, one can argue that a certain institutional setting, recognizing positive rights to genetic information, has better consequences than alternative institutional settings.[77] The most likely candidate to the obliged party that should execute such a right will, of course, be health care, since this is the party that is primarily involved in performing genetic testing.

However, also the limited scope of such an argument has to be acknowledged. If the basis of recognizing some rights is the promotion of some values for some individuals, the right can only be recognized to the extent and given the circumstances that these values are promoted for these individuals by recognizing the right. This means that positive rights to genetic information are special, since, as we have seen, the promotion of the values of genetic information generally most likely is dependent on the circumstances (see e.g. II.2.4 and II.3.5).

So the question thus becomes, should health care recognize any, derived and special, positive rights to genetic information? As already mentioned, there are few, if any, *explicit* arguments in favour of *positive* rights to genetic information about oneself specifically (see IV.3). However, there are general arguments in favour of unspecified rights to know that can be construed as such specific arguments. One example is Chadwick, who states the following under the heading of "*The right to know one's own genetic constitution*":

> This claim I do not propose to discuss in any great detail, because it is the least different from other areas of medicine and raises similar issues to claims of right to knowledge about one's medical condition, based on principles of autonomy and self-determination. The knowledge may enable to seek appropriate therapy or to take preventive or ameliorative action. (Chadwick, 1997, p 14)[78]

---

[77] This is the kind of argument that is indicated by Häyry and Takala in the quote at the outset of this section (IV.3).

[78] She also mentions the right to make informed reproductive decisions as a special ground for the right to have *genetic* information (Ibid). However, relevance for reproductive decisions is not unique to genetic information, since other medical information may be relevant for such decisions, i.e. about HIV (see I.4.3).

What Chadwick seems to be saying is that there is no difference with regard to the right to find out about one's medical conditions in general and genetic information that may be relevant for such conditions. That is, a right to genetic information relevant to medical conditions should be recognized to the same extent that the right to medically relevant information in general is recognized. The reason to recognize such a right is the two traditional values of biomedical ethics: patient autonomy and (health-related) well-being.[79]

Indeed, most western countries do recognize a positive right for all its citizens to have a proper diagnosis of their medical condition. The way in which this right is implemented is through a publicly funded health care system that is, or at least should be, equally accessible for all who needs it (with the striking exception of the USA). And the mentioned reasons of health-related well-being and autonomy seem to be good reasons for recognizing such a right.

However, these reasons can be irrelevant when it comes to presymptomatic genetic testing. To start with, one should that note such tests do not result in any diagnosis or information about one's medical condition, strictly speaking. They result in prediction of various probabilities of future medical conditions. But even so, the test may realize the mentioned values for the individual. However, health-related reasons are only relevant to the extent that there really are medical measures to take. And, as we have seen, finding out information from presymptomatic genetic testing can reduce autonomy (see II.2.3.2). Of course, there is genetic counselling, which aims at realizing autonomy and counteract consequences detrimental to this realization. However, if the basis of a certain genetic test, in the absence of health related reasons, is the promotion of autonomy (and psychological well-being), there cannot be any ground for providing these tests if it does not (or at least is very likely to) promote autonomy. This means that there can only be a positive right to the test if it is in the circumstances likely to be conducive to the value(s) that is the rationale of offering such presymptomatic genetic tests at all. This, in turn, means that the right to have some genetic information of one's own genetic constitution is unlikely to be general. Under what circumstances, then,

---

[79] As we have seen, autonomy conceived of as a value that should be promoted is somewhat of a novelty in biomedical ethics. However, it is unclear from Chadwick's quote whether "principles of autonomy" should be understood as including this novel idea of autonomy, or just the classic idea of respecting autonomy, which includes information giving necessary for informed consent (III.3.3).

does the positive right to have genetic information about oneself hold? I will divide this question according to the formerly introduced distinctions between having access to and receiving genetic information (IV.1.2).

3.2.1 The right to access

Up to this point, the arguments for a positive right to know have been neutral regarding the distinction between having access to and receiving genetic information about oneself. To start with: should a positive derived right to gain access to genetic information be recognized and, if so, under what circumstances?

The most interesting way to interpret access to genetic information in this context is "access" in the sense of knowledge about a method to receive genetic information. A positive right to access to genetic information would then mean a positive right to gain knowledge about how to get genetic information and, in this context, consequently a corresponding reason of health care to see to it that one gains this knowledge. That is, the question is if health care has any moral reason to inform anyone that there is genetic testing available.[80]

This depends on how the moral reason is understood more specifically. In one sense, the right to be informed about health care performing certain genetic tests should be uncontroversial, namely in the sense that health care has a reason, strong enough to ground an obligation, not to keep the availability of their services a secret. That is, if someone approaches health care with the question if they perform a certain test that they do perform, they should answer this question truthfully. It also seems rather uncontroversial to hold that health care has an obligation to tell someone who approaches health care herself with concerns of increased risk and who has indication of increased risk, for instance due to family history, a relative's test, or symptoms, that testing is available if it is. Not to do so would be negligent.

However, beyond that, the right to be informed that testing is available, and the corresponding reason of health care to inform, becomes more controversial. This is so, since informing about testing without the initiative from the individual herself and in the absence of indication of increased risk

[80] Of course, as previously stated, this right is only interesting if there also is a right to receive genetic information (see IV.1.2), which in this context would mean that genetic testing really is available. Let us grant that there is such right for now.

is problematic from the point of view of autonomy as well as well-being. Rather, such information could threaten autonomy, since "information" from public health care will often be thought of as recommendations (Clarke, 1998, p 401).[81] This is due to the fact that health care is considered to be an authority in these questions. "Why would they contact me with information about testing if there is no reason for me to get tested?" is a natural reaction to such an initiative from health care. Such information is also likely to increase general anxiety and worry, since the individual, who has no suspicion of increased risk and thus no worry to start with, may regard the offer as a reason to think that there is something to be worried about.

In fact, for health care to inform everyone (at least the competent adults) in a population that there is presymptomatic genetic testing for some specified medical conditions would, in a way, amount to genetic screening. Why this is so becomes clearer given a characterisation of genetic screening. At least two things differ pure[82] screening-programs from the kind of genetic testing discussed in this essay: 1) Health care, rather than the individual or the family, takes the initiative of testing. 2) There is no prior knowledge among those to whom the screening is directed of an increased risk common to all the individuals. Information directed to all adult citizens initiated by health care that there is genetic testing for some specified condition clearly fulfils both these conditions.

Genetic screening is very problematic from the viewpoint of the values of autonomy and well-being, partly due to the reasons already mentioned, and the circumstances in which it should be implemented are rare indeed.[83] I will not argue these points about genetic screening further, since this book is not about

---

[81] The threat to autonomy can be more or less grave, depending e.g. on how active the patient has to be in order to avoid testing (if the patient must actively resist testing and is not told about this possibility, the threat is more grave) and the existence of formal and informal sanctions. If the patient has to take active measures in order to avoid testing, testing can be called routine, and if there are sanctions, testing can be called obligatory (see Bennett, 2001, p 463-465).

[82] Screening-programs can be more or less pure, depending on the level of individual initiative and prior knowledge of increased risk. For instance, screening of populations for which there are some indication of increased risk (although low), e.g. screening-programs among Ashkenazi Jews for Tay-Sachs, is less pure than screening of populations for which there are no such indications, e.g. general screening for phenylketonuria.

[83] See Shickle, 1999, for a presentation and discussion of the widely used Wilson and Jungner principles of screening programs, which e.g. includes early and easy diagnosis and efficient and acceptable treatment.

genetic screening (I.2), a subject that would require a work of its own. Neither do I think I have to, since I think that this kind of argument has been made very convincingly elsewhere,[84] and there is no need for me to repeat it

Of course, there may be cases when such initiatives from public health care can be justified, for instance, if the testing is reliable and has high predictive value, if the condition in question is very serious and can be prevented efficiently and without harm, and if there is no reason to think that the affected individuals have prior suspicion due to family history (in which case there is reason to believe that they would have contacted health care anyway). But genetic conditions of this sort are rare indeed.[85]

So, there may be rights to be informed about the availability of presymptomatic genetic testing. But beyond the right to be informed of such testing when initiating contact with health care regarding this oneself or when there is prior indication of increased risk, any such right becomes controversial. In fact, due to potential damages in terms of well-being and autonomy, the obligation of public health care rather seems to be to abstain from directing the public towards presymptomatic genetic testing in almost all cases.

3.2.2 The right to receive

Is there a positive right to receive genetic information (from genetic testing) from health care, and then under what circumstances? If such a right is derived from the promotion of the values of well-being and autonomy of recognizing such a right, the general answer must be: to the extent that the recognition of such a right indeed promotes these values. As we have seen, these values are likely to be promoted only given certain circumstances (see e.g. II.2.4 and II.3.5). Thus, there can be no such right if these circumstances are not in place.

For genetic information to be likely to promote the values, the test has to have certain qualities: they must be reliable in the sense of not being likely to be false (either false positives or negatives), and the probability of the disease in case of a positive test must be unequivocal and rather high (see e.g. II.2.4). The last condition rules out most tests for multifactorial diseases, unless there

---

[84] See Munthe, 2002, and the anthology of Chadwick et al, 1999, and then especially Shickle's and Hoedemaekers' contributions.

[85] One example is phenylketonuria.

is some preventive measure to take in order to reduce the possibility of the disease in question. Furthermore, the patient must have a proper understanding of the genetic information and the consequences of testing, at least if autonomy and psychological well-being are likely to be promoted by testing (see e.g. II.2.3.2). This means that genetic counselling, or something of the like, probably will be required (see e.g. II.3.5), especially if there are no health-related advantages of testing.

So if there is some positive derived right to know, it will be special. And if the rationale of these tests is well-being and autonomy, one has to argue that these values are sufficiently promoted compared to alternative ways of spending the resources of health care that also would promote these values. Since genetic counselling will be required in order to ensure the promotion of the values, the genetic testing procedure can become expensive. This increases the possibility that there are alternative ways of spending recourses much more conducive to these values, which may make the circumstances in which legal positive rights to presymptomatic genetic testing are justified rare.

4. Conclusions

This chapter has dealt with the question of the individual's right to genetic information about herself from presymptomatic genetic testing: how this right can be understood and justified. Regarding the question about how the right can be understood, I demonstrated that there are at least 120 interpretations of "P has a right to genetic information about herself", depending on what it means to have a right to something in general and what it means to have a right to genetic information more specifically. Generally, claiming that someone has a right to something can be taken to imply a positive or a negative right, an absolute or a prima facie right, a basic or derived right, a special or a general right, and, specifically, claiming that someone has a right to genetic information can be taken to imply having a right to gain access to, receive or use genetic information. This analysis, which draws on traditional theory of rights, will hopefully be useful for making right-claims in this area more clear and precise.

I then discussed whether there indeed is any right to know, i.e. which such rights, if any, that can be justified. In this chapter I have focused on (thin) negative rights, which correspond to reasons for others not to prevent the right-holder in question from gaining access to and receiving genetic

information, and positive rights, which correspond to reasons for others to help the person to gain access to and receive genetic information about herself.

Regarding negative rights, the most extensive system of such rights defended (or, at least, indicated) is the Radical Libertarian position, which says that marketing and selling genetic testing directly to the index-person should be allowed and that this practice should only be regulated as to prohibit coercion and deceit. I used this position to develop an argument in favour of some regulation of commercial genetic home testing. This argument, then, tries to argue in favour of restricting negative rights to genetic information in various ways. However, some negative rights in this area are plausible.

More specifically, a negative right to genetic information through purchasing home tests should be recognized, given that (and to the extent that) 1) it does not undermine general trust in medicine and health care, 2) it does not excessively burden public health care financially, and 3) regulations that avoids harm and reducing of autonomy are implemented. Regarding 3), I have argued that harm and reduction of autonomy can be avoided (or at least ameliorated) by (i) controlling the quality of the tests, (ii) controlling the accuracy of the advertisement for them, (iii) demanding genetic counselling when testing is made, and (iv) prohibiting commercial genetic testing for some conditions altogether (maybe by allowing only public health care to perform the tests). The kinds, degrees, and proper instance of regulation, again, have to be determined in a piecemeal manner. However, generally speaking, the more serious the disease tested for is, the more unreliable the test is, the more difficult it is to interpret the result of the test, the less the predictive value of the test, and the less preventive measures are available, the more reason to regulate the marketing and selling of the tests.

Regarding positive rights, a right to be assisted with gaining access to and receiving genetic information from health care is plausible, given that circumstances are in place to promote the values of well-being and autonomy. I have argued that such circumstances are more likely to be in place if the individual herself initiates contact with health care and there is prior indication for or worry about the condition in question. Furthermore, for genetic information to be likely to promote the values, the test in question has to have certain qualities: it should be reliable and have high predictability. Moreover, genetic testing should be accompanied by genetic counselling, especially if

there is no preventive measure to take in order to reduce the possibility of the disease in question.

Generally, I have tried to argue that the proper basis for any right to genetic information, both positive and negative, is the values that can be promoted as a result of societal recognition of these rights. The values I have in mind are the values I argued provide the possible justification for presymptomatic genetic testing in the first place, namely well-being and autonomy. If this is correct, which I have argued that it is, the moral landscape of presymptomatic genetic testing becomes much easier to survey, since the rights in this area ultimately boils down to considerations of the values in it. As mentioned, I have also argued that given this basis, the recognition of some rights of the individual seems reasonable. However, these rights will be special (holding under the circumstances in which the values that are the basis for the rights really are promoted), derived (from these values), and prima facie (since they may be overridden by the values they are based on).

However, to take us from reasons in terms of values promoted by recognizing rights on the basis of these values, one has to seriously ponder the question of priority: are these values sufficiently promoted by some particular presymptomatic genetic testing compared to alternative ways of spending the resources of health care, which also would promote these values, for the implementation of the presymptomatic genetic testing in question to be justified? Rather than answering this question, I point it out, which, once again, shows that there is more work to be done.

Chapter V
The Individual's Right to Ignorance

1. Introduction

Just like the individual's right to know genetic information about her own genetic constitution is a recurring theme in the ethical debate on genetic testing (see chapter IV), so is the right *not* to know, or the right to ignorance regarding one's own genetic constitution. However, this right is to a greater extent explicitly defended in more specific terms.[1] This is probably due to the fact that the idea of a right to ignorance has been the subject of much more criticism than has the idea of a right to know. The main claim of this criticism is that ignorance is incompatible with moral ideals formulated in terms of autonomy (Harris & Keywood, 2001). Rather, autonomy has been claimed to be the foundation of a duty or obligation to know, and this duty has been claimed to be incompatible with a right not to know (Ost, 1984; Rhodes, 1998). In this chapter I will address both the defence of a right not to know and the criticism thereof.

The defence of a right not to know will be discussed rather briefly (section V.2). One reason for this is that *some* such *legal* right not to know is, and should be, rather uncontroversial.[2] Another is that negative (and positive) rights not to know correspond to moral reasons of others not to inform (or see to it that the right-holder does not get informed), and such reasons are discussed elsewhere in this book (see e.g. VI.3). However, I will present the most common arguments in favour of such rights and make some distinctions and clarifications, so that it becomes sufficiently clear what scope and strength such rights can be argued to have without becoming controversial.

Instead, the main part of this chapter will address the criticism of the idea of a right not to know, based on the (alleged) duty to know (section V.3). I will argue that there is no such general duty to be based on autonomy or Kantian

---

[1] See e.g. Takala, 2000 and 2001, and Laurie, 1999.

[2] This has been, I think, successfully argued elsewhere. See Laurie, 1999, Häyry & Takala, 2000, Häyry & Takala, 2001.

ethics, contrary to what has been claimed.[3] There may be such duties, however, on very rare occasions, where knowledge is a prerequisite for avoiding (significant risk of) serious harm to others. However, this only shows that there is sometimes no right to know in the sense of there being an option, i.e. it can be morally wrong to choose to remain ignorant about one's genetic constitution. No claims regarding rights of others to interfere in such choices, e.g. in terms of legally enforced rights or duties or institutional frameworks, follow directly from this, however.

2. Are there any rights not to know?

A common manoeuvre when defending rights not to know is to refer to the possible negative consequences for the individual of knowing. Accordingly, in the context of defending or discussing rights not to know, references have been made to unwanted changes in self-image,[4] the possibility of having one's autonomy reduced,[5] feelings of anxiety or depression,[6] or stigmatisation and discrimination[7], all of which can be the result of learning that one is (or is not) at risk of genetic disease. That is, the negative effects in terms of well-being and autonomy that were discussed in chapter II, which can be the result of genetic testing, are being used to argue in favour of some right not to know. If such an argument were successful, it would establish some derived right not to know. Moreover, the scope and strength of this right would be determined by the actual presence of these very reasons in particular cases. The right would then, presumably, be prima facie rather than absolute.

---

[3] Most elaborately by Rhodes, 1998.

[4] See e.g. Widmer, 1994, p 184, and Laurie, 1999, who relies on the notion of psychological spatial privacy, an "aspect of spatial privacy [that] protects one's own sense of the self." (p 119) She argues that this privacy can be invaded by getting genetic information about oneself, and that we thus should recognize a right not to know. This defence is elaborated in Laurie, 2002.

[5] See, e.g. Chadwick, 1997, p 19, Husted, 1997, p 61-64, and Takala, 2001, who writes: "Maybe those who want to uphold the right not to be informed simply know themselves well enough not to seek possibly disastrous knowledge. Being in control of one's life can then require some degree of self-chosen ignorance." (p 487)

[6] See e.g. Laurie, 1999, who writes: "the fear of future ill-health may very well ruin what turns out to be an otherwise healthy existence." (p 122)

[7] See e.g. Chadwick, 1997, who writes: "genetic knowledge may have serious social consequences for the individual in terms of stigmatisation and discrimination." (p 18) Of course, this type of consequences can only be the indirect result of learning that one is at risk, namely if this also leads to others learning about one's risk.

Besides this kind of defence, the most recurring defence of a right not to know refers, in one way or another, to privacy and privacy-rights.[8] However, privacy-rights are not self-evident but must be justified,[9] and this is usually done with reference to values like well-being and autonomy (VI.2.2). So, also defences based on privacy are likely to establish only derived rights not to know.

However, even if one grants that all these negative values can be realized by acquiring knowledge of some piece of genetic information about oneself, the question of which rights more specifically that can be derived from these values remains. Let us look at the three main elements of rights distinguished in the previous chapter: options, negative and positive rights.

So, first, can these values found a right not to know in the sense of an *option* not to know, at least for some persons in some situations? That is, is there ever a right to remain in ignorance regarding some piece of genetic information, in the sense that some persons in some situations do not do anything wrong by remaining ignorant of this information (about their own genetic constitution)? It should be clear that there *can* be such a right, perhaps most obviously when the individual stands to loose in terms of the values by getting to know some piece of genetic information, while at the same time not gaining much and no one else is affected negatively by her ignorance. In fact, as we shall see, the situations where it can reasonably be held that there is a duty to know, and thus no option not to know, are rare indeed (see section V.3).[10] Even so, there seem to be such situations, notably when there is significant risk of serious harm to others due to the ignorance of some genetic information about oneself. However, since I will discuss the question of a duty to know, and thus the corresponding criticism of an option to know, in the next section, I will leave it for now.

---

[8] See e.g. Hermerén, 1999, p 147-149, Laurie, 1999 and 2002, and Häyry & Takala, 2001, p 405-407.

[9] This is so, at least in the moral context (to see why, see VI.2.2). To claim this is not to deny Laurie's thesis (see 1999 and 2002) that privacy might be the most appropriate concept when defining and defending various legal rights (not) to know.

[10] One reason for the fact that these situations are rare is that even if there may be a moral duty to help others (most notably, blood relatives) by giving them access to one's genetic information, this does not imply a duty to learn about this information with regard to oneself (even if one perhaps is likely to find out anyway if one discloses to relatives). See Takala, 2001, p 486.

2.1 Negative and positive rights

Is there a negative right not to know? In one sense of negative rights, namely in the sense of some derived *legal* or institutional rights, the right to remain ignorant should be uncontroversial. What I am thinking of is the right not to be forced to have genetic testing. There are good reasons indeed for this. In a liberal society, when some kind of intervention can be both beneficial and burdensome to an individual, we normally leave it up to her to make the decision whether or not to accept this intervention (at least when the individual is a competent adult and making such decisions does not impose serious harm or risk of harm to others). This is in line with Mill's idea that people normally are the best judges of what is beneficial or burdensome for them and thus should be allowed to make decisions of this kind themselves. This is, of course, nothing but Mill's famous argument in favour of anti-paternalism: that others, and especially societal institutions, should not be allowed to force one into something only for the sake of one's own good (Mill, 1859).[11] Thus, forcing genetic testing upon someone may not only be damaging for her autonomy and well-being, but amounts to imposing medical intervention upon someone without her consent, i.e. coercive care. This is contrary to the principle of *respecting* autonomy (III.3.3). If one accepts the standard view in biomedical ethics that this is a basic right, i.e. a right that should be respected even if consequences would be better by not respecting the right (Beauchamp & Childress, 2001, p 176-177),[12] there is even a *basic* right not to be forced to genetic testing by public health care and other societal institutions. I will not take a stand on whether there is a basic right to have one's autonomy respected, but rest content with pointing out that if one thinks there is, which many seems to do, some rights not to know have a firmer basis than any right to know, since all those rights are derived (or so I have argued in chapter IV).

Furthermore, one can use this line of argument to go further and claim that it is wrong to disclose genetic information to someone without her consent. As emphasised repeatedly, it is primarily not testing itself, but the information that is the result of such testing that can be beneficial or burdensome for the individual (even if being coerced into testing can be unpleasant enough,

---

[11] This kind of argument in favour of a right not to know is used by Häyry & Takala, 2000. See also Häyry & Takala, 2001, p 410-412.

[12] This is quite compatible with the right being prima facie, i.e. overridable in circumstances where sufficient moral reasons not to respect the right is at stake.

regardless of the result). So why focus just on coercive tests, in the sense of testing without consent, and not also disclosure of genetic information without consent? If the former should be prohibited or, at least, severely restricted, it seems natural to conclude that the latter should be so too.

What is more, the claim that there is a right to ignorance in this sense not only should be uncontroversial, but also seems to be considered to be so. To my knowledge, no one has ever seriously claimed that institutions such as health care should be legally allowed to force presymptomatic genetic testing or genetic information upon the individual. Not even the most outspoken advocates of a duty to have genetic information about oneself have ever claimed this, and sometimes explicitly denied that this is what they argue in favour of.[13]

Even though this argument in favour of a legal negative right to ignorance seems to be both valid and sound, the scope of the right should be delimited clearly. For one thing, it is unclear if the standard rule of informed consent applies in all cases. I am thinking about the type of cases where one cannot ask for consent to disclose some information without at the same time disclosing that very information one is asking for consent to disclose. This is typically the case where some relative(s) of a person, P, has tested positively and P has no prior suspicion whatsoever that she might have an increased risk of the genetic disease tested for. In cases such as these, the relative probably cannot ask if P wants to find out whether P is at increased risk of having the genetic disease in question without P understanding that she has such an increased risk. That is, just by asking: "Do you want to find out whether or not you are at increased risk of being a carrier of some gene(s) that increases the risk of a particular disease?" P will normally understand that she has such an increased risk, if P also knows that the reason the question is asked is that a relative has been tested. So, in cases such as this, one (most likely) cannot ask whether someone wants to find some information about genetic risk out without revealing that information.

How should one handle situations such as this? I will argue that there are circumstances, even though rare, where consent of a person, P, to know that P

---

[13] See Rhodes, 1998, p 27: "Prescribing social policy and policy for the professions is beyond the scope of this paper." and "There may certainly be excellent policy considerations and personal reasons for not imposing information on someone who does not want it."

might be a carrier of some gene(s) that increases the risk of a particular disease can be presumed. In these cases, it might even be argued that P should be informed without the consent of the relatives (see VI.3.1.2). In these rare cases, there should be no legally protected right not to know *that one might be a carrier* and, in even rarer cases where the testing of a relative shows that P is a carrier for sure, that one is in fact a carrier. Since I will discuss this later, however, I leave it for know.

This kind of situation should be carefully distinguished from situations where the individual has some prior knowledge or suspicion of being a carrier of some gene(s) that increases risk of disease. Then it is certainly reasonable to demand of societal institutions, including health care that they ask whether or not the person wants to find out whether *she actually is at risk*, i.e. is a carrier of the gene in question. However, this should not, and probably is not, very controversial.

Is there also a negative *moral* right, in the sense that there are reasons against others informing a person that she has a certain risk of a genetic disease without her prior consent? Again, on the basis of the (negative) values in question, i.e. well-being and autonomy, there clearly can be such reasons. This is so, since the person may become significantly worse off in terms of both well-being and autonomy by gaining this knowledge (II.2.4) without anyone else being better off.

However, it can also be the case that there are reasons, perhaps even reasons strong enough to override reasons pulling in the opposite direction, for someone, P, to inform someone else, Q, of her risk of genetic disease on the basis of the very same values. It is reasonable to claim that an obligation to inform based on this is prima facie and holds to the degree that Q will be better off (or less worse off) by receiving the information in question.[14] In that case, one obviously has no absolute negative right not to know of this risk, since it is not necessarily wrong of others to inform one about it.

Nonetheless, since it is hard to know whether or not receiving the information in question will actually benefit a certain person, guesses about this should not be the basis of policy or regulation of the institutions that produce and handle genetic information. Given the Millian assumption that the individual, as a rule, knows better than anyone else what will benefit her, it

[14] I will argue in favour of both these claims in section VI.3.

seems plausible to leave the decision whether to know or not up to the individual herself. So the institutional right not to know is not undermined by the fact that receiving genetic information can benefit some individuals and that others, by virtue of this, may have moral reasons to provide this information to these individuals regardless of whether or not they have consented to this.

However, the claim that society should abstain from coercive interventions does not imply that society should protect the individual from getting the information against their wishes in all circumstances. For instance, no defender of a right not to know has ever claimed that relatives who inform a person that she has (or is likely to have) a certain genetic constitution should be punished or made to pay compensation. This means that it should be uncontroversial that some positive legal rights to be protected from knowing should not be recognized. However, there can be reasons indeed to enforce sanctions on some third parties, such as researchers, in the case of unsolicited disclosure of genetic information they have about a person to that person (or anyone else, for that matter), namely on partly the same grounds that legal negative rights not to know ought to be enforced. So *some* legal positive rights, in the sense of regulating against third parties to protect the ignorance of first parties, most likely should be recognized too.

3. A duty to know

It has been claimed that we have a general duty to know about our own genetic constitution (Ost, 1984; Rhodes, 1998),[15] at least if such knowledge is relevant for important decisions.[16] What is being claimed is, then, that there are strong reasons for knowing one's genetic constitution in such cases. These reasons may be seen as conclusive, in which case the duty is absolute. However, the duty may also be prima facie, i.e., strong enough reasons to the contrary may override the reasons to know. In the following, I will assume that the

---

[15] These authors both have a salient line of reasoning that I will ignore in the following. It has the following structure: X (autonomy) cannot be the ground for Y (the right not to know), since X is the ground for not-Y (the (mandatory) right to know (Ost, 1984, p 302-303; Rhodes, 1998, p 17)). This "argument" obviously presupposes what must be demonstrated, namely that autonomy is the ground for a duty to know but not a right not to know.

[16] Of course, the terms "relevant" and "important" are unclear and a more precise interpretation of them may be crucial to the credibility of the duty to know. I will return to this below.

supporters of a duty to know claim the reasons to know to be quite strong; if not absolute, the duty is still not easily overridden.

The most conspicuous argument in favour of this duty is that a person's right to remain in ignorance about her genetic constitution is incompatible with her autonomy.[17] In this section I will address this and other arguments in favour of the duty to know.[18] My own conclusion is that there probably can be such a duty in certain situations. However, the basis of this duty is not the one the defenders of the duty to know have argued that it is. More importantly, they have not established, and probably cannot establish, a general or absolute duty to know. However, this does not imply a general right to remain in ignorance, contrary to what seems to have been the received opinion. This is so, since it may be morally permitted to remain in ignorance, and at the same time morally permitted for others to see to it that one knows. That is, not knowing may be an option without any negative right.

A point of departure for the arguments to follow is that a duty to have genetic information about oneself is incompatible with the right not to know about this information: "if someone has an obligation to pursue genetic knowledge, she has no right to preserve her genetic ignorance" (Rhodes, 1998, p 15).[19] This is true in one sense of rights, but false in another. If one talks about rights in the sense of options, the right not to know is equivalent to it being morally permissible not to know, i.e. a person does not do anything wrong if she does not know. In this sense of right, the duty to know is incompatible with the right not to know, since the duty to know claims that it is wrong not to no, which the claim that it is an option not to know denies. However, the duty to know is not incompatible with rights not to know in the

---

[17] See e.g. Harris & Keywood, 2001, p 421, when discussing the right to ignorance of genetic information: "Ignorance of crucial information is inimical to autonomy in a way that other autonomy-limiting choices are not. For where the individual is ignorant of information that bears upon rational life choices she is not in a position to be self-governing." See Laurie, 1999, p 127, Ost, 1984, p 302-303, and Rhodes, 1998, p 17 for similar statements.

[18] In the following, "the duty to know" will be shorthand for "a person's duty to know about her genetic constitution, at least if that knowledge is relevant to important decisions". This, of course, does not imply that a person has to know everything there is to know about her genetic constitution, but only the relevant facts. "To have genetic information" is in this context taken as equivalent to "to know about one's genetic constitution".

[19] See Ost, 1984, p 37, and Häyry and Takala, 2001, p 404, for similar remarks. This is quite compatible with the claim that an absence of that duty does not imply a right not to know, as we just saw.

sense of positive and negative rights. This is so since it may be wrong not to know, and still wrong of others to see to it that one knows (there are moral reasons that others should not prevent one from being ignorant, i.e. a negative right) or wrong of others not to help one to remain ignorant (i.e. a positive right). This is so, even if it may strike one as odd that one does something wrong if one gives someone else knowledge that this someone else is obliged to have. So, a duty for P to know about genetic information about herself does not *imply* a duty, or even a right, for someone else to give P that information. There may be good moral reasons not to disclose such information to a party who nevertheless is obliged to have that information (see V.3.2). So in order for the argument in favour of a duty to know from denying the right not to know to be successful, rights must be interpreted as options. That is, what has to be argued is that it is wrong not to know or, at least, strong moral reasons for this being the case.

On the other hand, it may seem reasonable to claim that the right not to know genetic information about oneself implies that other persons do not have a right to disclose such information to the person (Rhodes, 1998, p 15).[20] However, once again, this is so only given a certain interpretation of the right not to know, namely as a negative right. Only then is it wrong of someone else to disclose the information to the person in question (and they thus have no right to do so), at least in the absence of overriding reasons to the contrary. If the right not to know is only an option, there are no implications of the rights of others. These remarks on the relationship between duties and rights should suffice for the following discussion to get of the ground.

First, a brief reminder. This discussion is essentially about "duty" and "right" understood morally, and not legally. There may be all sorts of reasons to regulate the practice of genetic testing in various ways, including rules of thumb that do not necessarily guarantee that the moral rights or duties of people are upheld. However, I will not enter such a debate. As mentioned earlier, I assume that a successful argument in favour of negative and positive rights makes a strong case for various regulations. However, the same assumption seems less reasonable when it comes to options, which then is the

---

[20] Rhodes writes: "When someone has a right to genetic ignorance, others have a responsibility to allow her that ignorance and to respect her choice not to know." (Rhodes, 1998, p 15) However, this is only so if the right not to know is a negative right. So here Rhodes, confusingly enough, changes the interpretation of a right not to know from an option to a negative right without explicitly stating this.

object of concern in this section, since it seems more difficult to argue that society should implement regulations preventing people from every type of moral wrongdoing.

3.1 Kantian arguments of autonomy

There are, in fact, a number of different Kantian arguments for the duty to know. Nevertheless, they have sufficiently much in common to deserve treatment under the same heading. They are all, in one way or another, founded on the Kantian idea of a duty to be autonomous – a duty to govern oneself (Kant, 1785, p 14-20). Of course, generally put like this, the idea is open to several, mutually incompatible, interpretations.

The interpretation that probably is most congenial to the intentions of Kant himself is that we have a duty to act out of reverence for the moral law. That is, we should act out of "pure" (morally praiseworthy) motives. The idea might seem obsolete, but it has been suggested (Rhodes, 2000, p 114).[21] This interpretation will therefore be addressed in due course (see V.3.1.2). I will concentrate on two authors that have explicitly defended the duty to know from Kantian ideas of autonomy, namely Ost and Rhodes.[22] However, I will also address authors that refer to the argument that choosing not to know is incompatible with one's autonomy (Harris & Keywood, 2001). I will argue that this is a mistake.

As mentioned earlier, the duty to know is assumed to hold only when the information is "relevant" to some decision (Rhodes, 1998, p 18). This is certainly unclear, but let us for now take it to mean that relevant information is information that would make the decision maker change or at least reconsider her decision.[23] If one takes "relevant" information for decision-making as information that *should* influence decision makers to change or reconsider the decision (see Rhodes, 1998, p 18; Ost, 1984, p 306 about reasoning referring to what the rational person would want to know), the claim becomes close to being tautological: we should have (have a duty to have) the information that

---

[21] Rhodes writes: "To summarize my position, the Kantian concept of autonomy expresses the core content of an individual's moral obligation, the duty to determine one's own action by the moral law." (Rhodes, 2000, p 114)

[22] It should be noted that both these authors emphasise that this is compatible with a policy that does not enforce unwanted information upon patients and clients.

[23] See also, Rhodes, 2000, p 115, where Rhodes instead uses the term "serious information" as information that is "likely to make a significant difference in decision".

we should have. No one is denying that. Indeed, the very question at stake is what information we do have a duty to attain.

The mentioned authors can be interpreted differently, but they do share one basic line of thought. Somewhat coarsely, it could be put as follows. Each one of us has a duty to be autonomous. In order to be autonomous (in a situation) one has to be a rational decision maker (in that situation). In order to be a rational decision maker one has to have or obtain information that is relevant for the decision. Genetic information may be relevant for a decision. If the situation of decision is such that genetic information is relevant to the decision, one is irrational if one refuses to take part of that information. One therefore fails to be autonomous and hence does not fulfil one's duty to be so. Thus, autonomy is the basis or foundation for the duty to know and can therefore not be used to establish a right not to know (in the sense of an option, an addition I will implicitly assume from now on).

In order to establish this line of reasoning as plausible, several things must be clarified. To start with, it has to be explicated what kind of duty we are dealing with in this context. Is the duty to be autonomous a duty towards others or a duty towards oneself? The general line of reasoning can be interpreted in both ways. In fact, Ost is quite explicit about defending the "duty towards oneself"-interpretation (Ost, 1984, p 307-309),[24] while Rhodes, if not as explicitly, is most naturally interpreted as taking the "duty towards other"-stance. Let us begin with the former.

3.1.1 A duty towards oneself

Omitting to receive genetic information relevant to a decision is, then, argued to be an omission to fulfil a duty one has towards oneself. How should this be understood? Ost seems to argue in the following way. We have rights and duties[25] by virtue of being autonomous. In other words, autonomy is the foundation of rights and duties.[26] In order to make an autonomous decision, one has to be rational. To refuse to receive information relevant to decision is to be irrational. One is therefore not autonomous (autonomy requires

---

[24] See e.g. "that there is a duty to oneself... seems on its face, implausible at best. I hope to make it more plausible." (Ost, 1984, p 307)

[25] Or are the "bearers" of rights and duties (Ost, 1984, p 303).

[26] "[W]e use the concept of autonomy to designate a moral status which justifies the predication of rights and duties." (Ost, 1984, p 309)

rationality) and can therefore not have rights (rights requires autonomy), including the right not to receive the information (Ost, 1984, p 309).[27]

This all sounds very strange. To begin with, if autonomy is the foundation for rights *and* duties, and failure to be autonomous destroys rights, failure to be autonomous should also destroy duties (including the duty to know). To this the answer probably would be the following. If one *can* be autonomous, one should be (has a duty to be) autonomous. If one fails to be autonomous when one can be so, one has forfeited one's rights. The general duty to be autonomous cannot, however, be forfeited.

But even if one accept this, many of the premises are unclear and, upon closer examination, not very credible. Of course, it is very controversial whether or not it is by virtue of being autonomous that we have rights and duties.[28] In order to determine the plausibility of that statement, we firstly have to have an analysis of autonomy. There is one interpretation of autonomy that makes the idea that we have moral obligations (or duties) only if we are autonomous plausible, namely if we take "autonomy" to mean the same as "able to make intentional decisions". If an individual cannot make an intentional decision in a situation she can hardly be praise- or blameworthy for the action. She cannot be said to be acting at all, in fact. However, this cannot be how autonomy should be interpreted in this context. This is the case, since we cannot have a duty to be autonomous, unless we have the ability to make intentional decisions.[29]

More importantly, it is by no means self-evident that only autonomous individuals have rights. No matter how generous an interpretation of autonomy one makes (being able to decide intentionally being at the most generous end), there are plenty of sensible moral theories that ascribes rights to beings who are not autonomous in this sense (at least derived rights). Even if one finds it hard to accept the claims of environmental philosophers, who claim that species or ecosystems have moral status and therefore rights, or animal-rights spokesmen, there is hedonism, according to which all sentient beings (whether they are autonomous or not) have moral status. If it is possible

---

[27] "If autonomy includes rationality, then one's efforts to act irrationally are violations of one's autonomy. If one's refusal of information is irrational, then this refusal is a violation of the mandatory character of autonomy... Thus, we can say that... receiving information about one's diagnosis, alternative treatments, etc., is both a right *and* a duty." (Ost, 1984, p 309)

[28] To this we get no argument from Ost, but only a reference to Kant (Ost, 1984, p 303).

[29] It is also obvious that Ost's discussion is about people with this ability.

to derive norms from values (which many philosophers of a consequentialist bent of mind tend to think it is) it is not implausible for a hedonistic utilitarian to ascribe non-autonomous but sentient animals, e.g., the right not to be arbitrarily tormented. It takes substantial moral arguments in order to establish that all theories that ascribe rights to some non-autonomous being(s) are implausible. To my knowledge, this has not been done yet.

Another way of defending that only autonomous beings have rights is to interpret "right" in an unusual (and unusually narrow) way, making it a matter of definition that only autonomous beings have rights. However, linguistic usage does not warrant any normative conclusions, since this move leaves it completely open for strong moral reasons that are not based on rights. For example, we may have a strong reason not to torment sentient beings, although they are not right-holders in the peculiar sense just stipulated.

Until someone has established that all theories that grant rights to (some) non-autonomous beings are implausible, let us leave the idea that autonomy is the only foundation of rights and duties. Let us instead rephrase the argument to render it more (at least prima facie) plausible. Most normal adults have the ability to act autonomously. In order to be autonomous, or make an autonomous decision, in a certain situation, one has to make a rational decision (in that situation). In order to make a rational decision in a situation one needs information relevant to the decision. To refuse to receive such relevant information is to choose to be irrational and, thus, not autonomous. It is wrong (towards oneself) to choose not to be autonomous. Therefore, no one has the right not to receive the relevant information. Therefore, everyone has a duty to receive the relevant information.

Perhaps a general note on relevant information is appropriate in this context. There can hardly be a general duty to try to get *all* information relevant to a decision before acting. This duty would make acting downright impossible, since we can always search for more information relevant to a decision. So the claim must be that one has a general duty not to refuse to receive knowledge one knows is relevant. This can be a general duty, and the examples I will discuss will not presume that the claim of a general duty to know presumes anything more. However, I will argue that even this can be compatible with Kantian ethics and/or autonomy.

The crucial concepts in this line of reasoning are, of course, autonomy and rationality. We still need an account of these concepts in order to assess the

validity of the argument. Since the defenders of the duty to know take Kant as their point of departure, the most natural way of doing justice to them seems to be to go to Kant's use of these concepts.

If we want a full account for these concepts, we would have to take the totality of the philosophy of Kant into account. That would take (at least) a book of its own and that book is not this one. Fortunately enough, we do not have to do this. It is enough with a rudimentary understanding of the concepts of autonomy and rationality of Kant in order to see that they cannot be used in any straightforward manner as a foundation of the duty to know.

As we already have seen, morally praiseworthy action and autonomous action is intimately connected in the ethics of Kant (see III.2.2.1). Furthermore, practical rationality[30] is intimately connected with autonomy (they can even be said to be identical). According to Kant, to act rationally is to act with the moral law as an end, or out of reverence for the moral law, that is to act on the maxim through which you can at the same time will that it should become a universal law (Kant, 1785, p 52). In other words, to act rationally is to act autonomously, and to act autonomously is to act morally praiseworthy. Let us for a moment forget the earlier scepticism towards the connection between moral praiseworthiness and autonomous action (see III.2.2.1). There may still be more particular duties (towards oneself) that are defensible on the basis Kant's ideas, such as the duty to know.

Ethical duty of commission?

According to Kant, we have a duty to strive towards our own perfection. This is a duty of commission (or an imperfect duty) that we owe to ourselves. That is, it is a duty to ourselves that we do not have to act on in every situation. Furthermore, it is a duty of virtue or an ethical duty. That is, it is a duty to have a certain end, not a duty to do certain (types of) actions, even if the duty to have an end can sometimes imply the duty to act in some specific ways.[31]

The duty to promote one's own perfection is the duty to develop one's talents. Kant tries to show that it is a contradiction in the will not to have this end (and therefore it is a duty to have it). For this argument, he uses two

---

[30] Kant makes a distinction between pure and practical rationality. In order to cut a very long story very short: practical rationality, as opposed to pure rationality, is about decision-making and action.

[31] See Kant, 1797, 6:379-6:413 for the classification of duties and 6:444-6:447 for the duty to increase one's natural perfection.

assumptions: (i) people have ends, (ii) if people have ends, they must want some necessary and sufficient mean to accomplish this end (if they are rational). The argument, then, is that in order to accomplish one's ends (whatever they may be) one needs abilities and talents. Since this is a necessary means, one must want to develop such abilities and talents. Otherwise, one has contradictory wants (given the assumptions).[32]

This argument can of course be questioned on several grounds.[33] However, let us assume that it is valid. Does it then follow that we have a duty to know genetic information about ourselves when such information is relevant to decision-making?

No, it does not. First, the argument only shows that we should have certain abilities and talents in general (those we need to accomplish our ends), not that we are obliged to have certain information in certain situations. Second, and more importantly, the argument rests on the assumption that we should have (or want) the necessary means to accomplish the ends we actually have. The rationality in question then becomes nothing but classic instrumental rationality: to be rational is to act as to (try to) realize the goals one has in an efficient manner. In that case, it depends on the situation whether increased knowledge generally, or genetic knowledge about oneself particularly, leads to the effective realization of one's goal. More specifically, it depends on what goal one has and on the means required to reach it. As we have seen (e.g. in II.2.3.2), it is far from obvious that acquiring genetic information about oneself would always be conducive to the realization of one's desires.

Ethical duty of omission?

My line of reasoning might lead to the following complaint. I triggered the argument against the possibility of arguing for a duty to know by supposing that the duty to know is an ethical duty of commission. As mentioned, such an ethical duty is the duty to have certain ends.[34] According to Kant, it is in the nature of these duties that you cannot, or at least should not try to fulfil them

---

32 This is a recapitulation of Nell's treatment of the argument. See Nell, 1975, p 88-90.

33 One obvious way is to question assumption (ii) on the basis of Humean psychology.

34 Except for the duty to oneself, to strive towards one's own perfection, Kant emphasises one more ethical duty: the duty to strive for the happiness of others (Kant, 1797, 6:398).

in every situation.[35] The duty is to *internalise* these ends as personal *policies*. *How* and *when* we should (try to) *act* on them is not derivable from the duties themselves.[36] It is therefore futile to use the notion of ethical duties of commission in order to found or derive more particular duties, such as the duty to know.

Instead, one should concentrate on ethical duties of omission. These are particular actions that follow from (or are necessary means to fulfil) our obligatory ends (Nell, 1975, p 54, 92). For instance, Kant argued that the prohibition against suicide is an ethical duty, since suicide would destroy the necessary material precondition for striving towards one's own perfection and the happiness of others. He also argued that drunkenness, gluttony and several other "classical" sins are prohibited by being ethical duties of omission (Kant, 1797, 6:421-6:428). Maybe a similar prohibition against refusing to seek out genetic information relevant to a decision can be argued to be an ethical duty of omission as well?

Unfortunately, this will not do either. Despite Kant's own alleged conclusions, it is hard to derive specific duties of action from the obligatory ends. It is an empirical matter which acts are needed in order to be able to strive towards (and accomplish) these ends (Nell, 1975, p 92). Of course, if you are drunk all the time, it will be difficult to strive towards your own perfection (develop your talents). So, maybe it is reasonable to argue for a duty to avoid becoming a drunkard on the basis of this obligatory end. But since the ethical duties of omission are grounded on the ethical duties of commission and the ethical duties of commission cut us some slack regarding their demands, it is not clear how and when we should abstain from drinking. Getting drunk every once in a while does not seem to be incompatible with adopting the general policy to strive towards one's own perfection and the happiness of others.

The same goes for the duty to know. Of course, if you never have any relevant information regarding decisions you make, you are highly unlikely to accomplish anything you strive for. But maintaining some degree of ignorance seems perfectly compatible with striving towards both your own ends and your own perfection. As we shall see soon, relevant information could even

---

[35] One reason for this is that they may conflict with each other (such as the to duties mentioned in the previous footnote). Another reason is that they might conflict with duties of justice or legal duties (such as the duty not to lie, which, of course, may conflict with the duty to help others).

[36] To some extent sometime is the minimum, of course.

work against accomplishing your ends. So there cannot be a general duty *towards yourself* to know, based on Kant's ethics.

Against this, one may hold that the most important duty according to Kant is to be worthy or act morally praiseworthy (out of pure motives). As we have seen, Kant equates moral praiseworthiness with autonomy. As has been claimed above (III.2.2.1), and as will be further elaborated below (see V.3.1.2), there are reasons to doubt the fruitfulness and plausibility of that equation. But even if one believes in this equation, it is difficult to see the duty to act out of pure motives as a duty one has to oneself. If it is a duty, it is a duty, period. Let us therefore leave the equation of worthiness and autonomy for now.

Against a duty towards oneself: Two examples

Let us instead elaborate further on the Kantian idea of the duty to strive towards one's own perfection. One purpose with such striving, as we saw, is that it is a means to accomplish our ends. In this regard, this duty (according to Kant, derived from the moral law and thus our autonomy) is very much alike the conception of autonomy presented and defended in chapter III above. In order to accomplish what you want you need capacities. You need the competence to make decisions and the means to realize your goals through acting on these decisions. Genetic information may be and may not be favourable for the development and upholding of these capacities. A few examples will demonstrate these points.

Jolene.[37] Jolene is a writer. Several of Jolene's female relatives on her mother's side, including her mother, have contracted breast cancer in their adult years. Therefore Jolene's sister took part in a genetic study, which established that she was a carrier of the mutation BRCA1 (see I.4.1). As a result, Jolene's sister decided to go through with a prophylactic operation, removing her breast tissue. The operation was successful and Jolene's sister seems satisfied with her life. When the study was done, Jolene was asked to test herself. Jolene declined. Seeing her sister being satisfied with her situation, she knows that if she were to test herself and the test showed she was a carrier too, she would also go through with the operation. However, she knows that she has a predisposition for depression. She became deeply depressed in her adolescence, when her mother fell sick with breast cancer. She then became

[37] This example was also discussed in II.2.3.2.

unable to live an active life for several years. She therefore considers herself to have good grounds for believing that a test that would show her to be a carrier of the gene would make her equally, if not more, depressed. She is on the verge of finishing her great novel. This project she considers to be her most important life project. She therefore declines the test in order to be able to realize one of her basic aims in life. Does she still have a duty (to herself) to know about her genetic susceptibility to breast cancer?

John. John is part of a family that is plagued by Huntington's disease. Many of John's relatives have tested themselves presymptomatically. Some of the tests were positive (indicating the tested to be a carrier) and some were negative. He is a stern bachelor and does not intend to have any children. However, he is facing an important crossroad in his life. He is ambivalent. On the one hand, he can stay on his present unqualified job, which he enjoys well enough, and spend more time on his hobby as an ornithologist. On the other hand, he can enter a lengthy education that hopefully will end in a job as a business lawyer. He knows that if he were to test himself for Huntington's and the result came out positive, he would not bother to invest time in lengthy education, since he could only practice the job for a few years to follow. However, he has decided not to take the test. He just does not want to know what the future holds for him regarding his health. Does he still have a duty to know about having or not having a genetic susceptibility to Huntington's disease?

In both these examples, genetic information is relevant in the sense that it would influence the decision-making of the persons. Also, in both examples the interests of others are supposed to be irrelevant. One difference between the two cases is that the avoidance of the genetic information is motivated differently. In the case of Jolene, the motivation is that genetic information would (probably) be an obstacle in the realization of the end she finds most important. In the case of John, the motivation is the avoidance of genetic information.

There are thus two ways in which genetic information relevant to a person's decision-making can decrease that person's autonomy. Firstly, genetic information can get in the way of realizing one's other ends. Secondly, avoiding genetic information can be an end. In both these types of situations, the acquisition of genetic information would decrease the degree to which the person leads her life according to her own basic desires.

In the case of Jolene, she could of course be mistaken about her own reaction. A positive result might not cause a depression. She might be as content as her sister. But then again, she might not. I do not wish to claim that we are the greatest experts on ourselves as individuals. But we tend to have some idea on how we will react to various circumstances, especially if we have experienced them before. And just as things might not be as bad as she thinks, they may be worse. She might be paralysed also by a negative result, feeling "survivor's guilt" towards her mother. Of course, she might also become sick before finishing the book and unable to fulfil her dream because of that. She has no guarantees, whatever she does. But she has good *enough* reasons to believe (we may assume) that she will be able to finish the book before symptoms emerge and that she would become too depressed to finish it if she were to know that she was a carrier.

How can she then have a duty to herself to know? It would (probably) decrease her autonomy. It would (probably) make her miserable. Even if we cannot infer from this that she has a right not to know, there does not seem to be anything that speaks in favour of saying that she has a duty to know.[38]

In the case of John, he could of course come to realize his other plans to a lesser degree because of his ignorance. He might opt for the education and find that the symptoms of Huntington's starts to emerge before he completes it. Then it might be true that he would have lived a more autonomous life in the sense of self-realization (see III.3.1.1) if he had taken the test and stayed on his old job. In other words, there are reasons of autonomy that speak in favour of testing. On the other hand, there are reasons of autonomy that speak against testing. He does not want to test himself. He wants to stay ignorant about his future health status. In order to find out what he ought to do, focusing on autonomy only, it boils down to what he wants the most and which of his desires are most authentic. It may very well be the case that the balance tips in favour of not knowing. Then it would be strange to say that autonomy is the foundation for his alleged duty to know.

For both Jolene and John, genetic knowledge can be a valuable instrument. It may help them to lead more autonomous lives and increase their respective capacity for doing this. But, then again, it might not. This is why Rhodes is

---

[38] To this Rhodes may agree, since the information cannot "be obtained at a reasonable cost", 2000, p 115 (which seems to be a prerequisite for the duty). However, this reservation will make the thesis of the duty to know either trivial (if it means that the duty only holds when the moral benefits of getting the information outweighs the moral costs) or in need of further defence.

wrong to conclude that autonomy always is a basis for the right to know and never to a right not to know (1998, p 17-18). She is right to insist that autonomy is the basis for informed consent, since information about e.g. treatment may be relevant to the individual's assessment of the treatment and the information thus "allows others to make choices according to their own light" (1998, p 17). She is wrong, however, to conclude from this that more relevant information always increases a person's ability to make choices and live according to her own lights, i.e. always increases the autonomy of the person. As the examples shows, even obviously relevant information can decrease the person's possibilities to live her life according to her own standards.

The same point can also be used to refute the claim that "absence of crucial information is inimical to self government, to the ability to control one's destiny, and hence inimical to autonomy." (Harris & Keywood, 2001, p 421) These writers makes a distinction between "autonomously chosen restrictions on autonomy which are consistent with autonomy understood as an ethical principle and such choices which are inconsistent with autonomy" (Harris & Keywood, 2001, p 419) calling choices of the second kind choices that are inimical to autonomy (Harris & Keywood, 2001, p 418).[39] They are thus claiming that choosing to decline crucial information[40] is *incompatible* with autonomy. They elaborate this claim:

> If I lack information, for example about how long my life is likely to continue I cannot make rational plans for the rest of my life. If I do not know that my life is only likely to last five more years, rather than say twenty five more, many of my priorities will be inappropriate and some will be self-defeating. Of course it is not necessarily irrational not to want to know one's probable life expectancy and many would prepared to forego autonomy rather than face the knowledge of a looming premature death. *However they cannot defend the wish to remain ignorant of a fact like that in the name of autonomy.* (Harris & Keywood, 2001, p 421. My italics)

---

[39] For instance, according to Harris & Keywood, 2001, the choice to sell oneself as a slave is inimical, whereas the autonomous choice to commit suicide is not (p 420).

[40] With which they mean relevant information in the sense defined above (V.3.1), see Harris & Keywood, 2001, p 421-422.

However, the conclusion (in italics) of this line of reasoning is surely flawed,[41] especially given their own characterisation of autonomy (which is very similar to mine): "[A]utonomy... [is] the ability and the freedom to make the choices that shape our lives in accordance with our own conceptions of what that shape should be." (Harris & Keywood, 2001, p 420) Obviously, this makes autonomy a matter of degree: one more or less has the ability and freedom to thus shape one's life. Then it should be equally obvious that genetic information, even such information that is crucial for decision-making, can both promote and damage autonomy, depending on the person and situation. I have just adumbrated two cases in which it is plausible to assume that crucial genetic information about the persons in question can damage their autonomy. And as we have seen in previous chapters, there is no guarantee that (genetic) information is conducive to autonomy; in fact, it might be the other way around (see e.g. II.2.3.2).[42] However tempting it might be to say that certain kinds of choices always promotes or damages one's autonomy, one should resist the urge to give in to such simplifications, in the light of the multitude of factors that can influence the autonomy of a person.

3.1.2 A duty to do one's (Kantian) duty

The equation of autonomy and worthiness

We have touched upon the Kantian idea of autonomy as worthy (or meritorious or morally praiseworthy) action several times (see e.g. III.2.2.1). This "orthodox" reading of Kant lurks in the background of some arguments for a duty to know. In fact, Rhodes has been quite explicit about it: "the Kantian conception of autonomy expresses the core content of an individual's moral obligation, the duty to determine one's own actions by the moral law" (2000, p 114). Let us call this idea the equation of autonomy and worthiness.

In Kant's writings, this idea rests heavily on his dualistic metaphysics. It also concerns the "free will"-debate. This is also the source of the problem with the equation of autonomy and worthiness: it makes the notion of "free" and

---

41 As is the first premise (at least on most standard accounts on rational plans), since I can make rational plans despite ignorance of my length of life, by assigning probabilities and values to each possibility and acting accordingly.

42 Takala, probably has this point in mind when writing: "Maybe those who want to uphold the right not to be informed simply know themselves well enough not to seek possibly disastrous knowledge. Being in control of one's life can then require some degree of self-chosen ignorance." (Takala, 2001, p 487) This point is validated by examples such as Jolene's.

"right" collapse into each other.[43] An idea with that implication ought to be abandoned, or so I will argue. Therefore, no argument resting on the equation of autonomy and worthiness can be successful, whatever it tries to establish (including the duty to know).

Before I argue this last point, let me recapitulate "the Kantian conception of autonomy" referred to by Rhodes. According to Kant, we are all part of the "natural" or *phenomenal* world. The laws of nature, which we are unable to change or break, govern this world. Everything that happens in the natural world is the necessary effect of the previous state in the world in conjunction with the laws of nature. That is, everything that happens in the natural world is causally determined, that is, Kant defends determinism regarding the natural world. A consequence of this is that to the extent that our actions are a result of what happens in the natural world (of which we are a part) they are determined. That is, given what has happened previously (which *is* given in the natural world) we could not have done anything else than what we in fact did.[44]

Since Kant formulated and believed in the dictum "'ought' implies 'can'", he believed that if we always are determined, that is, it is always true that we could not have done anything else than we actually did, then it cannot be true that we ought to do anything else than what we in fact do. But our moral discourse seems to presuppose that we could have acted differently than we in fact do. Otherwise blame and merit are pointless, Kant argues. That is, morality presupposes something that is incompatible with determinism.

Moreover, Kant realizes that indeterminism will not save "free will". To act freely is instead to act *autonomously* – to legislate oneself as opposed to being ruled by "external" and non-controlled internal factors. It is only in virtue of having the ability to reason that we have the ability to legislate ourselves. The dualism of Kant now rises to the surface. There is a world of phenomenon and a *noumenal* world that, so to speak, lies behind the world of phenomenon. We come into contact with this noumenal world through our reason. There are thus two kinds of motives behind our actions, the "empirical" motives

---

[43] This formulation might be misleading, since Kant is careful to distinguish between the theory of right (to act in accordance with the moral law, regardless of motive) and a theory of worth (to act out of (reverence for) the moral law).

[44] This last inference can, of course, can be questioned. See, for instance, Tännsjö, 1998b, chap. 10.

(wishes that are the effects of causes) and the "pure" motives (principled motives according to the moral law). When we act according to an empirical motive, we are part of the phenomenal world and, thus, determined. Thereby, we are only autonomous (free) when we act according to reason and legislate ourselves in accordance with the law of practical reason – the categorical imperative.[45]

To state the same reasoning in a more modern language: there is only one way to not be determined by previous causes – to govern ones' actions with reasons. This is the only way to acquire the capacity to choose among alternatives. In order for the reasons to really be reasons, and not just rationalizations of causes, they must be *reasonable* (or in accordance with the laws of reason). Conclusion: only when we are governed by reason, we are autonomous, and only when we are governed by reason we act morally. The law of freedom is thus identical to the moral law: the categorical imperative. It is important to emphasize that it is not enough to act in accordance with reason to be autonomous. We must act *out of* our reason(s) (out of "reverence for the law"), since it is our motive and not the behaviour itself that determines whether we are free or not.

Now we have a fuller understanding of Kant's equation of autonomy and worthiness. Therefore, we also are in a better position to see its shortcomings. If we equate autonomy and worthiness, we cannot autonomously act in a non-worthy or unworthy way.[46] That is, if autonomous, we cannot ever be blameworthy. The view that evil men are not acting out of free will is very humanistic. But it is very hard to believe in. Why should the very possibility of principled evil, i.e. autonomous action out of blameworthy motives, be excluded? Intuitively, it seems perfectly possible to legislate oneself according to morally abhorrent principles, such as sadistic, revengeful or mean ones (see III.2.2.1). An idea that excludes this possibility certainly carries a heavy burden of proof. And to refer to the foundation on a dualistic world-view of a noumenal and a phenomenal world as a further defence will not convince modern readers.

The following could be retorted. Kant surely recognized principled evil. Of course, our empirical motives are (by definition) determined. We do not

---

[45] I take it to be so that what I have said so far about Kant in this subsection is a fairly uncontroversial reading of the third part of Kant, 1785.

[46] However, Kant did not seem to think that this was so. See Nell, 1975, p 56.

choose them. But we choose whether or not we should act in accordance with them. We are not determined to act either in compliance with the preceding causes or with reason (then we would be determined nevertheless). Rather, we can sometimes overcome our natural inclinations and choose according to what we (think we) should do. When we *can* do that and do not, in fact, do that, we are blameworthy. We choose to not govern ourselves in accordance with the moral law.

However, if this is how we should understand Kant, the equation of autonomy and worthiness no longer holds. Autonomy is then not a prerequisite for choosing the worthy, but rather about the ability to choose either to do the worthy thing or to follow one's inclinations: there is a choice between what motives to act from, empirical or "pure" ones. We can, then, freely (autonomously) choose to act on our empirical motives or act on the morally praiseworthy ones. To be sure, if one accepts the ethics of Kant, it would be wrong not to act on the morally praiseworthy motives. But this conception of moral praiseworthiness is no longer identical to the conception of autonomy (although it still presupposes the possibility of choosing, since 'ought' still implies 'can'). So the problem with being ignorant cannot directly be that it is incompatible with remaining autonomous. Instead, one would have to argue that intentionally chosen ignorance on genetic information when this information is relevant to a decision is *immoral*. Given a Kantian basis of such a claim, one then would have to argue that such ignorance is in conflict with the categorical imperative.

The categorical imperative

Is it or is it not, then, in accordance with the categorical imperative to choose not to find out genetic information relevant to a decision? This question can be discussed at some length, not least since there is an enormous debate on how the categorical imperative should be understood. I will dodge some of these questions. As a point of departure, I will use the first and most famous formulation, *the Formula of Universal Law* (FUL): "Act only on that maxim through which you can at the same time will that it should become a universal law." (Kant, 1785, p 52)[47]

[47] Since this is the principle bidding for all rational beings regardless of goals or intentions, other formulations of the principles are just reformulations that put emphasis on other aspects on the categorical imperative (like the Formula of an End in Itself, p 66-67, and the Formula of the Kingdom of Ends, p 76) or derivations (like the Formula of the Law of Nature, p 52, or the

FUL is, then, a way of testing maxims. If the maxim is universalizable, to act on it is morally permissible. If, at the same time, a maxim prescribing the omission of this act is not universalizable, the action is obligatory (or a duty): it is not permissible to abstain from that action. If the maxim is not universalizable, to act on it is forbidden.[48] What, then, is a maxim? Kant defines it as a "subjective principle of action" (1785, p 51), that is, the actual principle, intention, or motive of the action.[49] It is a principle in the sense that it can be acted upon repeatedly, in different concrete ways, and in different circumstances (like the maxim "go to the store around the corner to buy some milk"). It is subjective in the way that it is the *actual* motive or principle of the agent acting on it. A maxim is also practical, that is, saying something about what actions to perform. A maxim thus is a practical principle an agent has (acts on) at a certain time, and can act on several times.

Which maxims, then, ought to be subjected to the test of the categorical imperative? "All maxims", seems to be the only answer if one should stay true to Kant's own formulations. But this is not obviously so. There are two schools here, with different ideas. On the one hand, we have the idea that the maxims are specific intentions regarding specific decisions in concrete situations. This is the narrow view. On the other hand, we have the idea that maxims are general principles a person is committed to, that is, the basis for her more specific intentions.[50] This is the broad view.

Fortunately enough, the subject matter we are currently investigating helps to limit the number of interpretation we need to deal with. The discussion is about something so specific as the duty to know about genetic information about oneself. Broad theories cannot help us here, since the purpose of these

---

Formula of Autonomy, p 70), Kant argues. This is, of course, controversial, but not something I will question here.

48 This is Nell's interpretation (Nell, 1975, p 73-74), which I will follow to a large extent. According to Nell, if a maxim and its omission both cannot be universalised (like e.g. "to sell tomatoes but not buy them"), the action(s) is (are) permissible (p 75-77).

49 This is also Nell's interpretation of Kant. It has the advantage of presenting a solution of the problem of relevant act descriptions (which description should be universalised): the actual intention of the individual is the maxim that should be universalizable. See Nell, 1975, chap. 2-3.

50 Brännmark, 2002, p 198-208, argues that the latter interpretation is the proper one if the purpose is to defend a reasonable version of Kantian ethics. To this question, I am neutral. However, I have used his terminology of "narrow" and "broad" maxims.

is to supply a moral framework (Brännmark, 2002, p 97).[51] Within these frames one has to use one's judgement in order to solve more particular issues (like the question of whether one should test oneself genetically or not). In order to acquire direct guidance on the duty to know, we thus have to turn to the narrow interpretation of maxims: it is the specific intention to do a specific act that must be universalizable if that act is to be morally permissible.

How should one universalise, according to the categorical imperative? Well, the important thing is that the maxim can be consistently universalizable at all, not whether we would want it to be universalised. This is what Kant means when he says that we are legislators – a person should be able to consistently hold the maxim she acts on, were it a universal law (of nature). Can the law be upheld? Is the action of the maxim possible if the law is a universal law? This is the question we should ask ourselves when applying the categorical imperative.

In order to determine whether a maxim is consistently universalizable, we must formulate a universalization of the maxim. This can be done by formulating the *universalised typified counterpart* (UTC) of the maxim in question. If a maxim schematically can be formulated as this: "To — if ..." (where "—" denotes some action and "..." denotes some circumstances), the UTC will be "Everybody to — if ...". For instance, the maxim "to lie if I think I can get away with it" has "Everybody lies if they think they can get away with it" as its UTC (Nell, 1975, p 61-63).

In order to get a contradiction when universalising a maxim in this manner, we need some background assumptions (Nell, 1975, p 70-74). For instance, we need certain empirical assumptions. Take Kant's classical example of breaking promises in order to avoid a financial predicament. Kantians who are sympathetic to Kant's attempt to show that this maxim cannot be consistently universalised has roughly argued along the following lines. If it became a universal law of nature to break promises when one is in a financial predicament, no one would trust promises made out in such situations. A presupposition for a promise to be possible (as a promise) is that the person you make the promise to takes the promise as a promise.[52] If it is a law of

[51] Even if one can argue that such a framework can generate certain constraints, e.g. against murdering and harming someone else (Brännmark, 2002, p 202).

[52] Let us take this conceptual claim for granted.

nature that everybody in a financial predicament who promises something breaks this promise, it is thus not possible to act on this maxim (you cannot make the promise). The maxim is therefore not consistently universalizable.[53]

However, this conclusion is too hasty. In order to reach this conclusion, we have to presuppose many facts about the world and us. One crucial empirical supposition is that people know that no one is honest when they make a promise in this kind of situation. This, furthermore, presupposes that people learn from their mistakes (Nell, 1975, p 66, 74). These suppositions may seem reasonable, but the categorical imperative is silent upon which empirical assumptions we are allowed to make. And a contradiction can be derived from any maxim whatsoever given the appropriate empirical assumptions. Given the empirical assumption that anyone who visits her old mother goes nuts with her nagging and kills her, one can derive a contradiction from the maxim "Go to visit your old mother every Sunday". This would be impossible, since there soon would be no old mothers to visit.[54]

The solution lies in the same spirit as the solution to the problem of relevant act description, where it is the intention that the agent in fact has that should be universalised. A maxim or an intention can only be formulated against the background of some empirical assumptions. I cannot intend to rob a bank if I do not at the same time have a lot of beliefs, e.g. that there are banks, that they can be robbed, and other intentions, e.g. the intention to take out my pistol, the intention to get away with it. That is, when I formulate a maxim, I do it from some empirically necessary assumptions and I also presuppose some normal and foreseeable consequences. These are, then, part of my maxim and demarcate the empirical assumptions that make the derivation of the contradiction possible. For instance, a normal and foreseeable consequence of the UTC of "To rob a bank", that is, "Everybody robs a bank", is that there will very soon be no more banks. It is impossible to rob a bank if there are none, so the UTC of "to rob a bank" is contradictory.

What makes a consequence "normal and foreseeable"? The agent must realize that the consequence is a part of the maxim. The agent is an agent of

---

53 Or, rather, the action of promising becomes impossible. This reveals an ambiguity in the test. Is it the maxim or the action that should be impossible? For simplicity, I will presuppose that if any one them becomes impossible, the contradiction is established.

54 Further empirical assumptions, like that there are a finite numbers of old mothers, that no one could have an intention to do something they know to be impossible, and so on, would of course be needed.

this actual world, who assumes the ways of this actual world. Probably no one who intends to steal thinks that a copy of the stolen object will materialize itself directly after the theft, since she knows that it is not the way this world works. This is, then, an actual presupposition of the maxim and thereby a part of the system of intentions and beliefs we are allowed to refer to when determining whether the maxim is consistently universalizable.

This makes the moral status of an action extremely dependable on the presuppositions that are built into its maxim, and therefore the psyche, of the actor (Brännmark, 2002, p 185). And maxims in general are probably very sensitive to the specific situation of the agent, since agents are sensitive to the situations they are in. This is important to keep in mind in the following. If one believes are utterly strange and unusual, the maxims one acts upon may be universalizable, even if the action is considered deeply immoral by most people.[55] However, my point here is not to call into question the plausibility of the theory, but to see whether it can be used to found a duty to know.

Is it, then, in accordance with the categorical imperative to avoid finding out genetic information relevant to a decision? Well, as we just saw, that depends on the maxim of the agent. Let us try the maxim "To avoid finding out genetic information (about risk of future disease) relevant to a decision".[56] The UTC of this maxim is, then, "Everybody avoids finding out genetic information relevant to a decision." Is this consistent? Is it possible to act on the maxim if everyone were to do this? It is hard to see why that would not be possible.

To this, both Rhodes and Ost probably would object that their point was more general. I am including *genetic* information in the maxim. Is this really part of the maxim? In order to know whether a belief is part of a maxim one has to ask oneself if the maxim is dependent on the belief. Take the maxim "To steal a car if I am born in Stockholm, dark-haired, six feet tall, plays the clarinet and is named Juth." This maxim is universalizable. Obviously, it is so in virtue of being so specific. If it were a natural law that anyone with these characteristics stole cars, this would not pose any threat to the existence of cars in particular or a well ordered society in general. But is this really my maxim? Someone who claims to have maxims of this sort probably would not be believed to be

---

[55] Take the maxim "To torment an atheist in order to save the human race from extinction due to the wrath of god". This maxim seems to be universalizable.

[56] I take it for granted that the maxim-holder thinks that genetic information *may* be relevant to at least one of her decisions, since she would otherwise be very unlikely to have such a maxim.

honest. This since the maxim does not seem to be dependent on the characteristics: "Would you really refrain from stealing the car if you had dyed your hair green the same morning?" If one cannot truthfully answer yes to that question, the colour of the hair is probably not part of the maxim after all (Nell, 1975, p 71-72). Rather, it is a rationalization in order to render the maxim universalizable.

This line of reasoning may be thought applicable to the "genetic"-part of the maxim. Is it really essential to the maxim that the information is *genetic*? If it is not, the maxim rather is "To avoid finding out information relevant to a decision." The UTC to this is "Everyone avoids finding out information relevant to a decision." This looks far more difficult to universalise consistently. Any person needs information relevant to a decision in order to make one. Otherwise, it could be claimed, like flipping a coin, one leaves it up to chance what one does and this is not decision-making at all.

However, this is not convincing at all. From the fact that one does not find out or refuses to accept information relevant for a decision it cannot be derived that one has no information relevant to the decision-making. To be sure, any person at least has to *believe* some things in order to make a decision in a certain circumstance (see III.2.3.1). For instance, it is necessary to believe that there are alternatives of action one decides among. But it does not take very much *information* (if information is conceived as true believes, it actually takes none) in order for it to be *possible* to make a decision (remember the test of universalizability). I can make a decision on what to have for lunch (let us say that there is only two possibilities I take into account) without knowing anything about what I choose between (besides that they are different options of lunch) by flipping a coin and decide to go for whatever the coin shows (like heads for meal 1 and tails for meal 2).[57] If I make decisions in this manner, I will probably not be very successful in realizing my aims, but this is something else. There is a distinction between decision-making (and the capacity to make a decision) and efficient decision-making (and the capacity to realize one's aims through one's decisions and actions).

More importantly, it is highly unlikely that anyone acts on a maxim as coarse as "To avoid *any* information relevant to a decision". Most people already have information relevant to their decisions. The question is whether

[57] I will not pursue the terminological objection that this is not really a decision. Why would it not be?

or not they should find out more. Jolene (IV.3.1.1) is already aware of the nature of the disease the test is about. She also knows (or considers herself to have good reasons to believe) that she will be depressed if the test reveals that she is a carrier of BRCA1. John also is familiar with the disease he is testing himself for. John knows that a test result would not interfere with any reproductive plans he has (since he has none). And so on.

The typical situation of decision looks like Jolene's and John's; it is characterised by partial ignorance. Therefore, maxims will not typically be of the type "To not have any information of relevance to the decision". Since maxims are sensitive to the persons (due to the fact that they are different persons and that they are in different situations) the maxims will rather be of the following character "To avoid further information that is relevant to this and that decision in this and that way". These kinds of maxims are universalizable, since they are more specific. (Try some for yourself!)

Furthermore, since maxims are sensitive to differences in situations, it *may* be of relevance to them that the information is genetic. Of course, this may be due to the fact that one holds unrealistic beliefs about the nature of genetic information (see I.4.1 about genetic essentialism). But it may also be due to the fact that the genetic nature of the information is of significance to the reaction of oneself and others. One may become depressed as a result of a positive result. Then the maxim is something like: "Avoid to find out information if it most likely makes me depressed". Of course, this maxim is not about genetic information *per se*. But it is about genetic information in the situation when such information is the very information that most likely will make one depressed if acquired. Or one may have good reasons to believe that one will be isolated in a family where most of the living relatives are carrier if a test reveals that one is not a carrier. Then the maxim might be something like: "Avoid to find out genetic information about oneself if it may stigmatise me in the eyes of my family".

Examples such as these, of course, can be multiplied. But the point should be clear already at this stage. Since maxims may vary, there can be no *general* duty to know based on the categorical imperative, even if there *may* be situations where a maxim that contains the intention not to know is not universalizable. It depends on the maxim. And maxims depend on situations and persons.

So Kantian ethics, on a more careful reading of it, most likely cannot be used to argue in favour of a general obligation to know. The general lesson for

moral philosophy is that duties and worthiness in a Kantian setting are not so "square" as has been presupposed. Differences in situations may allow for exceptions to general rules, such as "Do not lie". However, if one wants ethics to be sensitive to the particulars of a situation, which has seemed reasonable to many, this should only be good news for Kantian ethics. Furthermore, it shows that very "principled" moral theories do not have to be insensitive to particulars of situations. And this is good news for moral theory in general.

3.2 Duties towards others: Arguments of non-harm

There are of course other ways of arguing for the duty to know. One obvious way is to claim that it is a duty towards others and, more precisely, a duty not to harm others. Such a duty may, of course, have a Kantian foundation (Brännmark, 20002, p 205). But principles of non-harm are not particularly Kantian. They may also be justified in a more consequentialistic framework.

The duty not to harm is usually separated from the duty to benefit others (Beauchamp and Childress, 2001, p 114), even if the limit between non-harm and beneficence is unclear. However, the duty not to harm is usually considered to consist in or found duties of omission, while the duty to benefit consists in or founds duties of commission (Beauchamp and Childress, 2001, p 115). One reason that the limit between non-harm and benefit is unclear is that this related distinction between actions and omissions is unclear and ethically controversial.

However, even if we were to overlook this problem, to use a principle of non-harm that founds duties of omission in order to justify a duty to know would be problematic, to say the least. This is so since finding out information about one's genetic constitution (or anything else) is certainly not an omission on any version of the acts/omissions distinction. Because of this, and since it is hard to draw a line between actions and omissions, I will understand the principle of non-harm in a way that may be considered unorthodox in biomedical ethics. To harm someone is to cause adverse consequences for someone through ones actions *or* omissions to do something that one could have done. "Adverse consequences" may also be what we normally would call absence of benefits. Furthermore, in this context, adverse consequences should be interpreted in terms of subjective well-being, i.e. in accordance with hedonistic and preferentialistic theories of value (see II.4.1.4). This means that

"harm" in this context will not include harming the autonomy of someone else.[58]

All this may give the impression that "non-harm" is to be equivaent to traditional utilitarianism. This is not so, however (see III.4.2). I wish to include a broader range of ideas, including such that attaches greater moral weght to inflicting harms than to producing benefits and theories that includes risks and possibilities in their ideas of right-making characteristics.

A prerequisite for any argument for a *duty* to know is that the harm that is to justify the duty is of a sufficient magnitude. How great the magnitude should be in order to be "sufficient" is, of course, far from clear. Howeve:, very marginal harm cannot be enough. You cannot claim a duty of someone else to refrain from harming you from the prick of a small injection if that injection is necessary for you to become immune from a very dangerous and contagious disease. The harm to you has to be bigger than that in order to justify a duty.

Can the duty not to harm someone else be used to argue for a duty to know? I think only a brief moment of thought is enough to see that a *general* duty to know in all (or most) circumstances cannot be grounded on a duty not to harm (or any reasonable non-harm principle, for that matter). A few examples should be enough to make this clear. The examples show that a person can harm someone else by *acquiring* genetic information rather than refraining from this.[59]

An obvious example of this is the case of purchasing life insurance after having gone through with a genetic test. The result of this test may render you uninsurable. Say that you are planning to buy a house for your family and you need a life insurance in order to get a mortgage for the house.[60] Then taking the test may make you uninsurable and therefore rob you of your chances of

---

[58] I have already discussed harming autonomy, and then argued that harm of autonomy can result from finding out genetic information (see e.g. V.3.1.1). And what holds for the divalue of the person tested holds for other persons as well, as we will see (chapter VI). So the nove of referring to harm in terms of autonomy is not open for anyone who wants to argue for a *general* duty to know. Besides, the points I will make about consequences in terms of well-being in this subsection can be reformulated to be about consequences in terms of autonomy.

[59] This book contains lot of such examples. See e.g. chapter II, passim.

[60] As has been the case in UK for some time (Sandberg, 1995, 1554).

buying the house.[61] This, in effect, does not only harm you, but also your family. Avoiding the information could thus have had less damaging effects.[62]

Another, perhaps more mundane, example is the following. Let us imagine woman who has Huntington's disease in her family. Let us assume that she herself is a carrier of the gene for Huntington's disease. If she were to test herself, she would find this out. She would then not be able to keep this from her husband. However, if he were to find this out, he would become depressed and thus unable to lead an active and enjoyable life. Instead, he would, with agonizing fear, wait for the day of the outbreak of disease. If she does not find out this information beforehand, he will be able to cope with the situation when she starts to show symptoms. It is waiting for a catastrophe he cannot manage. Thus, for the woman not to get the information at all would have less damaging effects with regard to her husband.

Of course, examples such as these can be multiplied. However, these two should be enough to establish that there is no *general* duty to know to be had from the duty not to harm people. Not only is it conceivable that not getting genetic information would not harm anyone, it is also conceivable, not to mention likely, that getting information may be more harmful to others than not getting it in certain situations. Therefore, the idea of a duty to know has to be modified.

One modification that would be true to the idea of non-harm would be to say that we have a duty to know when the omission to know would harm someone else. Of course, the duty would then not be a duty to know, but a duty not to harm. But if this duty can be shown to imply a duty to know in many and/or important cases, there may still be some warrant for sometimes talking of "a duty to know".

Despite her Kantianism, Rhodes has provided a string of examples where omissions to know are characterised by their potentially adverse consequences to others (1998, p 12-14). Furthermore, she claims that one only has a duty to know "when the information can be obtained at a reasonable cost" (2000, p 115). These are reasons that all fits consequentialism like a glove!

Since Rhodes continues by arguing for a duty to know (at least partially) in virtue of standing in certain relations to others (which makes the argument

---

[61] This is so at least if no or partial regulation is implemented (see VII.1), given certain other prerequisites (such as not having or having to renew your insurance and so on).

[62] This case is not only conceivable but also actually quite common. The fault may of course be with the system of insurance, but that is another question, to which we will return in chapter VII.

more Aristotelian than consequentialist),[63] Takala and Häyry, have outlined an explicitly consequentialistic way of dealing with the duty to know in a response to Rhodes' argument. Let us therefore extrapolate this argument and see how far it takes us. Let us furthermore start with Rhodes' own cases. They are neatly summed up by Takala and Häyry:

> Professor Rhodes' examples are the cases of Tom, Dick, Harry and Harriette (1998, pp. 12-14). Tom has to decide whether to participate in a population study which would provide scientists with a more accurate picture of Huntington's disease. Dick has been asked to take part in a linkage study to find out what his cousin Martha's chances are for having a child who does not suffer from Marphan syndrome. Harry, who has a strong family history of Huntington's disease, faces the choice of genetic testing because he is planning on marrying Sally and starting a family with her, although he may die young and pass on the disease to their children. And Harriette and her husband have decided not to find out if they are recessive carriers of the Tay-Sachs gene and to have a child despite the fact that the child's life can be short and full of agony. (Takala and Häyry, 2000, p 109)[64]

Let us begin with Tom. As Takala and Häyry points out, the duty for Tom to know does not follow from his alleged duty to participate in the study, since "the accumulation of scientific data does not require that he himself be informed" (2000, p 111). As will be argued later (VII.6.2), under some very special circumstances, Tom has a duty to participate. However, he has no duty to know. The same goes for Dick, who can participate in the linkage study without finding out what the result was regarding himself.

Let us move on to Harry. "Harry, who has a strong family history of Huntington's disease, faces the choice of genetic testing because he is planning on marrying Sally and starting a family with her, although he may die young and pass on the disease to their children." (Takala and Häyry, 2000, p 109) Does Harry have a duty to know?

---

[63] See VI.3.2.2 for a discussion of this idea.

[64] For a description of Huntington's disease, Marfan syndrome and Tay-Sachs, see I.1.4.

From Rhodes' example, it is clear that Harry knows that his father died of Huntington's disease and he has also understood that he has a 50% risk of carrying the gene (Rhodes, 1998, p 13-14). So it is really not a question of not having a clue to whether he is a carrier or not. As is common in situations such as this, there is a suspicion based on familiarity with the disease through personal experience. But he does not know *for sure* whether he is a carrier or not. Does Harry have an obligation to find this out?

As Takala and Häyry points out, in a consequentialist framework, Harry has an array of obligation, depending on what he does more specifically (2000, p 109-110). The example is under-described if we are to determine whether he has a duty to know. Will he harm others by his ignorance of his genetic status? As already mentioned, that depends.

Sally perhaps has no idea about the history of the disease in Harry's family or at least not about the genetic nature of it. Then the allegation of fraud is not farfetched: Harry knows something of great importance to their future and their potential children without telling her about it. The potential harm of this fraud is of course immense. If he is a carrier and starts to develop symptoms, she will probably find out about his disease and become devastated with his secrecy. "I ought to have been told before we had a child", she would probably say. But deceiving his spouse in this way is not in itself a result of his ignorance of whether he is a carrier for sure. He could find this out and still deceive Sally. Thus, the deception is a wrongdoing and something he should refrain from, regardless of any alleged duty to know.

More likely, however, she does know about the fact that Harry is a potential carrier, the nature of the disease and that he might be disabled in various ways at a relatively young age from it. Do *they*, then, have a duty to find out about for sure whether he is a carrier or not?

If the duty is to be based on any non-harm idea, this duty probably is not towards *themselves*. They both know that Harry may suffer from Huntington's disease, regardless of his knowledge of carrier status. They probably have agreed on not finding out. If ignorance caused anxiety to them, they probably would have decided to find out anyway. Alternatively, Harry has decided to remain ignorant against Sally's wish. This, of course, can reasonably be described as harming Sally (certainly according to preferentialism and probably according to hedonism). But then she probably will reconsider having a family with this man, who disregards her wishes on such important questions. *If* Sally wants him to find out, he harms her. He then, at least, has a moral reason to

find out. In order to find out if he ought to act on this reason based on non-harm, he has to consider whom he would harm by finding out his carrier status, including himself,[65] and ponder what course of action would effect the least serious harm all things considered.

However, as the example stands, the duty to know most likely is a duty he has towards his future offspring. This is the person(s) he risks harming, by transmitting the disease. Can Harry's and Sally's ignorance harm their future offspring?

It is important to keep in mind that Harry and Sally are only planning to have children at this point. So they do not harm any existing person by their ignorance. The alleged victim of the harm is a future *possible* person – a person that might or might not come to exist. Is it possible to harm an individual that does not yet exist?

Before tackling this question, it is important to keep in mind that the potential harm is independent of the information. The potential harm lies in passing on the gene for Huntington's disease, not in doing this knowingly or unknowingly. The reasoning that can lead to a duty to know then has to rest on some further idea of *risk* of harm: by not knowing about one's carrier status one risks passing on the (gene for the) disease.[66] It may be claimed that this is an illegitimate risk to impose on someone else, at least if one has not done one's best to clarify the facts of the case (by finding out one's carrier status). So in order to establish that Harry has a duty to know, it is not enough to show that passing on Huntington's disease harms the person it is passed on to. One also has to show that if the risk is high enough to pass it on if ignorant, one has to avoid ignorance. However, in order to be successful, the argument also has to establish that passing on Huntington's disease is to harm the person it is

---

[65] This general idea is compatible with weighing probabilities, and weighing his harm lower than Sally's. However, no non-harm principle totally disregards the harm of anyone in particular.

[66] The idea of *irresponsibility* is quite salient in Rhodes' argument. The idea is then that not only actually harming someone is a moral reason against doing something, but also inflicting *risk of harm* can constitute such a reason, at least if the harm is grave, and the probability of it is great, enough. This idea explains her use of the parallel to "the driving blindfolded"-example (Rhodes, 1998, p 16). We have a duty to keep our eyes of the road because of the serious risk of harm we otherwise would inflict on others. Certain kinds of activities (such as driving or family founding) create certain kinds of obligations (e.g. of a non-harm kind) it would be irresponsible not to live up to, or so the idea goes.

passed on to. Since this is not an actual person, but a possible future one, the question thus becomes: can being brought into existence harm a person?

This relates to the non-identity problem and the problem of future generations. Therefore, this discussion will to a great extent draw on Parfit's (1984) seminal discussion of these topics. The non-identity problem is about the fact that our decisions will not only affect existing people, but also will affect which people will exist. This is obviously so with regard to reproductive decisions.

So, once again, is Harry harming the future child if he passes on the gene for Huntington's disease? Well, either a therapy to cure the disease has been developed or it has not. If such a therapy has been developed, the child can find out if (s)he has the disease for himself when (s)he is old enough. Then Harry has no duty against the child to find out if he is a carrier now.[67] Or no therapy has been developed. In that case, the only way to guarantee avoidance of giving birth to child that could contract Huntington's disease is through testing the embryo in utero or in vitro. In the first case, abortion can be implemented if the foetus is found to be a carrier. In the other case, one can go through with a PGD and discard the embryos that are carriers. However, without therapy, we are not avoiding *the harm* to the child with the gene for Huntington's disease, we are avoiding *the child* with the gene for Huntington's disease.[68]

This is, of course, nothing but the non-identity problem. The only way to use the knowledge of carrier status (in reproductive decisions without therapies) is to choose a child who is not a carrier. Granted that being a carrier of the gene for Huntington's is better than not existing at all, that is, that one still has a life worth living even if one will contract Huntington's sometime in the middle-ages, one cannot claim to have been harmed by being born with the gene. If Harry refuses to find out whether he is a carrier or not, it turns out that he is and he passes on the gene to his child, the child cannot complain: "You passed on this disease to me that you could have avoided passing on. You have harmed me." To this Harry's reply obviously is: "If I had avoided the

---

[67] Even if he probably has a duty to tell the child that he is a potential carrier when the child is old enough.

[68] I am here, of course, resting on the premise that if one makes an abortion or discards an embryo, the very same child cannot in fact be born through later pregnancy or grow from another embryo. Although not self-evident, this assumption should be uncontroversial (especially regarding abortion). See Parfit, 1984, p 351-356.

disease I would have avoided you. You would never have existed. Have I harmed you by bringing you into this world? Would it have been better if you had never existed?"

One cannot resort to the person-affecting view either in order to claim that there is a duty to know. The person-affecting view says that we cannot act wrongly unless we act wrongly towards some (timelessly) existing person (Tännsjö, 1998b, p 162). However, this idea can only be used to argue in favour of a duty to know if ignorance leads to the birth of a child whose life is not worth living, which we assumed was not the case with the life of someone with Huntington's disease. This is so, since we cannot be said to wrong someone by making her exist, if her life is worth living and there is no way we can better her life and still preserve her identity (as is the case here). (Of course, things become much different regarding other diseases, which can be argued to make the person's life not worth living, as we soon will see).

In fact, the only way to argue in terms of harm and benefits in favour of a duty to know in the case of Harry is to refer to some version of the total version of utilitarianism (see II.4.2), according to which we should act as to make the world as good as possible.[69] This argument can be made, for instance, if one assumes that the alternative for Harry of not finding out whether he is a carrier will lead to the birth of child that is a carrier and the alternative of finding out whether he is a carrier will lead him to find out that he is, and lead to reproductive measures that results in the birth of a child that is not a carrier. Furthermore, one has to assume that the life of the child who is not a carrier is, on the whole, better than the life of the child who is not. Given the truth of all these assumptions, Harry should find out whether he is a carrier.

Obviously, all these assumptions are practically useless or highly controversial. To rely on some total version of utilitarianism is in itself highly controversial, and is not something that Rhodes does.[70] The assumption of the consequences of the alternatives can, of course, be done. However, such assumption will hardly be helpful in a practical situation of choice, since one does not know beforehand whether Harry actually is a carrier, which the assumptions just take for granted. Furthermore, in an practical situation of

---

[69] In fact, in this case, referring to the average version of utilitarianism (see II.4.2) would also do, but this need not bother us here.

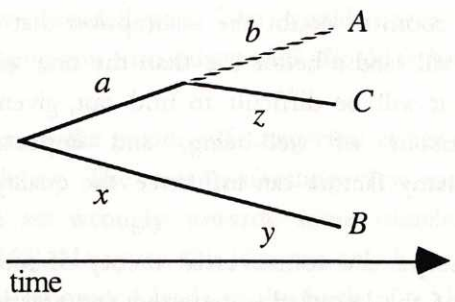
[70] This is obviously so, since Rhodes refers to the irresponsibility of posing others to certain risks (see this section above), and irresponsibility and risk does not enter the moral picture of total views, which only claims that we should make the world as good as possible in actual terms.

choice, there is always room to doubt the assumption that the person without Huntington's disease will lead a better life than the one without. Even if the assumption is correct, it will be difficult to find out, given the difficulties of interpersonal comparisons of well-being, and impossible to find out beforehand, since so many factors can influence the quality of someone's life (Gren, 2004).

But even if one accepts the controversial theory of total utilitarianism and ignores the problem of the knowledge required for practical action-guidance, it is still unclear whether the theory implies a duty to know. This is due to further theoretical complications regarding what set of actions the utilitarian reasoning should really be applied to – a problem often discussed under the heading of future mistakes. Let me illustrate.

Let us assume that Harry is a carrier of the gene for Huntington's disease, but is not yet aware of this, since he has not yet gone through with genetic testing. Now, he and Sally plan on having a child, something they can carry out regardless of whether he goes through with testing or not. So they are really facing two decisions: one of testing and one of having a child. Let us assume that if they have a child without testing, the child will also be a carrier of the gene for Huntington's disease. On the other hand, if he goes through with testing, he can take measures to ensure that the he has child will not be a carrier (e.g. by PGD). However, if he finds out that he is a carrier, he will not, in fact, choose to have a child, even if it remains true that he could do so (Sally would still be prepared to go through with PGD and pregnancy, we may assume). Let us assume that the child who would exist if Harry chooses not to test himself, i.e. the child who is a carrier of the gene for Huntington's disease, would lead a life worth living. This would be better than no child at all, since, we can assume, no side-effects of having or not having any child will make any difference.[71] Let us furthermore assume that having the child that is not a carrier of the gene for Huntington's disease is clearly better than having the child who is. The situation can be illustrated in the following tree.

[71] According to total versions of utilitarianism, the comparison between no child and some child is viable, since it is a comparison between the values of two possible histories of the world. This explains why utilitarianism can be used in order to establish a duty to know.



Let *a* be the alternative of "performing a test for the Huntington's disease' gene" and *x* the alternative of "not performing a test for the Huntington's disease' gene". Furthermore, let *b* be the alternative of "having a child (who is a non-carrier)", *z* "not having a child", and *y* "having a child (who is a carrier)". *A*, *B*, and *C* are the compound alternatives consisting of the respective alternatives that may follow each other (*a*+*b*, *a*+*z*, *x*+*y*), which we can call projects.

Now, what should Harry do? Given that no other consequences will be relevant, according to the total view that one should make the world as good as possible, Harry should go through with project A. But in order to do this, he must perform a, which he should not do, since it would lead to z being performed and thus effect project C to be carried out. So, it seems as though A as well as *a* should and should not be performed. Obviously, such a conclusion must be avoided (at least for the theory to found a duty to know), so utilitarianism has a problem.

The general theoretical problem is that actions can be subdivided into more specific actions. So the question becomes which set of alternatives we should choose from: which is the relevant alternative set?[72] There are numerous ways of trying to solve this problem.[73] However, there is still controversy on which solution, if any, is the correct one. So even on a theoretical level, it is unclear whether there is an answer to the question of what duties are implied by total utilitarianism. And this is bad news for anyone that tries to argue in favour of such a duty in the case of Harry (and relevantly similar ones), since no other consequentialist *or* Kantian theories can be used to argue in favour of such a *general* duty in this kind of case, as we have seen.

---

[72] Bergström, 1966, was the first to present this problem.

[73] See Carlson, 1995, Feldman, 1975, and Tännsjö, 1998b, to mention a few.

Things are different if we finally turn to cases such as Harriette's and her husband, who "have decided not to find out if they are recessive carriers of the Tay-Sachs gene and to have a child despite the fact that the child's life can be short and full of agony" (Takala and Häyry, 2000, p 109). In this case, it can be argued that their potential child will not have a life worth living if the child is unfortunate enough to inherit the gene from both her parents.[74] It might be that we sometimes are prejudicial against handicaps, deeming such lives not worth living when they really are worth living (Vehmas, 2001, p 475). However, this does not rule out that there can be cases where disease is so serious as to render it not worth living for the person experiencing it. For instance, this might be the case with Tay-Sachs, where "the child's life can be short and full of agony". Then it seems reasonable to claim that the child is harmed by being brought into existence, and that this harm is serious enough to make the act of bringing it to existence wrong.[75] If this is so and one knows beforehand that one runs a high enough risk to produce such a child, it does not seem unreasonable to say that one has an obligation to take measures to see to it that this does not happen, including finding out relevant genetic information about oneself. However, once again, this merely shows that in some types of rare[76] circumstances, we may have good reasons to know our genetic constitution. From this, we cannot infer that these reasons motivate enforcing the duties based on them. We need independent arguments to get from lack of options to enforcement privileges (IV.1.1.1).

4. Conclusions

This chapter may come through as quite "negative", since much of it consists of criticism of suggestions made by others. One such suggestion is that Kantian ethics favours a general duty to know. A more careful analysis of Kantian ethics reveals this suggestion to be implausible, or so I have argued. In

---

74 That the child can have a life no worth living is maybe even more obvious in cases regarding Lesch-Nyhan and Krabbe's (I.4.1).

75 What one should say is thus not that it is better for the child not to exist, but that it is better, on the whole, if the child never exists, and if the child is brought into existence, the child is harmed.

76 Even though the risk to contract a disease at some point in life due to a single gene disorder is 2-4% (Wahlström, 2002b, p 24), few of these diseases can unambiguously be claimed to make the affected person's life not worth living, and there is seldom initial suspicion that would make it an alternative for the parents to seek the genetic information in question.

connection to this, I have also argued that to knowingly abstain from genetic information relevant to a decision need not be incompatible with one's autonomy, contrary to what has been claimed. Moreover, I have levelled criticism against arguments of non-harm in favour of a general duty to know. This criticism is valid even if these considerations are given a non-Kantian consequentialistic basis, or so I have argued.

However, hopefully, the critical stance of some discussions does not hide the fact that much of the criticism has been used to argue in favour of quite a few positive conclusions. For instance, it should be clear from my criticism that Kantian ethics, autonomy, and consequentialism, in some cases, can provide reasons to know, perhaps even reasons strong enough to imply a duty to know, at least in rare cases. However, in spite of this, my criticism indicates a rather extensive right not to know in the sense of an option. That is, as a rule, those who choose to remain in ignorance do not make a choice that is morally impermissible.

Furthermore, I have argued that, even if there at times may be a moral duty to know, this is in no way incompatible with negative, or even positive, rights to ignorance. At least, the legal right not to be forced to genetic testing or to be informed about one's genetic constitution without one's consent should be recognized. This should hardly come through as very controversial. Although such a right has its limitations, e.g. due to the fact that it seems unreasonable to enforce sanctions on relatives who choose to reveal such facts and that, at times, consent cannot be obtained without revealing some information one is asking for consent to reveal,[77] the legal right to ignorance should be rather extensive as well. Besides Millian arguments of a consequentialist kind to this effect, such a right can even be argued to be basic, since not to respect it amounts to not respecting autonomy conceived of as a right. So, indeed, there seems to be some rights to ignorance.

---

[77] I will return to the question of when one should inform relatives of their risk, when consent can be presumed, and what to do in practice when relatives should be informed in the next chapter.

Chapter VI
The Relatives' Value of and Right to Genetic Information

1. Introduction

Genetic information, by its very nature, is informative of others. This truism is repeated so often in debates on genetic testing as to give the impression that this fact alone settles important normative issues. However, the knowledge of one person's genes does not provide knowledge of another person's genes, unless one has proper background knowledge (about genetics, for instance). The fact, nonetheless, remains that, due to the hereditary nature of genes (they provide the very mechanism of biological heredity), we sometimes can infer quite precise things about whether or not a certain relative to a person has a gene (or at least about the probability thereof) from the fact that the person has this gene.

In this chapter I will discuss the questions of the relatives' value of and right to genetic information, and then mainly the latter 'right-question'. 'Relative' is a vague conception indeed, and its meaning is certainly dependent on culture and time. In order to avoid discussions about the scope of the question I will therefore state what kind of relatives I am primarily interested in. I am interested in close blood relatives and other family members. With close blood relatives I mean others with whom one can reasonably expect to share the gene or genes tested for. This is the group of people that clinical geneticists are interested in when constructing a family tree or pedigree of the index-person (Harper, 2001, p 5-7), and I will not presuppose any wider definition. When I am talking about other family members, I mean other members of the modern Western nuclear family, and then primarily the spouse. Due to the hereditary nature of genes, I will take more interest in close blood relatives (which henceforth will be called relatives for short) and less with other family members.[1]

[1] I had some things to say about the rights of the spouse in V.3.2.

More precisely, this chapter will deal with the question of the relative's value of and right to receive information *from the genetic testing of the index-person.* As a matter of fact, the index-person is not always one person: often a family and/or a group of relatives together contacts health care in order to find out about their genetic propensity for some disease. I will disregard this complication.[2] My focus will be upon the question of relatives that have not themselves initiated genetic testing.

The question about whether and when a relative should receive information about the genetic testing of the index-person is foremost a question that is brought to stand in the clinical context, i.e., it arises in the health care setting run by health care professionals. The reason for this is that genetic testing is primarily made in this setting. The exception is, of course, home tests done by the index-person herself (IV.2). This kind of situation is rarely discussed regarding relatives right to be informed, however, and although some of what follows has relevance for this situation, I will disregard this complication too.

The focus of the current debate is whether the result of genetic testing should be disclosed to relatives. This will also be the focus of my discussion. In order to answer this question, we will have to look into the question about the relatives' value of and right to genetic information. However, I will give the 'value-question' considerably less attention and the reason is the following. To the extent that genetic information about the index-person is telling about the relative, the information may realize the same *values* for the relative as for the index-person. That is, if P's having genetic information about P can increase, e.g., the autonomy and well-being of P, this will hold regardless of who P is (whether P is the index-person or a relative to the index-person). The same goes for the avoidance of harm or any other negative value that can be prevented by having some genetic information. And the other way around, the negative values potentially realized by receiving genetic information can affect the relative as well as the index-person. Generally speaking, it seems reasonable to claim that the more positive values that can be realized and the more negative values that can be avoided by disclosure to the relative, the stronger

---

[2] The complication gives rise to some additional interesting questions, such as: When there is a conflict of interest between index-persons, who should decide? Who is the index-person to whom the health care professional is primarily obligated? See Parker & Lucassen, 2003, p 72, for a presentation of a case where these questions becomes relevant.

the obligation to disclose (see VI.3.1). And, again, the other way around: the more negative value that can be realized by disclosure to the relative, the stronger the obligation *not* to disclose. The magnitude of the *likelihood* of realizing such values will, of course, also be taken into account when considering disclosure. However, the general point remains: as far as values goes, the same ethical considerations will be relevant regarding relatives as regarding the index-person. So there is no reason to ask separately, what values genetic testing will realize for the relative, since this would only be to repeat the previous value-discussion (see chapter II). Thus, values will be discussed only to the extent that they are relevant to the right-question, and the corresponding question of reasons for an obligation to disclose genetic information to relatives.

When it comes to relatives' right to genetic information, the most common way to discuss such a right is to discuss a corresponding duty or obligation to disclose.[3] This is often presupposed to be an obligation to see to it that relatives actually gets informed, not only to abstain from preventing relatives to acquire the information in question, which then corresponds to a positive, rather than a negative right of the relatives in question to be informed. Often, the obligation is primarily ascribed to the index-person. If there is an obligation of the index-person to inform the relative about the result of genetic testing, there is a right of the relative to receive this information (see IV.1.1.1). As we will see, it has been argued that this obligation holds, at least partly, *because* the index-person is a relative or because genetic information about the index-person (sometimes) is also genetic information about the relative (see VI.3.2). The idea, then, is that we have special moral reasons towards certain other parties in virtue of them standing in certain relations to us (e.g. the relation of family or blood relative).

A further question that is often discussed in relation to this question is whether health care professionals should inform the relatives if the index-person refuses to do so, or if they should inform the relatives *rather* than the index-person altogether. In connection to this question, one can also ask the general question who has the most reason to inform the relative (given that the

---

[3] As we saw in IV.1.1.1, rights, strictly speaking, correspond to reasons rather than obligations, even if the reasons in questions can give rise to obligations. However, the discussion regarding relatives' rights has been cast in terms of corresponding obligations rather than reasons (see e.g. Rhodes, 1998), so I will at times follow this way of talking. However, it should be kept in mind that the obligations may be overridable ones.

relative has a right to the information). Questions like these, in turn, give rise to questions about how the practice of presymptomatic genetic testing should be regulated and institutionalised. Particularly, the institution of genetic counselling and its ideal of non-directiveness have been questioned, due to potential conflicts between this ideal and the interests of relatives.

Having provided a picture of the subject at hand, we can now consider the more particular questions that I want to discuss. These may be divided into questions arising *before* and questions arising *after* testing. Questions arising before testing are the following:

(1) Given that a genetic test can reveal genetic information about a relative, should the relative have to consent to the testing as a prerequisite? Given what circumstances (if any) should such consent be required?
(2) Should the relative be informed about the fact that a test will be performed or not? Given what circumstances (if any)?
(3) Who should provide this information? The index-person or some health care professional? Given what circumstances?

I will focus on question (1), which will be discussed in section VI.2. If the answer to this question is "no", the other questions will be of marginal interest. The reason is the following. Obviously, the relative can have an interest in receiving the result from a genetic test of the index-person, an interest that can be met only after testing. The only interest independent of this a relative can have in knowing that the index-person is planning to go through with testing, i.e. *before* testing, is that such knowledge allows the relative to (try to) prevent the testing, since the relative can have an interest in the index-person not receiving information that reveals facts about her genetic constitution. And, as I will argue when discussing (1), relatives should not be allowed to prevent testing. So question (2) (and, consequently, question (3)) will become uninteresting if my argument regarding question (1) is successful.

Questions arising after testing are the following:

(4) Do the relative(s) have a right to the information that a test has been performed and/or the results of the test and does somebody else,

thus, have a reason to inform the relative thereof (perhaps a reason strong enough to make it an obligation)? Given what circumstances?[4]

(5) Who should provide this information? The index-person or some health care professional? Given what circumstances?

(6) Should health care professionals try to persuade the index-person to disclose the information if the index-person is reluctant to do so? To what extent and given what circumstances (if any)?

(7) If the index-person still refuses to disclose, are there reasons for the health care professionals to inform the relative anyway (against the wishes of the index-person)? Given what circumstances (if any)?

(8) Does the relative have a right *not* to receive the information that a test has been performed and/or the results of the test and does everybody else, thus, have a reason to abstain from informing the relative thereof (perhaps a reason strong enough to make it an obligation)?

Although I will have something to say about each of these questions, I will not tackle them to the same extent. In general, the questions that have actually been up for debate will receive more attention, as will the questions I think are more interesting. The question that will receive most attention is (4) and the other questions will be addressed when discussing that question. Question (8) can be answered on the same theoretical basis as (4), or so I will suggest (see VI.3.1.1). Questions (5)-(7) will be discussed as more practical concerns against the background of the general answer to question (4). I will not reach a definite answer to these practical questions, but only make some suggestions relevant to answering them (see VI.3.1.2). Regarding question (5), an overlooked distinction between the ones who are obliged to see to it that relatives are informed and the ones that should do the actual informing is made.

Furthermore, there are questions relating to the institutional setting of disclosure to relatives and family. For instance, let us grant that there is a right of a relative to receive some information about a genetic test, should this right be codified and/or enforced somehow? How should it be codified or enforced more particularly? Should there, e.g., be a code of conduct for genetic counsellors including this type of item? If yes, should there be

[4] It may be so that the reasons for informing fail to found a right to the information, but nonetheless makes it *allowed* for somebody else (the index-person and/or the health care professional) to disclose the information (i.e. founds an option for the party that can inform the relative). I will almost entirely ignore this possibility.

measures taken against breaching of the code or should the code just function as non-enforced rules of thumb? These questions are, of course, interesting, and some of what I will have to say about the reasons to disclose will have relevance for these questions (see VI.3.1.2). However, they will be treated more ephemerally.

It is obvious that the questions are legio also in this context. I will not motivate the focus of every question, so I am relying on the beneficence of the reader. Having said this, let us turn to the questions, starting from the top.

2. Requiring the consent of relatives

Should there be a requirement that relatives consent to the genetic testing of an index-person? This question becomes pressing when the test of an index-person is highly predictive of some relative(s). As many types of genetic testing are presently conducted, the testing presupposes a preliminary genetic analysis of some blood relatives, which indicates whether or not to suspect hereditary disease and establishes what genetic mutation to look for in the case of testing. In some cases, familiar heredity can be established but no mutation can be identified (either due to lack of material or to lack of knowledge of the particular mutation at work). In such cases, no testing is possible. However, also when testing is possible, this has been established through a genetic analysis of family history. To the extent that this analysis has made use of medical records, contact with a family physician, or contact with the relatives themselves, informed consent will have to be obtained from the relatives in question. If consent is denied, the analysis of the family will never get off the ground and there will thus be no testing. Thus, the question of whether or not the informed consent of relatives should be required may seem like a non-starter. This is true as long as presymptomatic genetic testing presupposes additional genetic family analysis.

However, it is more and more common to skip the initial step of family analysis, since people in affected families often know what mutation is at stake (through the testing of someone else) and specialists often know what to look for anyway. In the near future, this can be expected to become increasingly the standard, due to the development of knowledge about genetic mutations and technology for simultaneous testing of a large number of genes. Consider the following case, which illustrates how this trend makes the question of whether or not to require the relatives' consent a live issue:

> A woman, Rachel, comes for an appointment at a clinical genetics unit following a referral by her family doctor. Rachel was referred to the Unit because she had requested a 'breast cancer gene test' and was aware of a very strong family history of the disease. Six close relatives had been diagnosed with this cancer at an early age. Her only living affected relative was her grandmother, who had herself been a patient at the genetics unit and had tested positive for one of the BRCA1 mutations. The case was made more complicated when Rachel revealed that her mother, the grandmother's daughter, was as far as Rachel knew unaffected and had no contact with the genetic service. Rachel said that she no longer got on with her mother and would not want her to know that she had been tested. This presented a problem for her family doctor and for the geneticist. If a test were provided to Rachel and the result turned out to be positive, her mother would also be positive for the mutation. To carry out a test on the daughter would be to test the mother without her knowledge and to do so in the context of a family which relationship were already strained. (Lucassen, 1999, p 323)[5]

Cases like this are not uncommon (Parker, 2001, p 453). The motives for the index-person not to inform her relatives vary. Sometimes it is due to family conflict (as the example above suggests) and sometimes the index-person feels that she wants to protect others from "bad news" (Adelswärd & Sachs, 2002, p 81-86). Regardless of motive, one may wonder if the index-person should be tested at all without the consent of close blood relatives in cases like Rachel's, since the test, if it is positive, will reveal that the mother is a carrier for sure.

The question of the requirement of relative's consent is ambiguous. It can be about the moral reason for obtaining consent or about the desirability of regulations of genetic testing requiring consent. From now on, I will focus on the question whether consent *should* be required and presuppose that if the answer is yes, this provides a powerful argument in favour of implementing this requirement in the practice of genetic testing. I will, however, leave the question of how the requirement should be implemented open for now.

In general, there are two types of argument with regard to the question of requiring the consent of relatives. First there are arguments that refer to general norms within health care, such as informed consent, confidentiality,

[5] This case is also quoted in Parker, 2001, p 451-452.

and privacy. Then there are arguments that refer directly to the basis or foundation of these norms, and then primarily ideas about respecting autonomy and consequentialist arguments. I will argue that arguments of the first kind will not settle the issue, but that considerations of consequence weighs in favour of not requiring the consent of relatives. Such requirements would also face problems of moral arbitrariness.

2.1 Informed consent

Should the consent of relatives be obtained, then? The following line of reasoning indicates that it should.

> Genetic testing is predictive, interpersonal, and identifying. It is generally agreed that genetic testing should only be carried out with the informed consent of the patient. To test one person can in some cases be to carry out a highly predictive test on someone else. If we are serious about informed consent in genetic testing should we not apply the same standard in both cases? (Parker & Lucassen, 2003, p 72)

This argument suggests that the generally accepted norm in bioethics of informed consent to medical interventions speaks in favour of obtaining informed consent also from relatives, if the testing of the index-person is "highly predictive on someone else".[6] In order to assess the validity of this argument one has to determine what informed consent is and whether requiring informed consent from the index-person also speaks in favour of requiring informed consent from the relative.

There are different conceptions of informed consent (Beauchamp & Childress, 2001, p 77-98). A minimal conception requires health care professionals to disclose medical information about the intervention according to the "professional community's customary practices" (Beauchamp & Childress, 2001, p 81) and then obtain consent in the form of expressed consent. It has been claimed that this form of consent is insufficient, since the basis of informed consent is some principle of the respect for the patient's autonomy and this minimal consent is compatible with the autonomy of the

[6] I will presume this condition is clear enough for the rest of this section, until the last subsection, where it will be discussed (see IV.2.5).

patient not being respected (Beauchamp & Childress, 2001, p 81-83).[7] Therefore, it has been argued that informed consent should involve the patient's actual understanding of the medical intervention and that the health care professional should find out what information the patient regards as relevant (Beauchamp & Childress, 2001, p 83, 88-93).

I concur with this criticism of the minimal conception of informed consent and have argued that the conditions of understanding and relevance (at least) should be included if the aim is patient autonomy (see II.3.3.5). However, this point is less important in this context. The question is if the same sort of informed consent should be obtained from the relative as from the index-person, regardless of the kind of informed consent one favours. That is, the argument states that informed consent (whatever idea one has on the conditions for informed consent) should be obtained from the index-person *and* the relative. However, if an important point of informed consent is to protect autonomy, and a certain conception of informed consent does not achieve this, the conception should be rejected. Nonetheless, I will not presuppose that even the minimal conception is an unreasonable conception, since nothing I will have to say regarding the question at hand will hinge on this. Just choose your own favourite conception of informed consent.

Now, should the consent of the relative be obtained, when the test of the index-person is "highly predictive" about the relative? The most reasonable way to interpret Parker is presumably the following. Consider the case of Rachel. It may not seem too farfetched to claim a positive test on Rachel is, in effect, a positive test on Rachel's mother. It can thus seem reasonable to claim that whatever speaks in favour of obtaining the consent of Rachel, also speak in favour of obtaining the consent of Rachel's mother.[8] Thus, if the consent of the daughter should be obtained (which we assume it should), then the consent of Rachel's mother should. In order to see whether this conclusion is warranted, we have to investigate what speaks in favour of obtaining consent from the daughter and investigate whether this really speaks in favour of obtaining informed consent from the mother. As previously mentioned, the most important (or at least the most usual) argument in favour of informed

---

[7] This is obviously so, since the professional community's customary practice need not be respectful of autonomy at all.

[8] This will be questioned later (VI.2.4 and VI.2.5).

consent is that it is necessary in order to respect the autonomy of the patient. So, we have to investigate whether not obtaining the consent from the mother is in someway disrespectful of her autonomy. I will execute this investigation below (see VI.2.3).

However, another possibility is to understand the argument as appealing to some implicit norm of justice. Consider again the case of Rachel. It could be claimed to be unjust that Rachel gets to know something about her mother if the mother does not get to know this herself or gets some corresponding information about Rachel. However, as a general principle of justice, it seems unreasonable to claim that whenever someone, P, gets to know something about Q, it is unjust that Q does not also receive that information, and even more unreasonable to claim that it is unjust that Q does not get a corresponding piece of information about P (then it would be very hard indeed to hold just interviews). Furthermore, even if one were to argue in favour of such a principle of justice, it would only support that Rachel should inform her mother in case of a positive result of testing, and not that the consent of the mother has to be obtained before testing.[9] I will investigate the argument for informing the relatives of the result of genetic testing in section VI.3.

2.2 Confidentiality and privacy

Respecting the confidentiality of patients and relatives (or "third parties" as they are sometimes called) can be considered to be relevant to the issue of requiring the consent of the relatives. Parker, when discussing Rachel's case, writes:

> Insistence on the confidentiality of the index patient would mean that the confidentiality of third parties, such as Rachel's mother, who had genetic diseases, or susceptibilities of such diseases would routinely be breached. To carry out a test on Rachel would at the same time be to carry out a test on her mother and this highlights why informed consent

[9] I take it for granted that the argument should not be interpreted as the question-begging one that since genetic testing on a person requires informed consent, and this testing can be highly predictive of someone else, the informed consent of this someone else should also be obtained. To fall back on the claim that testing without obtaining the consent of relatives is unjust is only to repeat the question-begging claim while adding "and this is unjust". As an independent argument, this is insufficient.

> is also an issue in such cases. Respecting the confidentiality of the index patient would mean that third parties would be tested without their knowledge or consent.... (Parker, 2001, p 452)

What is being indicated in this passage is that testing Rachel without neither requiring the consent of her mother nor letting her know about the testing (or the result thereof) is to breach the mother's confidentiality while respecting the daughter's. That is, there is a conflict of confidentiality: "confidentiality pulls in several directions at once and it is not immediately clear what would be involved in 'respecting confidentiality'." (Ibid) There are two issues at stake here: (i) whether testing Rachel without informing her mother of the testing (or the result thereof) is at odds with respecting her mother's confidentiality, and (ii) whether testing without requiring that her mother consents is at odds with respecting the mother's confidentiality. In this section, question (ii) is the one up for discussion: Is testing *without first requiring* that the mother consents to the testing to breach *the mother's* confidentiality? Furthermore, in light of the alleged conflict of confidentiality, one can ask: Is *requiring* the mother's consent to breach *Rachel's* confidentiality?

In order to answer these questions, we will have to take a closer look into what confidentiality is, and what the respecting of and breaching of confidentiality consists of. The idea of confidentiality is much like the idea of secrecy, i.e., to avoid further disclosure of something someone else have told you (often about herself). For someone, P, to preserve or respect the confidentiality of somebody else, Q, is to protect or abstain from forwarding information that Q has disclosed to P. To breach the confidentiality of someone else is thus either to fail to protect or to forward this information, at least if it is done without the consent of P. If P has a right to confidentiality, it is a violation of this right to breach it without the consent of P. Generally, some kinds of relationships are considered to give rise to such rights and, thus, corresponding obligations of the party that has been informed not to "redisclose" this information to a third party. The relationships between a priest and a member of the congregation in the situation of confession or the one between a lawyer and the client are familiar examples. Another is, of course, the relationship between the doctor (or other health care professional) and the patient.

The principle of confidentiality (i.e. the right to have one's confidence preserved) is a central tenet in medical ethics and an ancient one at that (to be

found already in the Hippocratic Oath). When it is questioned, it is not so much the principle itself as the weight and scope of it. Certainly, the feasibility of the principle has been questioned, on grounds of being impossible to realize in modern health care where patient's information is shared between a great numbers of professionals (Beauchamp & Childress, 2001, p 304-305). But this has only been taken to imply that the principle cannot be fully realized, but only approximated.

The reason for this relatively unquestioned position of confidentiality is that the basis for respecting patient's confidentiality is rather firm. First, to respect patient's confidentiality seems to be a part of respecting patient's autonomy. The simple reason is that confidentiality includes, by definition, that redisclosure of patient's information demands the consent of the patient. Thus, confidentiality is about respecting the wishes of the patient (regarding the spreading of information) and respecting the wishes of the patient is, in a sense, to respect the autonomy of the patient (see III.3.3).

Second, for the doctor and other health care professionals to preserve the confidentiality of the patient is crucial for the patient's trust in the doctor in particular and the health care system in general. If the patient cannot trust the doctor not to forward information about her, she may be reluctant to share information or even to contact health care at all. This, in turn, would decrease the possibility of the health care professional to make the proper diagnosis and, thus, recommend the proper treatment. If people's trust in health care is damaged to the extent that they are reluctant to make contact at all, this will also lead to omissions to prevent, palliate or treat diseases. That is, without confidentiality, no trust, and without trust, less well needed health care. To this it might be added the uneasiness one might feel if one cannot feel confident that the information one discloses is protected accordingly. So there are good consequentialist grounds for confidentiality as well.

The fact that the basis for confidentiality is strong in general makes the breach of confidentiality problematic (even if justified on occasion). So if requiring the consent of relatives for testing (or disclosure of result of testing) were a breach of the index-person's confidentiality, this would make a strong case against such a requirement. And similarly, if *not* requiring the consent of relatives for testing (or disclosure of result of testing) were a breach of these relatives' confidentiality, this would make a strong case in favour of such a

requirement. But is requiring or not requiring consent a breach of anyone's confidentiality?

In order to answer that question, let us once again turn to the case of Rachel. Is testing while requiring the mother's consent to breach Rachel's confidentiality? No, it is not. When requiring consent, the doctor is saying that testing will not be performed unless the patient accepts that consent from relatives is obtained. To issue such a condition for testing is not to breach any confidentiality, since it is not a case of redisclosure of any information to anyone else about the patient. Nor is it a failure to protect some information. It is just saying that in order for a test to be made at all, the consent of someone else has to be obtained.

It is perhaps easier to see why this demand is not a breach of confidentiality if we consider some examples of what would in fact have been such breaches. It is clear that Rachel does not want her mother to find out about her testing and, presumably, about her plans of having a test.[10] If the doctor reveals Rachel's plans to the mother, he will betray her confidence. This would, then, constitute a breach of confidentiality. And to contact the mother after testing is done, informing her that testing has been performed (or the result thereof), would also be to breach the confidentiality of the daughter. But to require that consent should be obtained, as a prerequisite of testing is, in itself, no breach of confidentiality. This can be done without the mother's knowing of Rachel's plan and, thus, without any redisclosure and breach of confidentiality whatsoever. If Rachel refuses to accept the requirement, no testing will be done and, hence, no information about the test can be disclosed to the mother. If Rachel accepts the requirement, she has consented to the mother being informed about her testing. In neither of these cases there is a breach of confidentiality.

Is testing Rachel without demanding the mother's consent to breach *the mother's* confidentiality? No, it is not, for the simple reason that the situation does not involve any *re*disclosure of any information that the mother has given to the doctor. Even if the doctor knew that the mother is a carrier beforehand, Rachel's receiving a positive result of the test is not disclosing *that* information, but giving Rachel information of herself that allows her to infer that the mother is a carrier.

---

[10] It is not clear from the case whether Rachel actually has performed the test or just has contacted the doctor to have a test performed.

Of course, it might be argued that these simple answers just miss the point. One could argue that the daughter has a right to test herself without obtaining the consent of the mother, and if she decides to do this, neither this decision nor the result of the test should be redisclosed to the mother. Or one might claim that the daughter should not be allowed to have a testing that can lead her to realise that the mother has some susceptibility to some disease without the consent of the mother. But neither of these arguments can be based on a reference to confidentiality alone, as we just saw. So it is not the case that "confidentiality pulls in several directions", at least not when it comes to the question of whether the consent of relatives should be required. In fact, regarding this question, confidentiality pulls in no direction whatsoever.[11]

However, it might still be claimed that some information about a person should not be available to anyone else, unless the person herself voluntarily releases it. That is, it might be claimed that person has a right to control the access of others to information about oneself. This idea is commonly cast in terms of *privacy*.[12] Privacy is a state of limited access of others to aspects of the person, and a right to privacy is a right to control this access. Such a right, then, creates a protected zone or personal sphere around the person where the individual is especially entitled to non-interference of others as well as control over what is happening. In this case, the question regards the right to informational privacy, i.e., the right to control who has access to information about oneself. Of course, respecting confidentiality is one way to respect someone's privacy, but confined to cases of redisclosure[13] of information of a person given or obtained from that person. Thus, there may be ways to respect informational privacy that do not involve confidentiality. Can any such claims of privacy be used to argue for or against the requirement to obtain the consent of relatives?

I think claims of privacy can be used to argue both in favour and against this requirement, depending on how the right to privacy is understood more

---

[11] Parker would, I guess, concur with this conclusion. The reason that he talks about confidentiality in this context is that he also discusses the question of redisclosure of test result, which is a question of confidentiality, and the basis of such rights, i.e. autonomy and trust (Parker, 2001, p 452-453).

[12] I will return to this (see section VII.4).

[13] The redisclosure can be both active and passive by failure to prevent such redisclosure, e.g. by not properly protecting the journals of a patient.

precisely. If one emphasises the access-part of the right, it could be claimed that the right to informational privacy does not only contain the idea that one has control of the access of others to the information, but that one also should have the right to control one's own access to the information in question. That is, one claims that the right to privacy contains or entails a right of the individual to know of her own genetic information without this being conditioned on the consent of someone else. If the relative's consent must be obtained in some cases in order to be tested, they can veto the testing by not consenting.[14] This, of course, limits the individual's access to her genetic information, and can thus be claimed to be an illegitimate limitation of her right to privacy.

Perhaps even more obviously, the mother in the case of Rachel can use considerations of privacy to argue in favour of the requirement to obtain her consent. If testing can be done without her consent, Rachel can get information of her being a carrier of BRCA1. This would mean that she does not fully control who else has access to that information, which is a limitation of her informational privacy.

However, rights to privacy must be justified somehow. It is not necessarily so that an action being a breach of privacy is a reason against performing this action. For instance, we do not recognize a full right to informational privacy, i.e. all forms of access to all aspects of the person should not and cannot be in full control of the person herself. This is so, even regarding information that in one sense or another can be considered to be very personal, for instance a person's sex, occupation, hobbies, parents, and so forth. We all need and share information about each other all the time, and sometimes a piece of information is just plain obvious (e.g. about a person's sex or occupation). Extensive rights to privacy are therefore impossible to protect, and often not desirable. Thus, one has to provide justification of what kind of privacy that should be protected.

To simplify, there are two common ways of justifying rights to privacy: with reference to the instrumental value of recognizing such rights, or with

---

[14] The right to gain access to one's own genetic information without the consent of relatives can thus be described as a negative right, since the requirement of consent allows the relative to *prevent* the index-person from receiving that information. However, it can also be described as a positive right, since gaining access to genetic information most likely involves help from others (e.g. geneticists). This highlights the difficulty of drawing a precise line between negative and positive rights (see IV.1.1.1).

reference to the principle of respecting autonomy (Beauchamp & Childress, 2001, p 295-297).[15] Let us suppose that these ways of justifying rights to privacy are the only one's there are. We can then see that confidentiality and privacy are basically justified in the same way.[16] Since privacy can be used both to claim that there should and should not be a requirement of the consent of relatives, reference to privacy alone cannot solve the issue of whether there should be such a requirement. Rather, we should turn directly to the justification or basis of the claims to privacy and confidentiality, and see whether this can solve the issue.

First, just a brief reminder of why justifying rights of privacy on the basis of the personal and sensitive nature of genetic information will not do the trick of settling the issue of whether we should or should not demand the consent of relatives. Take the case of Rachel again. The mother could claim that since genetic information is especially personal and sensitive, she should have a right to control this information. Therefore, she should be able to prevent the daughter from obtaining this information by vetoing her genetic test. The daughter, on the other hand, could claim that since genetic information is especially personal and sensitive, she should have a right to control this information. Therefore, she should have access to it herself without being prevented by the vetoing of others. That is, from the same premise, two conflicting conclusions can be claimed to follow. In lack of reasons to the effect that one person's argument is flawed while the other is not, this shows the insufficiency of just referring to the (alleged) fact that genetic information is especially personal and sensitive in order to settle normative issues. Considerations of privacy, unlike considerations of confidentiality, thus seem to pull in opposite directions.

The justification of privacy, as well as confidentiality, can then refer to the principle of respecting autonomy or to consequentialist claims regarding the instrumental value of privacy and confidentiality. The latter type of reason will be the subject of subsection VI.2.4 below. Before that, I will consider the former line of reasoning.

---

[15] There are other ways, like Thomson's attempt to derive them from basic or fundamental rights, but this attempt has serious drawbacks (Beauchamp & Childress, 2001, p 296).

[16] Because of this, and because of the fact that confidentiality is a subclass of privacy, they are easily conflated.

2.3 Respecting autonomy

As previously mentioned, the most important (or at least the most usual) argument in favour of informed consent is that it is necessary in order to respect the autonomy of the patient. It has been claimed that arguments of respecting autonomy (as well as arguments of a consequentialistic kind) speak both in favour of demanding the consent of relatives *and* against such a demand: "respect for patient autonomy and the demand to avoid causing harm each appear to call both for testing without consent [from relatives], and testing only with consent." (Parker, 2001, p 451)[17] In light of this alleged conflict, there are, once again, two questions: Is testing without first requiring that the mother consents to the testing to violate the mother's autonomy? And: Is testing Rachel only with requiring the mother's consent to violate Rachel's autonomy?

In order to answer these questions, we have to take a closer look at the principle of respect for autonomy once again. Why is this idea thought to support the obtaining of informed consent from anyone, be it an index-person or a relative, in the first place? The idea can be fleshed out as follows. In health care, the decisions of the adult and competent individual ought to be respected (at least if this does not mean inflicting serious harm to someone else). This means that individuals should be allowed make their own decisions according to their own wants without being coerced or manipulated. To perform a medical intervention (treatment or testing) without obtaining or regarding the consent of the individual is to ignore the want of that individual and, thus, to coerce the individual into the intervention. This is a failure to respect the autonomy of the individual. To knowingly abstain from disclosing information that is relevant to the decision of the individual about the medical intervention in order to have the individual making a certain decision (perhaps one that the individual would not have made if she had that information) is to manipulate the individual. This is so, since the decision is not the result of the want of the individual (even if she thinks it is), but the result of the health care professional's wants. This is also a failure to respect the autonomy of the individual. So, the purpose of informed consent is to avoid coercion and

---

[17] See also the following statements: "testing third parties without their consent [would] fail to respect their autonomy" (Parker, 2001, p 452) and "This [requiring the consent of relatives] would mean that patients would only be able to gain access to genetic testing with the agreement and permission of others; surely in itself a failure to respect patient autonomy?" (Parker, 2001, p 453)

manipulation, since those are incompatible with respecting the autonomy of the patient (see also III.3.3).

If the purpose of consent is to avoid coercion and manipulation (and thereby respecting the patient's autonomy), then the first question is if Rachel's mother is coerced or manipulated through Rachel having the test without her mother's consent.

The following line of reasoning suggests that Rachel's mother is neither coerced nor manipulated through Rachel's testing. The only thing that would constitute coercion or manipulation of Rachel's mother to test herself would be if she were coerced or manipulated to have a genetic test herself. But she is having no genetic test at all: Rachel is. How can she be manipulated or coerced into doing something she is not even doing?

However, this line of reasoning gets the argument for demanding Rachel's mother's consent all wrong, it might be claimed. The core of the argument for requiring her consent was that, even if she has not had the genetic test herself, she is, in fact, tested if the result of the test is positive, i.e. others would *know* that she is a carrier of BRCA1. The *testing* in itself is not the object of concern, but the *result* of test is. A positive result for Rachel's test would, in effect, be a positive result for the mother since, at least, Rachel and some health care professional would have the information that Rachel's mother is a carrier. The idea, then, is that testing Rachel would, in effect, also be to test her mother. And if we demand consent in the first instance, we should do so in the second.

However, this is questionable. A presupposition for the test on Rachel giving information or knowledge about her mother being a carrier of the gene is that the test is positive. If the test on Rachel, on the other hand, is negative, it is as uncertain as it was before testing whether Rachel's mother is a carrier (there is still a 50% risk, since it is established that Rachel's grandmother was a carrier). So the test is a test on Rachel that could have implications for the knowledge of whether the mother is a carrier of BRCA1 (given proper background knowledge), not a test on the mother.[18] The question of whether the fact that the result of the test can reveal something about the mother means that her consent should be obtained too is the very question at stake, and cannot be settled by just referring to that fact again.

---

[18] *Pace* the rhetorical formulation of Lucassen that this is so (Lucassen, 1999, p 323).

Neither would Rachel be coerced or manipulated by a requirement of relatives' consent. She is certainly not manipulated by openly being presented this condition for testing, since it is only to tell her what she has to agree to in order to get tested. She is obviously not coerced into testing either. It might be claimed that such a demand is coercing her into *not* testing herself. But she is only coerced in a weak sense: there is a condition of testing that she might find so unacceptable as to choose not to test herself. That is, she cannot have it her way all the way: she cannot, e.g., both avoid telling her mother about her plans of testing and have the test performed. And this is not how coercion is normally conceived of when talking about coercion in health care. As we saw above, traditionally, coercion *into* having some type of care has been the kind of coercion that respect for autonomy is supposed to protect the individual from (Tännsjö, 1999, p 17-18). So, it cannot be in the traditional sense respecting autonomy, i.e. avoiding coercion or manipulation, that someone's autonomy is violated by testing with, or without, the requirement of the relatives' consent.

Rather, it is some weaker idea of respecting autonomy one must have in mind when claiming that (not) requiring the consent of relatives is to violate someone's autonomy, namely 'respecting autonomy' in the sense of 'respecting wishes', i.e., doing something in accordance with someone's wishes. Surely, a lot of things may happen as a result of testing, without the mother's consent, which is contrary to her wishes. In this sense, then, the mother's autonomy could be violated. To start with, the mother may not want the daughter to test herself. Without a requirement that the mother's consent is obtained, the daughter can test herself against the wishes of the mother (she will perhaps never know about it, but it could still be against her wishes). But this cannot be a part of reasonable ideal of respecting autonomy, since any reasonable principle of respecting autonomy has to be based on the idea of *personal* autonomy (see III.3.3), which means that the right to have one's autonomy respected cannot include matters that regard others. In this case it means that *my* autonomy is not violated by the mere fact that I do not want *you* to get tested and you do. It has to be demonstrated that this decision somehow regards me.

However, this seems to be a straightforward task in the discussion at hand, since the test can reveal information about a relative (it will if it is positive); information that, then, in some sense regards her. And the mother may not

want the daughter to find out that she (the mother) is a carrier of BRCA1, which the daughter will do if the test is positive. And for you to find something out about me surely regards me (or so we may assume). Furthermore, the mother may not want to find this information out herself, but if the daughter has a positive test, this may happen. So in the sense of 'respecting wishes (regarding information about myself)' the mother's wishes *may* be violated by Rachel's testing (if she has any of these wishes and the test is positive). A right to veto such testing with a demand to informed consent of relatives will protect autonomy in this sense.

In the same sense of "respecting autonomy", requiring the consent of relatives in order to get tested *may* lead to the index-person's autonomy being violated. This is so if the index-person wants to get tested without telling the relatives and/or if the index-person wants to make the decision of testing herself. If there is a requirement that she obtains the consent from the relatives in order to get tested, the index-person cannot have it her way regarding these decisions. So, in this sense, there really is a conflict of autonomy. This is not a very surprising result: if some piece of information is potentially about several individuals, and some of these individuals, P, want to have the information while others do not want P to have that information, some in this group of individuals that the information is about is bound to have their preference frustrated. So reference to what different people want cannot settle the issue.

However, it is doubtful whether this conflict should be cast in terms of *respecting* autonomy, since to interpret 'respecting autonomy' just as 'respecting wishes' is to interpret the idea of respecting autonomy more weakly than what is common in biomedical ethics. Rather, it should be cast in terms of a conflict of the value of autonomy: granted that the individuals' wishes are basic and authentic (enough), they all could lead less autonomous lives (less of the lives they want to live), which is bad according to the ideal of self-realization, due to there being or not being a requirement for the consent of relatives. In the case of Rachel, the mother would do so, if Rachel then finds out that she is a carrier of BRCA1 (which she can do if there is no requirement for the consent of relatives and given that the mother does not want Rachel to know that she is a carrier of BRCA1). Rachel would, on the other hand, do so if her mother finds out about her plans of testing and refuses to go through with testing (which she can do if there is a requirement for the consent of relatives and given that Rachel does not want her mother to find out about her testing-plans and wants to go through with testing). Construed as a conflict in term of

the value of autonomy, Parker is right to insist that reference to autonomy can be used to support both testing without consent from relatives and testing only with consent. Then the issue will be difficult to settle indeed only with reference to autonomy. However, the conflict should not be construed as a conflict of respecting autonomy. Otherwise, there will be great difficulties in resisting demands of patients, since understanding respect for autonomy as respect for wishes implies that patients can claim that their autonomy is violated every time they do not get what they want. Rather, the conflict should be understood as being about which of two competing values or interests is most important to actualise, i.e. in consequentialist terms.

2.4 Consequentialist arguments

This takes us to the instrumental reasons for confidentiality and privacy. Recall the consequentialistic line of reasoning supporting confidentiality: that certain information from a patient is not forwarded or is duly protected, is a prerequisite for the patient's trust in the doctor and the health care system in general, a trust without which the patient will be reluctant to share information (which will lead to worse care), or even reluctant to contact health care at all (which will lead to no care). A similar line of reasoning can be presented regarding privacy: if information about a patient considered to be especially personal (like, maybe, genetic) is disclosed without the consent of the patient, this can damage the patient's trust in health care and if done routinely a general distrust in health care institutions may result.

Does any argument of this kind speak in favour of or against demanding the consent of relatives? Parker claims that also arguments of this kind pull in both directions (Parker, 2001, p 452-453), so there is a conflict of consequences as well as one of autonomy. The point above about how to analyse the conflict of autonomy between Rachel and her mother may seem to point in the same direction. On closer inspection, however, I would say that the claim of a conflict of consequences is more doubtful, since the pull in the one direction seems to be stronger than the pull in the other.

Let us first turn to the consequentialistic argument against requiring the consent of relatives: "Would people come for genetic testing if they knew that this information would be shared with relatives? In many cases, one suspects not." (Parker, 2001, p 453) This argument does not really mention trust at all. And this is as it should be, since trust is primarily an issue when it comes to breaching confidentiality and, as we saw, requiring the consent of relatives is

not really about breaching confidentiality at all: requiring the consent of relatives is not to reveal something to someone else about the patient, but to require that the patient reveals something to someone else in order to get a service. It is not clear why openly making such a condition for the access to a service would undermine any trust or confidence at all.

What the argument does is to skip the "trust-step" of the standard argument of confidentiality and move directly to a detrimental effect of requiring consent, which may also be effectuated by distrust: less testing. The thought is the following. Requiring the consent of relatives may discourage or deter people from genetic testing, since they may be reluctant to let relatives know that they are testing themselves or reluctant to place the final decision of testing in the hands of relatives. And since testing may realize values (and avoid negative values) to persons tested, if people are discouraged or deterred, less value (or more negative value) may be realized.

Even though it is far from self-evident that more testing will realize more value, as seen in chapter II, let us grant that values are regularly realized by testing, so that less testing will have detrimental consequences. Does, then, the requirement that relatives should consent to testing lead to less testing? This question is empirical, but, as Parker says, the answer is probably yes. The development of molecular testing that can be done individually has been presented as an improvement compared to old testing procedures that required the cooperation of the whole family, just because reluctant family members could, and sometimes did, veto the testing of one individual (Harper, 1996, p 55).[19] So persons from families with strained relations or persons who for various reasons know that their relatives do not want to know may very well abstain from testing due to requirements of relatives' consent.

Against this it might be held that if testing is important enough, for instance, if it is a question of life and death, most people will opt for testing despite the requirement of the consent of relatives. This obviously is the case when there is a fatal hereditary condition for which there are efficient medical measures. But in these cases, it certainly seems unreasonable for relatives to be able to veto testing, since the values that can be realized from testing are so great as compared to the disastrous consequences that could result from

[19] Harper, 1996, p 55, writes: "The advantage of newer specific genetic testing approaches that no longer make it essential to sample the whole family is strikingly illustrated here; the different family attitudes to information and testing may remain frustrating, but at least they no longer need to prevent the member who does wish to know her risk from attaining this."

abstaining from testing (see II.2.1). However, in cases such as these, there certainly is a strong case for informing relatives if the test shows that they may be at risk, also against the wishes of the patient. But this is another (although related) question to which I will return (see VI.3.1). Rather, generally speaking, if one is reluctant to do a test *due to* the fact that one is concerned that relatives might find this out, it is unlikely that a *requirement* to obtain the consent of relatives (and thus a requirement to let them know that you are planning to test yourself) will lead one to become less reluctant.

Is there a similar argument to be evoked in favour of requiring the consent of relatives? Parker seems to think there is:

> [T]esting third parties without their consent... would also be likely to lead to harms comparable to those associated with breaching the confidentiality of the index patient. Would confidence in the genetic service not be undermined by the realisation that people were being routinely tested for inherited conditions without being informed of the results? Would it not be further undermined by the knowledge that such information was at the same time being made freely available to their relatives? (Parker, 2001, 452-453)

From this passage, it is unclear what is being claimed to undermine the confidence in genetic services. Is it not informing relatives of results from testing the index-person when the result has implications for the genetic constitution of the relatives in question, or is it not obtaining consent from the relatives in order to test the index-person when the result of such testing could have such implications, or both? Since both consent and informing relatives are mentioned, probably both (or whichever one of them), but as we are concerned exclusively with the second question here, I will leave the first one for now.

Will, then, not requiring the consent of relatives for the testing of a patient lead to an undermining of the trust, or confidence, in genetic services (a part of health care)? Maybe, but not necessarily in the way "likely to lead to harms comparable to those associated with breaching the confidentiality of the index patient." (Ibid.)

Recall once again the consequentialistic argument for confidentiality. This argument says that undermining trust is bad because it can lead to people

abstaining from informing health care professionals properly or abstaining from health care altogether. So distrust is bad because it leads to worse or less health care. But it is hard to see why this should apply in this case, that is, it is hard to see why worse or less health care would be a consequence of not requiring the consent of relatives in genetic testing. Why should anyone think it relevant to anyone's decision of genetic testing that a relative already has or may have information that may result from such testing?

Of course, "confidence" may be undermined by not requiring the consent of relatives in another sense of confidence: relatives (and people in general) may be upset about or resent the fact that someone else can get this information about them without their consent. But this is not undermining confidence in the way relevant to the standard argument for confidentiality. So, in the argument against demanding the consent of relatives, we have the second step of the consequentialistic argument for confidentiality (it will lead to less testing), but not the first (it will lead to less trust). And in the argument for demanding the consent we have *a version of* the first step (it will, in a sense, lead to less trust), but not the second (it will lead to less testing).

Comparing these negative consequences, I think the scale tips in favour of not requiring the consent of relatives. It seems worse that some people are deterred from genetic testing altogether than that some people are upset about the possible access of others to genetic information about them. Ultimately, this depends on the degree of deterrence and the consequences of people being deterred as compared to the degree of resentment and consequences of people being upset. Of course, it is always hard to determine this kind of consequences and naturally, it can only be settled empirically. For instance, it may be so that people will be so upset with the fact that relatives can get information in this way that they withdraw support from society offering genetic testing at all, leading to a public outcry for not providing, or even forbidding, such testing. This may surely lead to less, perhaps no, testing. But this is an empirical speculation lacking any substantial support, as compared to the already existing empirical indications of deterrence from testing when requiring the consent of relatives.

2.5 The problem of arbitrariness

As we have seen, arguments have been put forward both for and against the requirement of relatives' consent. I have argued that arguments referring to the general norms within health care cannot settle the issue. The norm of

informed consent is the one being at stake, and thus cannot be used in a way that is not question-begging. The norm of confidentiality does not apply, and the norm of privacy can be used in either way. There are two kinds of justificatory principles of health care one can resort to: autonomy and consequentialistic arguments. The principle of respecting autonomy as traditionally conceived of in biomedical ethics, i.e. avoiding coercion and manipulation, does not apply and autonomy in a weaker sense does not settle the issue. However, consequentialist concerns seem to weigh in favour of not requiring the consent of relatives as a condition for testing. In this passage, I would like to argue the case against requiring relatives' consent further.

As we have seen, the issue of requiring the consent of relatives only becomes pressing when the test of the index-person is (highly) predictive of some relative. Otherwise, relatives have no interest in having a say about testing. At least, they have no interest of the same kind as the index-person, relating to the genetic information and the possible values of getting such information. This is why the question of the relatives' consent is only discussed in relation to genetic testing that is (highly) predictive of someone else, an assumption taken for granted also in my own discussion above.

However, the actual predictability of genetic tests with regard to relatives may vary considerably (I.4.1). This means that anyone who tries to make a case for requiring the consent of relatives on the basis of such predictability faces a question: how predictive should the testing be in order for it to be reasonable to require the consent of relatives? In order to answer this, we will have to say something about how to determine the degree to which a test is predictive of someone else. Let us once again return to the case of Rachel. As previously noted, a prerequisite for the test on Rachel giving information about her mother is that the test is positive. If the test on Rachel is negative, it is as uncertain as it was before testing whether Rachel's mother is a carrier (there is still a 50% risk, since it is established that Rachel's grandmother was a carrier). What we know before the test, when the question of the mother's consent is relevant, is that Rachel has a 25% risk of being a carrier. In the light of this fact, what are we to say: that the test means a 25% risk of testing the mother and thus that the predictability of the test is 25%? Let us grant this for now. Is this risk of testing her mother sufficient to warrant requiring the mother's consent? If so, how about cousins on the mother's side? How about second cousins? At what point on a sliding scale would the predictability become too low to warrant requiring the consent of a relative?

Moreover, it does not seem unreasonable to claim that not only the predictability for the relatives but also for the index-person herself is relevant for the plausibility of requiring relatives' consent. Suppose that a gene that increases risk for diabetes with 15-30% before the age of 50 in comparison to the population in general is found, and suppose there is a test determining whether or not one is a carrier of that gene. It seems reasonable, at least prima facie, to say that the (alleged) reason to obtain the consent from relatives in order to do this testing is weaker than the reason for doing so for e.g. Huntington's disease, where a carrier is sure to get the disease eventually (if she does not die first). So how predictive, in this sense, should a genetic test be in order for us to demand the consent of relatives?

As these questions indicate, the general problem is the following. To require the consent of relatives *before* testing presupposes that we settle the issue of which degree of predictability that is high enough in order for the requirement to "kick in". Besides difficulties in determining the degree of predictability regarding the relative and determining whether and how the degree of predictability of the test itself should be relevant, there seems to be no answer to this question that is not morally arbitrary.[20] Say that you answer "25%". Then it can be asked: "Why not 30%? Or 20%?" If we do not know for sure that testing will reveal something about the genetic constitution of the relatives in question, any way of specifying the likelihood of such possible revelation required for an obligation to obtain the consent of relatives to kick in seems arbitrary.

Furthermore, it should be noted that many medical tests in health care besides genetic tests might be revealing of someone else, which makes the moral arbitrariness of requiring the consent of relatives for genetic tests even more obvious. Tests for sexually transmitted disease is one example. If Jill, who has been sexually faithful to Jack her whole life, tests herself for gonorrhoea and the test turns out to be positive, she will know that Jack is a carrier of the bacteria of the disease. Should we thus demand that the consent of Jack is to be obtained in order for the test to be performed?

---

[20] The only non-arbitrary line to draw is when testing one person is revealing of someone else for sure. But this is very rare. One example is genetically identical twins and another is genetic carrier detection for the gene for fragile X on the father. If the test is positive, any son must be carrier too, and the same goes for negative testing. But then they are very likely to be symptomatic, which makes the question of presymptomatic testing irrelevant.

I think that we should not. And the simple reason for this is that Jack could then veto the testing of Jill. This veto could lead to Jill being seriously harmed, harm that Jill has contacted the health care system to avoid. In this regard, the situation is exactly analogous to that of Rachel and Rachel's mother: to demand that Rachel's mother's consent should be obtained in order for Rachel to test herself is to leave the decision of Rachel's testing to Rachel's mother; only if Rachel's mother consents, Rachel can have the test.

Of course, there are differences between the gonorrhoea test and the BRCA1 test. They are different kinds of tests for different kinds of things. One difference may be said to be that the latter test is more "directly" revealing than the first, since the first test requires background knowledge of Jill in order to be revealing of Jack (e.g. about her sexual faithfulness to him). Thus it might be claimed that the family doctor of Rachel (let us assume that she is also the doctor of Rachel's mother) would know about Rachel's mothers status as carrier the very same moment she would find out that Rachel is a carrier (if that is what he would find out). On the other hand, the family doctor of Jack and Jill would have to know that Jill had no other sexual relations in order to conclude that Jack is also infected.

However, this alleged difference is, at best, merely a difference in degrees. Genetic information in general also requires background information in order to be revealing, e.g. about the mechanism of heredity and about the familial relations between the concerned parties. Moreover, Jill's family doctor may know Jill well enough to be very confident in her assurance about her faithfulness to Jack. Then it is hard to say that this test is not equally revealing. The fact that the degree to which a medical test is revealing of someone else is due to background knowledge holds with regard to medical testing in general, genetic or not. Furthermore, it may be claimed that the gonorrhoea test is more directly revealing than a test for BRCA1 in another sense, since it reveals actual presence of a disease and not just the propensity thereof.

The problem of drawing a non-arbitrary line of predictability and comparisons with other medical tests strengthens the case against requiring the consent of relatives. Together with the consequentialist arguments and the absence of considerations to the contrary we are certainly warranted to reject the idea of requiring such consent.

3. Disclosure to relatives

In the introduction of this chapter, a distinction was made between informing relatives before testing (that testing will occur) and after testing (that testing has occurred, or the result thereof). The main reason to inform relatives before testing is, naturally, that doing so gives relatives the possibility of affecting whether testing is done when test results can reveal information about the genetic constitution of the relatives in question. I argued that there are reasons to deny them that possibility. However, maybe the relatives' possible interest in being informed about the result of such testing should be recognized nevertheless. That is, the question of whether, and, if so, when, how, and by whom, relatives should be informed about the genetic testing of the index-person(s) remains unanswered, even if one concurs that the consent of the relative(s) should not be required in order for testing to be performed.

However, as mentioned above (VI.2), contact is often made with relatives before testing, since constructing a pedigree often is an essential component of the testing procedure. In order to construct a pedigree, estranged or unsuspecting relatives may have to be contacted. Contact is then made for the sake of the index-person rather than the relatives. Of course, one could then ask whether these relatives should be contacted. However, to abstain from testing only because one thinks that one should not contact certain relatives is, in effect, to let them veto testing, which I have argued that they should not be allowed to. This, of course, does not exclude the possibility that the index-person does the right thing when abstaining from genetic testing in order not to upset some relatives. Neither does it exclude the right of the relatives to abstain from participating in the pedigree (for instance by denying access to their medical records). Nonetheless, the relative should not be allowed to stop the genetic test (even if the predictive value of the test may be undermined by some relative's refusal to reveal facts relevant for the pedigree).

Because of this, the main question to address is whether (and, if so, when, how, and by whom) test *results*, i.e. after testing, that have implications for the genetic constitution of relatives should be disclosed to them. I will discuss this question by investigating arguments for and against claims to the effect that different parties have reasons to do this. Some of these arguments are about the general claim that there are reasons for informing relatives, but does not address the question of *who* has this reason (see VI.3.1.1). But some arguments are about the question of the more exact party that has the alleged reason in question (see VI.3.2). Perhaps surprisingly, some of these arguments are not

really about who should inform, but rather about who has reason to see to it that relatives do get informed, irrespective of whether they do the actual informing themselves. For instance, even if the index-person has special obligations towards her relatives, it does not follow that the index-person should do the actual informing. It could be that health care professionals should do that instead (see VI.3.1.2).

This leaves us with three questions: should relatives be informed of the result of genetic testing (and, if so, when and how)? If they should, who has the most reason to see to it that they are informed? And who should perform the act of informing them? In relation to addressing these questions, I will also address the question of whether it should be allowed or forbidden to inform relatives.

It should be kept in mind that these questions arise only in certain circumstances. The index-person(s) seeking genetic testing has prior knowledge, or at least suspicion, of being at risk for genetic disease. If the index-person knows that her relatives has the same knowledge or suspicion, she may very well leave the decision to seek genetic testing to these relatives. The question of disclosing the result of genetic testing to relatives thus arises primarily when there is reason for the index-person to believe that there are relatives at risk that are unaware of themselves being at risk. Furthermore, disclosure is important primarily when the result of the test is positive, since only positive results increases the initial risk of the relatives.

3.1 Well-being and autonomy

As we will see in this subsection, reasons to inform relatives are sometimes cast in terms of well-being and autonomy, or can at least be reformulated in this way. This is helpful, since it allows us to use previous findings in formulating a general theoretical answer to the question of whether and, if so, when relatives should be informed. However, this answer leaves many practical questions of when to act on these reasons unanswered, since we will not always know when the reasons are present. I will discuss some merits and flaws of suggestions on how to answer the practical questions after addressing the theoretical question.

3.1.1 Theoretical solution

Consider the following statement:

> Genetic testing of one person can produce information that will make predictive testing available to other family relatives that would not otherwise have been possible. This information may enable them to make more informed reproductive choices, to make choices about surveillance, or to avoid unnecessary treatment. If this information is not made available relatives may die or suffer serious harms as a result. (Parker & Lucassen, 2003, p 73)

What this argument says is that relatives can be better or, rather, (much) less worse off by receiving genetic information from the index-person, than they would have been if this information had not been disclosed to them. More precisely, well-being (or avoidance of "ill-being" or harm) may be realized for the relatives, for instance by giving genetic information that makes the relatives "avoid unnecessary treatment", or the autonomy of the relatives may be increased, for instance by giving them genetic information that "enable them to make more informed reproductive choices". That is, very much the same values that can be realized for the index-person by receiving genetic information (II.2.4) may also be realized for the relatives.

However, this last claim needs to be modified somewhat. Some of the values that can be realized for the index-person are unlikely to be realized for the relative. Perhaps most obviously, the psychological well-being of removing the anxiety of uncertainty may not be an advantage of disclosing genetic information to relatives, since they may not have any prior suspicion and hence no uncertainty to remove. Rather, one may give rise to anxiety by informing of previously unsuspected genetic risk. It is well known from genetic counselling that some index-persons are reluctant to contact relatives just because they do not want to cause anxiety and distress (Adelswärd & Sachs, 2002, p 83; Clarke, 2003, p 80). This is probably the reason why Parker and Lucassen mention health-related advantages and promotions of autonomy as examples of the potential benefit of disclosure to relatives. The reason to disclose results from genetic testing when there are no health-related advantages thus seems weaker in the case of relatives.[21]

---

[21] Although there may be psychological advantages for relatives, e.g. strengthened emotional bonds within family and time for psychological adjustment to cope with the (more or less probable) disease (see II.2.2.1).

Nonetheless, the fact that well-being and autonomy may be realized for relatives provides reasons for disclosing the information to the relatives, just as the realization of such values for the index-person provides reasons for testing her. This is not to say that anyone in particular has such reasons, only that at least someone does. If the reasons are strong enough and if there are no reasons strong enough to the contrary, someone thus has an obligation to disclose the information.

Now, generally, the following principle seems to be somewhat reasonable: when obligations are based on values (realization of positive or prevention of negative values), the more value that can be realized and negative value that can be prevented, the stronger the obligation. For instance, if one can prevent someone's death by disclosing some information, the obligation to disclose the information is stronger than if one can prevent some minor inconvenience by disclosing the information.[22] That is, it seems reasonable to claim that the more benefited the relative would be by receiving the information, the stronger the obligation to disclose it, ceteris paribus.

Moreover, the converse seems to hold equally: the more harm the relative would suffer as a result of receiving some (genetic) information, the stronger the obligation *not* to disclose it. And, as we have seen, receiving genetic information may also produce negative values or harm (see e.g. II.2.4). This means that the argument above does not support a general obligation to disclose to relatives, but only an obligation to disclose when and to the extent that the relatives in question actually would be benefited by the information. Indeed, when and to the extent that they would be harmed by the information, there is an obligation of corresponding strength not to disclose it.

This indicates a theoretical solution to the problem of disclosure to relatives: there is a moral reason to disclose if, and to the extent that, relatives would be benefited by disclosure and a moral reason not to disclose if, and to the extent that, relatives would be harmed by disclosure. In those cases where there are reasons pulling in both directions (i.e. where both benefits and harms would result), the overall strength of the reason to disclose or not comes down to the relative strength of these reasons (in turn determined by the magnitude of the harms and benefits in question). As already indicated,

---

22 Given the usually correct assumption that the negative value of death is greater than the negative value of some minor inconvenience.

benefit should be understood broadly, both in terms of well-being and autonomy (as a gradual value) and also as to include avoidance of harm. This general solution could be interpreted more precisely in numerous ways. For instance, it is compatible with the common sense-view of morality that it is (much) more important to prevent harm than to improve the situation of someone already well off (i.e. the idea of an elevated weight of evil). However, I think few would be inclined to abandon the view that if an action benefits someone already well off, this gives the person who can perform the action at least some reason to perform it, even if the reason is easily overridden (perhaps a desire not to perform it would be enough in some circumstances). So even if the details of the solution can be fleshed out in different ways depending on the ethical theory one favours, the general character of the solution seems sound on a theoretical level.

3.1.2 Practical solutions

However, a practical problem remains, since it may be hard to know before disclosure whether or not the relatives would actually be benefited or not by the information. The only certain way of finding that out is to disclose the information, but then the question of whether one should do so or not is no longer open. One way to tackle this is to say that information should be disclosed to those relatives who want the information in question, presupposing that the fact that they want it is a strong indication that they will be benefited by it. However, this will only push the problem a step further. Remember that the question of disclosure arises primarily when there is reason to believe that the relatives do not have any prior suspicion of increased genetic risk. If one knows that they have prior suspicion and yet have abstained from genetic testing, this constitutes a reason to believe that they do not want to have the result of the test. However, without prior suspicion, the only way to find out if they want some information about increased genetic risk for disease is to let them know that there is such information. And this may very well be something they do not want to know about. To put it more concisely: the only way to find out whether or not they want to know is to let them know. So by finding out who wants to know, one will fail to respect the wishes of those who do not want to know. So even if there is a theoretical answer to the question of when genetic information should be disclosed to relatives ("only when they would be sufficiently benefited by it"), the practical problem of *how to decide* when to disclose this information remains. I will now

address some possible suggestions regarding how this practical problem should be solved.

The index-person's decision. One practical solution is to leave the decision to the index-person herself.[23] This solution has some advantages. Firstly, it protects the confidentiality of the index-person: if she does not want to reveal genetic information about herself to relatives, she does not have to (I will return to this below). Secondly, one can expect that most people are more acquainted with the situation of their relatives than are e.g. health care professionals, which makes them good candidates for determining whether or not the relatives would be sufficiently benefited by the information. One can also expect that most people are benevolent towards their relatives,[24] and therefore willing to decide according to their best interest.

However, even if index-persons often are acquainted with and benevolent towards their relatives, it is well known from genetic counselling that this is not always so. Index-persons may be in conflict or have no contact at all with their relatives. Thus, genetic information "could also become a tool of revenge in dysfunctional families" (Knoppers, 2002, p 85), for instance by non-disclosure when relatives would be benefited by the information or by disclosure to relatives in order to upset them.

The health care professional's decision. In the light of these problems, one may propose that health care professionals (and then primarily the geneticist and/or the genetic counsellor) should make the decision, at least in some circumstances. The obvious drawback with this proposal is that it threatens the confidentiality of the index-person. Relatives are likely to learn that the reason that they are being contacted about genetic risk is the positive test of the index-person, in which case they will receive genetic information about her. If it is up to the health care professional to contact the relatives, this can be done

---

[23] This strategy is implemented in, for instance, the UK (Hallowell et al, 2003, p 74-75) and Sweden.

[24] Some empirical findings seem to support this, for instance Hallowell et al, 2003, who performed interviews on women who were diagnosed with breast and ovarian cancer and who tested for BRCA1/2. A large majority of these women stated that their primary motive for testing was the good of their relatives in some way or another, e.g. in terms of their autonomy and/or well-being (see primarily Ibid, p 75-77).

without the consent of the index-person, which clearly makes it a breach of confidentiality.

Another problem of letting health care professionals make the decision of whether or not to disclose is that health care professionals may be more eager to disclose than relatives.[25] This may lead to disclosure even in cases where the relative is not benefited and even harmed by receiving the genetic information in question.

In order to avoid these problems, one could confine allowance for health care professionals to decide whether or not to disclose to situations where it seems obvious that relatives would suffer serious harm if they were not informed. In such circumstances it may seem reasonable to presume consent to being informed on part of the relatives. This strategy would limit the cases of breaches of confidentiality, and is in line with general norms of biomedical ethics. It is also a strategy that is gaining in popularity (Knoppers, 2002, p 86). However, this leaves us with specifying the conditions that have to be fulfilled in order for breaches of confidentiality to be allowed. Here is a suggestion:

> In the situation of repeated refusal by the patient, four conditions must be met before it is seen as ethically permissible for the physician to breach medical confidentiality: (1) the condition in question must be serious with (2) a high probability of occurrence, (3) in an identifiable blood relative(s) and (4) prevention or treatment must be available. (Knoppers, 2002, p 86)

To this it should be added that the prevention or treatment available must be efficient and not too burdensome, since the value of the prevention or treatment can be questioned if it can be experienced as being as burdensome as the condition it is a prevention or treatment for (see II.3.4.2). Even if these conditions are vague (like "serious" and "high probability"), they will most likely make the situations where health care professionals are allowed to take over the decision to disclose from the index-person rare indeed. As we have seen, there are no efficient and non-burdensome preventions or treatments for almost all monogenetic diseases. And multifactorial diseases probably will not have a high probability enough for condition (2) to be fulfilled (see I.4.1).

---

[25] There seems to be some indication that they are, perhaps partly because they often also have the role of the researcher interested in collecting data (Adelswärd & Sachs, 2002, p 84-86).

Nevertheless, since the basis of respecting confidentiality in health care as a general rule seems firm enough (VI.2.2), and the value of relatives' knowledge can be questioned unless there are obvious benefits of knowing, conditions like the ones above seem plausible.

Contractual solutions. However, this still leaves health care professionals with some room to breach confidentiality. One could try to sidestep this problem in the following way. Whenever the index-person asks for genetic testing and the above conditions are fulfilled, she is told that relatives will be informed if the result indicates that they are at risk. This can be made in the form of a contract.[26] Then, whenever the index-person consents to testing she also consents to relatives at risk being subsequently informed. Thus, it is not a breach of confidentiality.[27] It is neither to require the consent of relatives in order for testing to be done, since the consent of the relatives does not have to be obtained. No other person than the index-person has to consent to testing in order for testing to be done.

However, even if such a contract preserves the confidentiality of the index-person in a formal sense, it could be argued that the same argument that justifies confidentiality could be directed against this proposal: one could claim that a contractual term stating that relatives will be contacted if they are at risk may deter the index-person from going through with testing, just like a threat of breach of confidentiality may do so. And then the relatives who could have been benefited will not get the information anyway, since the index-person will not test herself in the first place.

The index-person's decision and persuasion. In the light of all of these problems, one could once again resort to the position that the index-person should always have the ultimate decision. One could also add that "informal encouragement of family discussion" (Parker & Lucassen, 2003, p 72) or "seeking to persuade them [the index-persons] to pass on relevant information to others" (Clarke, 2003, p 81) may be recommendable in some circumstances. But once again, this would still leave us with the problems of relatives not being informed

---

26 Doukas & Berg, 2001, have made a similar proposal.

27 However, it is a restriction of the index-person's privacy, since it circumscribes the control she has over her genetic information: she cannot get the testing without agreeing to the terms, which could lead to the spreading of the information.

when the index-person persists in her refusal, or relatives being informed by the index-person in an adverse manner.

This only goes to show that there may not be a neat solution to the practical problem of deciding when to inform relatives. When it comes to values like well-being and autonomy, there can always be conflicts, and difficulties predicting and controlling outcomes. If the basis of some solution is to be sought by reference to these values, one will have to know quite a lot about what would happen if different strategies were implemented. That is, some empirical questions need to be answered, for instance the following: If we allow the overriding of the decision of the index-person on some occasion, how great would the threat to trust in genetic services and the negative effects of non-occurrence of testing be? If we set up contracts stating that the result will be disclosed to relatives if they are at risk, how great would the negative effects of non-occurrence of testing be in that case? If we allow index-persons to make the decision all by themselves, how many relatives that could have been benefited by being informed if we adopted some of the other solutions will not be thus benefited? How many will receive information that is in fact harmful to them?

Without pretending to have an answer to these questions, I would say that experiences from the practice of genetic counselling provide some clues on how to solve the practical problem. One lesson from genetic counselling seems to be that one should not underestimate the importance of respecting confidentiality. Not doing so can be counterproductive from the point of view of the relatives, since doubts about the confidentiality being protected can lead to defection from genetic testing by the index-person, in which case the relatives will remain uninformed anyway. Angus Clarke, one of the pioneers of modern genetic counselling, writes: "Any sense of, "You had better tell her [the blood relative in question] now because otherwise we will", would be damaging and likely to lead to further blocks in family communication." (Clarke, 2003, p 80) Furthermore, to have weaker requirements of confidentiality in genetics than in health care in general runs the risk of starting "down the slippery slope towards "paternalistic" medicine in which other family members and health care professionals would be able to decide what is best for the patient." (Parker & Lucassen, 2003, p 73)

Moreover, since the day of Hippocrates, the primary concern of the health care professional has been the person in front of her looking for help, i.e. the

patient (see II.2). This has many reasons. One is pragmatic: the needs and wants of the patient in front of you stands in a clear light, while the needs and wants of potentially concerned third parties normally will be a subject of more or less qualified guesswork. Another reason is that primary attention to the patient is crucial for patient's trust in health care professionals. This does not mean that health care professionals can totally disregard the interest of third parties. If the goal of health care is to promote well-being and (perhaps) autonomy, the well-being and autonomy of third parties cannot be totally irrelevant (see III.3.2.3). But as a rule, the interest of patients should be the primary concern of the health care professional.

This means that if confidentiality is to be breached, there should be very good reasons indeed for doing so. Other possibilities, like persuasion, must be tried first. A contractual solution may seem somewhat more attractive in the light of the importance of confidentiality. Even if such a solution may lead to defection too, it is more likely to preserve trust, since the terms of disclosure are out in the open to start with. However, if the level of defection were to be larger than the number of relatives that would not have been contacted if there were no contract, this solution looses its rationale. And whether this is so, seems hard to find out.

Another lesson from genetic counselling is that genetic counselling can solve much of the practical problems (Clarke, 2003). Discussions between counsellor and counselee may very well make the counselee abandon her reluctance to inform relatives in those cases where there are reasons to believe such disclosure to be in the relatives' interest. This may be considered to be persuasion a type that is incompatible with the norm of non-directiveness, but many forms of "persuasion" can in fact be quite compatible with this norm (II.3.3.5).[28] For instance, if the persuasion consists in encouragement of family communication prior to testing by informing that the consequences of not informing relatives of genetic information they reasonably can be expected to want may be devastating also for the index-person herself (e.g. something like "if there were any hope of reconciliation it will almost certainly be lost by such an omission"). Pointing out such psychosocial consequences of genetic testing is increasingly becoming an integral part of genetic counselling and is

---

[28] *Pace* Clarke, who writes that "seeking to persuade them to pass on relevant information to others... will often entail a radical departure from strict adherence to the ethos of non-directiveness" (Clarke, 2003, p 81).

done for the sake of the index-person herself. It is thus well in line with the concern for her autonomy and well-being, the ultimate rationale against which any standard of non-directiveness should be assessed (see II.3.3.5). Of course, other forms of persuasion, such as outright moral blame directed at the index-person, are harder to reconcile with the ideal of non-directiveness. However, if the harm of the relative(s) of not knowing is great enough, such persuasion may be preferable to any alternative. The interest of relatives can therefore justify deviation from non-directiveness, and this may be better than blunt breaches of confidentiality.

Finally, the fact that there sometimes is an obligation to inform relatives leaves the question of who has this obligation. In the next section, we will address arguments that claim that it is the index-person who primarily has such an obligation, due to the special relation she has to her relatives. However, even if one concurs with such an argument, it does not follow that the index-person herself should do the actual informing of the relatives. The obligation, if there is any, is to see to it that relatives are informed. There may be good reasons to let the index-person delegate the actual informing to some health care professional.[29] One such a reason is that misunderstandings of the information are less likely to spread among the relatives if a trained professional does the actual informing. Another is that it may be difficult for the index-person to contact relatives: it may be hard to be the messenger when you are bringing bad news (Adelswärd & Sachs, 2002, p 71-86). If the genetic counsellor or some other professional offers to do the informing, some reluctance to inform may fade. If nonetheless the index-person does the informing, the counsellor must try to ensure that she has understood the information properly and is willing to take on the task.

3.2 Special obligations due to special relations

As we have seen, there are arguments in favour of disclosing genetic information to relatives, referring to more or less traditional health care considerations in terms of well-being and autonomy. However, it has also been claimed that one has special obligations to see to it that relatives and family members are informed, by virtue of them being relatives and/or family

[29] This shows that what Hermerén, 1999, p 154-155, calls the messenger approach (that the index-person informs) and the clinical approach (that the health care professionals inform) can be combined.

members. The underlying rationale is well known in moral philosophy: that some relationships between individuals give rise to special moral reasons or obligations (Kagan, 1998, p 125-137).[30]

3.2.1 Special obligations due to genetic bonds

Do we have special obligations towards our blood relatives,[31] only due to the fact that they are our blood relatives? In order to answer this question, one has to demarcate it from other related questions. The question is not about whether or not most of us think that we have such an obligation. I think many do. But I am taking it for granted that the view that many people considering something to be morally relevant in itself makes it morally relevant is implausible (see also I.3). So the (alleged) fact that many (or perhaps most) people believes that we have special obligations towards our blood relatives is not the object of discussion here. The question is rather whether or not there are any reasons for believing that we indeed do have such obligations.

The question is neither about whether certain social bonds gives rise to obligations (see VI.3.2.2), nor about whether some general obligations like "do not harm" can generate obligations towards one's relatives. The question is whether the fact that one is a blood relative to someone else in itself gives rise to certain moral reasons, perhaps strong enough to imply obligations, to that relative, and, then, particularly the obligation to disclose genetic information to that relative. So the question is: does blood relatedness as such carry any moral weight, or to put it differently, is blood relatedness morally relevant?

Although the view that blood relatedness is morally relevant in this sense is often indicated, not least in the saying that "blood is thicker than water", it is rarely explicitly claimed and even more rarely defended. However, Rhodes seems to hold that view: "moral responsibility depends on a variety of factors including blood ties" (Rhodes, 1998, p 25). Rhodes grants that social bonds "typically" are more important in justifying moral claims than "blood ties": "Blood alone does not tell the story of our moral responsibility to one

---

30 Proponents of this idea often draw on Aristotle's writings, and then especially *Nicomacean Ethics*.

31 As I said earlier, with blood relatives I mean the group of people that clinical geneticists are interested in when constructing a family tree of the index-person. This is normally those who I inherited my genes directly from (mother and father), those who inherited their genes directly from me (my children) and relatives with common ancestors close enough to have a high probability of sharing certain genes (usually siblings and maybe parents siblings and cousins, but seldom further).

another. The bonds that have moral weight and give us thick responsibilities to one another typically include a social component." (Rhodes, 1998, p 21) But to say that blood does not tell the story of moral responsibility *alone* is still to claim that blood has *something* to say in that story.[32] Is there anything to this claim?

The first thing one has to ask oneself is what is meant by "blood ties". The interpretation that seems to be the most natural when it comes to the obligation of disclosing *genetic* information is in terms of similarity or commonality of DNA between two persons. Rhodes also favours this interpretation: "Commonality of DNA seems to be and important component of blood ties..." (Ibid.) However, "blood ties" cannot mean "genetic communality", at least if interpreted as "genetic similarity".[33] This is so since genetic similarity cannot be the morally relevant relation, at least not in order to ground an obligation to disclose genetic information to relatives. The reason for this is that it is *possible* that my genetic constitution is more similar to someone else's who is a complete stranger who share no ancestors with me for the last 1.000 years, than it is like any of my close relatives, like my siblings, parents, or children. In fact, it is even possible (although unlikely) that there is a complete genetic match between such a perfect stranger and me. But disclosing some genetic information about myself to this person is not informative of this person's genetic constitution, unless we know about our genetic identity to start with. Our genetic match thus provides no reason for inferring facts about the genetic constitution of that other person from facts about my genetic constitution. So mere *similarity* of DNA is of no relevance in itself to the obligation to inform relatives of one's genetic constitution. Rather, it must be to stand in certain (genetic) relations of heredity, like father-, mother-, or brotherhood, that can be of moral relevance, since only then knowledge of my genetic constitution can be telling of their genetic constitution. Therefore "genetic relatedness" rather than "genetic similarity" is the only reasonable interpretation of "blood relatives" to whom one may have obligations.

---

[32] See also the quotation below about the case of Dick, where she clearly states a responsibility due to "biological ties".

[33] Which is Rhodes interpretation (Ibid).

Does genetic relatedness give rise to an obligation, at least of a prima facie kind,[34] to see to it that genetic information is disclosed to relatives? Rhodes brings the case of Dick to the stand in order to argue in favour of such obligation (Rhodes, 1998, p 23-24). Dick can participate in a family linkage study, and his participation is important, maybe crucial, in order for his cousin Martha to find out whether or not she is a carrier of the gene for Marfan syndrome:[35]

> Dick's case is particularly interesting because it is only his blood ties that give him an obligation to participate in the linkage study. No one else can do it for her and no one else could take his place. Dick's case make the point that we have some of our responsibilities because of our unique ability to help, others only because of our biological ties. So morality is not entirely constructed out of socially created links. (Rhodes, 1998, p 24)

Here Rhodes makes an important point that threatens to undermine the whole idea of genetic relatedness giving rise to special obligations. Sure, we can grant that Dick has a moral reason to participate in the linkage study: he is the only one that can help Martha (or so we can assume). Surely, if you can do someone else some good, or help her to avoid or alleviate something bad, this is a reason to do so. But then we do not have to refer to genetic relatedness, but only to (rather) uncontroversial ethical concerns of a consequentialist kind: to do good and to do no harm. Of course, it is the fact that Dick and Martha are blood relatives that makes it true that Dick has a unique ability to help Martha. Analogously, the fact that I am the only one driving by you when you are bleeding to death on the side of the road (to take a well-known example) makes me the only person that can help you. But in neither of these cases, one need not resort to the incidental facts about blood relatedness or geographical location in order to argue in favour of a prima facie obligation (i.e. a moral reason) to help, but only to principles like "do good" and/or "do not harm". If someone else, who were not a blood relative to Martha was the only one

---

[34] Rhodes mentions "*prima facie* duties that must be taken into account in moral deliberation." (Rhodes, 1998, p 23) With prima facie duties (or obligations) I take her to mean always existing but overridable moral reasons, i.e. what Kagan calls pro tanto reasons (Kagan, 1989, p 16-17).

[35] One can discuss whether this is disclosing genetic information, but one could easily change the case so that it is obviously about disclosure. See I.4.1 for a short description of Marfan syndrome.

who could do her good, this person would have the reason to do so and no one else.

Of course, one could claim that genetic relatedness has *some* moral relevance, since "it would be more terrible to ignore her [Martha's] need than it would be to ignore a stranger's." (Rhodes, 1998, p 24) In order to continue the analogy, probably many would intuitively think it even worse to drive by one's sister bleeding to death on the side of the road than a complete stranger (or that the person driving is even more blameworthy or cruel or something of the like). However, this intuition probably draws on our normal conception of sibling relations as being a strong emotional and social bond. Probably, most people picture their own sister, who they love and care about, on the side of the road. If you remove that, little of the intuition may remain. Ignoring a perfect stranger to whom you are not genetically related seems as bad as ignoring some perfect stranger in the side of the road, to whom you happen to be genetically related (perhaps without your knowledge).

In fact, the impression that genetic relatedness is morally relevant may fade if one considers that many people you think you are related to biologically in certain ways are, in fact, not related to you in this way. In order to take an extreme, but nonetheless realistic, example: it might be that a mistake in the hospital in which you were born led to a swap of babies, so none of the people you think are your blood relatives are actually so. Were one to find this out, I suspect that in most cases (at least if no conscious deception has taken place from any of the involved parties) this would not lessen the emotional bonds and sense of obligation we would feel towards our "social" relatives. This only goes to show that we care much more about social bonds than genetic ones, something that Rhodes concurs with when discussing what reasons we give for having certain responsibilities: "More likely reasons [than genetic] would be related to the intimacy and dependency of our previous relationship, or the strength of our feelings, or the history of our interactions" (Rhodes, 1998, p 21), i.e. social bonds.

Since the alleged moral relevance of genetic relatedness really rests on other concerns, like doing good, avoiding harms, or special obligations due to social bonds, there seems to be little intuitive appeal in granting genetic relatedness independent moral relevance. Rhodes gives no reasons why we should do so. And such a reason seems hard to come up with, since there are reasons against granting genes or genetic information in general moral relevance in itself (see I.4.3). Of course, letting a relative know that she has a

susceptibility for an avoidable genetic disease can be a good thing to do (at least instrumentally), and even an obligation, but to think that this obligation is even partly due to us sharing some molecules due to hereditary links seems odd, to say the least. Relations may give rise to obligations, but it is hard to see why genes in themselves give rise to obliging relations.

3.2.2 Special obligations due to social bonds

Do (some of) our social relationships give rise to special obligations towards those we have these relationships with? It is a classical idea in moral philosophy that they do, and perhaps the most classic work invoked when formulating or defending this idea is Aristotle's *Nicomachean Ethics*. Rhodes also invokes this work when claiming that some such relationships give rise to "*prima facie* duties that must be taken into account in moral deliberation." (Rhodes, 1998, p 23) More precisely, she demonstrates that Aristotle argues that "(1) Family relationships count. (2) Social relationships count. (3) The history of a relationship counts. (4) The particulars of the relationship and situation count." (Ibid.)

Because of this, we may have special obligations to disclose genetic information to e.g. cousins (Rhodes, 1998, p 24), partners (Ibid.), and siblings (Rhodes, 1998, p 25).[36] As Rhodes herself notes, there may be all sorts of ways to found special obligations to others whom we stand in special relationships to (Rhodes, 1998, p 22). One way to found such special obligations is to argue that there is something in the nature of the relationship from which the obligations follow. I have already claimed that this attempt fails regarding genetic relatedness. This leaves us with the present question of whether social bonds give rise to special obligations.

One way to found *some* special obligations towards *some* family members and relatives is to argue that some such relationships are based on *contracts* the breaching of which we have strong moral reasons to avoid. One such argument could refer to promises (Kagan, 1998, p 140): some family relationships seem to presuppose or entail that one promises to take on various responsibilities. For instance, in our society, the obligation of fidelity

[36] The context of Rhodes' discussion is really an argument against a right not to know, because of a duty to know (see V.3), but she seems to presuppose that the obligation to share genetic information with others entails that one knows about it. But a duty to inform someone else is something different than a duty to know about this information oneself (which is indicated by Häyry & Takala, 2000, p 111).

seems to be presupposed in the relationships to spouses (even if this obligation can be waived by explicit agreement). The idea that relationships implies promises is most plausible when it comes to (partly) voluntary relationships, such as relationships to spouses and one's children, since involuntary promises do not seem to be (morally binding) promises at all. Thus, this kind of argument cannot found a duty to disclose to most blood relatives, like parents, siblings, and cousins, since these relationships are not voluntarily chosen.

Other possible ways of founding special obligations towards others can be by referral to considerations of consequence,[37] fair play (Kagan, 1998, p 138-143), or more metaethical considerations, e.g. communitarian one's (see VII.5.3).

This is not the place to evaluate all these possible foundations to special obligations towards relatives and family. For all I know, we might have such special obligations. But one has to be very careful in order to determine what particular obligations that special obligations towards relatives and family entail. The subject of discussion here is the obligation to disclose genetic information to relatives. As we have seen, such disclosure may be beneficial to the relative(s) in question, but we have also seen that it may not be. Whatever the basis one proposes to the special obligations towards relatives and family, the idea must be that one may have a duty to act *beneficially* towards them (or to act in their interest or something of the kind). This means that whatever special obligations towards relatives and family one has, it does not entail a general obligation to disclose genetic information, but only an obligation to do so when they would be sufficiently benefited by it. To do so when they are harmed by it must be contrary to whatever special obligations one has towards them. If there are special obligations towards relatives, it cannot very well be obligations to harm them. This means that special obligations towards relatives cannot be an *independent argument* for the disclosure of genetic information. It can only *strengthen already existing moral reasons* to disclose, or not to disclose, such information.

Furthermore, it has been claimed that special obligations to relatives and family is not the kind of obligation that should be regulated:

---

[37] Anyway, considerations of consequences can argue in favour of *recognizing* some obligations as part of some relationships, since relying on people fulfilling their socially assigned obligations can be an efficient way of achieving good consequences through coordination and division of labour.

> If the postulated duties are founded on the Aristotelian remarks concerning friendship and family ties, then they need not, and cannot, be reasonably enforced by legal regulations or professional codes. It would presumably be alien to Aristotle's thinking to insist that physicians or public health authorities should direct or coerce us into doing good to our family members or friends. (Häyry & Takala, 2000, p 110)

In the rights-parlance presented earlier (see IV.1.1.1), this amounts to the claim that even if relatives have a moral right to genetic information, and relatives have a corresponding moral reason to see to it that they are informed, we should not institutionalise this right into regulation, i.e. make it a legal right. At least this is so if the special obligations are founded on "Aristotelian remarks".

Since I share, what I take to be, Rhodes view that Aristotle was not entirely clear on how the special obligations due to some relationships should be founded or justified (Rhodes, 1998, p 22), I am not sure that this argument is valid. I suppose it depends on the kind of justification given for the special obligations. For instance, if it is based on some conservative idea of family values, Häyry and Takala might be right. But if it is built on some contractual idea of promises or fair play, it is not obvious that the obligations should not be enforced by regulation (or other institutional pressure).

However, personally, I have no idea what basis, if any, for the idea that social bonds gives rise to special obligations is correct. If one shares Häyry's and Takala's interpretation of Aristotle and agrees to the substantial point that these kinds of special obligations to relatives and family should not be in any way institutionalised, the practical implications of the argument from special duties will be of minor consequence. Of course, if one agrees that one has special obligations towards family and relatives due to (and then only if there are) social bonds between them, it would be more problematic to withhold from them information that would be sufficiently beneficial for them to receive, than it would be to withhold such information from a complete stranger. However, given that one accepts Häyry's and Takala's line of reasoning, this in itself does not imply any right or obligation to affect the

obliged party. And I personally know of no reason not to accept their line of reasoning.[38]

4. Conclusions

This chapter poses the question about the relatives' value of and right to genetic information. I have focused on blood relatives, since it is information about their genetic constitution that can be revealed by testing the index-person. Regarding the value that may be realized for relatives, they are the same as for the index-person, i.e., primarily and basically, well-being and autonomy.

Regarding the rights of relatives, I first discussed the pre-test question of whether or not there should be a requirement that relatives consent to the genetic testing of an index-person. I investigated some arguments for and against this and argued that confidentiality and respecting autonomy pulls in neither direction regarding this question, while privacy and consequentialist considerations pull in both. However, I argued that consequentialist considerations probably pull more towards not requiring the consent of relatives. Together with the problem of determining a limit of predictability for tests on relatives, and a morally non-arbitrary one in particular, and arguments of comparisons to other medical testing, reasons weigh heavily in favour of not requiring the consent of relatives. Or so I have argued.

I then discussed the question of whether (and, if so, when, how, and by whom) relatives should be informed about the result of genetic testing of the index-person. As the possible values of receiving such results are the same for the relatives in question as for the index-person, I argued that there certainly are reasons to inform relatives if, and to the extent that, the same values would be realized for them as for the index-person.

However, since it may be very hard to know what benefits that would in fact be realized by disclosure and that these benefits would sufficiently outweigh the potential harms, one should be very careful to infer an obligation to disclose, even if there *can* be such an obligation. This corroborates the findings in the previous chapter regarding an alleged duty to know. However, it leaves us with the practical problem of *how to decide* when to disclose the information in question. I argued that in rare cases, the possible benefits are so obvious that relatives' consent to being informed can be

[38] Evidently, this uncertainty is a result of my uncertainty of whether there are special obligations due to special relationships and what the basis of such obligations is.

presumed: for instance when the disease is very serious and very likely given genetic disorder, and there is efficient and not too burdensome preventive measures to take. However, even then, it is not obvious that the confidentiality of the index-person should be breached. I presented several models on how to solve this practical problem, and concluded that they all have downsides. Nonetheless, I indicated that the problem of deterrence from testing due to threat of redisclosure should not be taken lightly, no least since such threats may be counterproductive from the point of view of the relatives. However, I indicated that proper counselling can solve some of the practical problems, and that persuasion may be preferable to binding contracts and breaches of confidentiality.

I then argued that these conclusions are not affected in any radical way by ideas of special obligations due to special relations. The idea of special obligations due to genetic bonds was argued to be implausible. The idea of special obligations due to social bonds was not questioned, but was found to be, so to speak, symmetrical with the obligations to promote well-being and autonomy already discussed. That is, such alleged obligations cannot be used to argue in favour of any separate obligations to reveal genetic information, but only to strengthen reasons to benefit and avoid harm already present.

So, should we be our brother's keepers? We certainly should, but not by revealing genetic information about them whenever we can and not necessarily because they are our brothers.

Chapter VII
Third Parties' Right to Genetic Information: Insurance Companies

1. Introduction[1]

Besides individual people and their close ones, the possibility to predict the onset of disease and premature death (or at least to determine the risk thereof) through presymptomatic genetic testing is of interest also to other parties. Employers, business associates and insurance companies have obvious economic reasons for knowing about an individual's susceptibility to disease; there is a risk of economic loss if you establish a long time contract with or hire someone who probably will contract a disease. Researchers are interested in mapping the frequencies of various genetic deviations in order to establish family patterns and develop cures. Health institutions have similar motivations, and also an interest of using genetic information to foresee coming expenditures, an interest they share with society at large. And so on.

In this chapter, I will address the right to genetic information with regard to these kinds of parties.[2] However, taken literary, this task would be enormous, because of the many parties involved. Therefore I will concentrate the main part of the investigation to insurance companies: to what extent, if any, should insurance companies have access to genetic information? One of many reasons to chose this particular focus is that the question of insurance companies access to genetic information is the most thoroughly discussed question of third parties' right to genetic information. Because of this, many issues of relevance to other third parties have been dealt with in this context. Another reason is that many ideas of autonomy, privacy and justice will be brought to a head in this context, which will be clear in the following discussion. Despite the strong focus on insurance companies, I will then use the results of that

[1] Sections 1-5 of this chapter draw heavily on two previous publications: Radetzki, Radetzki and Juth, 2003, chapter 7, and Juth, 2003.

[2] I will ignore the value-question, since the value for these parties obviously coincide with the interest they have in genetic information. So, for instance, the value for insurance companies is that genetic information allows them to protect themselves from economic risks.

discussion as a basis for some remarks regarding a couple of other third parties' right to genetic information (section VII.6).

Another limitation of the discussion in this chapter is that I will mainly be concerned with insurance companies' *legal* right to genetic information (see IV.1.1.2). That is; should insurance companies have access to genetic information or should this be regulated in any way? Because of this limitation, I will not deal with the question of any putative moral duty to reveal such information to insurance companies. The reason for this limitation is that the question of insurance companies right to genetic information has, almost without exception, been discussed as a question of regulation. The practical importance of settling this issue also makes the discussion more interesting.

The question of insurance companies access to genetic information can be subdivided into two questions. (i) Should insurance companies be allowed to demand that people applying for insurance are to be tested before the establishment of the insurance contract? (ii) Should insurance companies have the right to information from tests already performed?[3] If the answer to the first question is affirmative, it will obviously be so for the other as well. There is no point in insurance companies asking for new tests if they are not granted access to the information from them. The reverse is, however, a possible and also defended position: insurance companies should be allowed to ask for the results from already performed tests, but not to demand new ones.[4]

The reason to emphasise the distinction between these two kinds of regulation issues is that they correspond to two types of regulation of insurance companies' access to genetic information that has played a central role both in debate and actual policy making. A further reason for upholding this distinction is that there are important differences between the two forms of regulation with regard to autonomy, privacy, and economic consequences, as will be evident in the following.

The position that insurance companies should be allowed to ask for the results of tests already performed as well as demand that the individual must

---

[3] A distinction between access to and use of genetic information has been made (Mayer et al, 1999, p 42). In this discussion the distinction will be ignored. It is taken for granted that the right to access to genetic information implies a right to use that information to differentiate premiums.

[4] For instance Sandberg, 1995, has defended this position, at least if the insured amount is above a certain specified amount. Below this amount they should not have access to already made tests either.

undergo testing in order to be insured will in the following be called *absence of regulation*. The middle position is that insurance companies should be allowed to ask for the results from tests already performed, but not to demand new ones. This position will be called *partial regulation*. The position that insurance companies should not be granted access to genetic information whatsoever (at least not from genetic testing) will be called *total regulation*. Each of these ideal-types of regulation can, of course, vary in different dimensions and degrees. In Sweden, for instance, access to results from tests already performed is permitted only when the insured amount exceeds a pre-specified amount of what is currently about 50.000€ (see VII.1.1).

A few more preliminary remarks are required. Regulation should be understood broadly, so that it not only includes laws, but also moratoriums and other kinds of binding agreements between insurance companies and the state (or other relevant regulating societal institutions). Some countries in Europe (e.g. Sweden and France) have, at least temporarily, chosen the last mentioned method of regulating insurance companies access to genetic information. Other countries (e.g. Denmark and Belgium) have chosen to regulate insurance companies access to genetic information by law (Radetzki, Radetzki and Juth, 2003, p 30-37).[5]

The relevant type of insurance in this context is *personal insurance*, that is, insurance against loss of income or for health care in case of disease (health insurance), insurance to compensate for loss of income in case of the premature death of family providers (life insurance) and insurance to secure income in old age (pension insurance). The focus will be on health insurance and life insurance. This focus is chosen due to the conflict of interest between the insurance seeker and the insurance company when it comes to these forms of insurance. This conflict of interest arises when the insurance seeker is a genetic high-risk person,[6] since she then has an interest of not disclosing the information, while the insurance companies have an interest of disclosure. Therefore, this situation will give rise to ethical dilemmas: whose interest should yield? This is not the case with pension policies, since both the genetic high-risk person and the insurance companies have an interest in disclosure of genetic information in that case. The reason to focus the

[5] In the case of Sweden, legislation that establishes the former agreement as a law is pending.

[6] A genetic high-risk person, or a high-risk, is a person who has a higher probability of having a certain genetic disease than the population at large.

attention to genetic high-risk rather than low-risk persons are that they stand to lose the most from insurance companies' access to genetic information. Sometimes life and health insurance will be discussed as a lump, and sometimes it will be necessary to emphasise the difference between them.

We have already seen that the values that genetic tests can realize give rise to various interpersonal conflicts of interest (see e.g. chapter VI). This will become even more evident in the following. How these conflicts should be solved is a question of justice (who should, under what circumstances, receive which benefits and burdens). Therefore considerations of justice will be the most important ethical consideration of this chapter. However, there are also other ethical concerns that arise in this context. Therefore, a classification of different ethical considerations is necessary. The most recurring and important ethical reasons or arguments for and against insurance companies access to genetic information will be placed in one of the following categories: (i) arguments of consequences in terms of well-being; (ii) arguments of autonomy; (iii) arguments of privacy; and (iv) arguments of justice. These arguments will be discussed in the mentioned order.

Already at this point, it is important to emphasise that different ethical considerations can support different conclusions. Considerations of privacy, seems to speak straightforwardly in favour of total regulation (see section VII.4), while some considerations of consequence seems to speak in favour of partial or even absence of regulation (see section VII.2). It might seem, therefore, that in order to be able to answer the question of what sort of regulation there should be, one has to take a stand on the question of the relative weight of these different ethical considerations. Appearance is deceptive, however. In the following, I will argue that several plausible ethical theories, in spite of their theoretical differences, seem to point in the same direction when it comes to the more general conclusions.

Furthermore, it is hardly possible to defend a full-blown ethical theory in this limited context. That would require something much more than this inquiry can contain. Nevertheless, I hope to show that we can learn something about ethical theory in general by applying different ethical theories to more concrete questions such as this one. For instance, I will argue that this particular discussion shows that questions of privacy are secondary to other ethical concerns, and that some ideas of justice are dubious (Walzer's) or altogether unacceptable (Nozick's). Apart from this, no stance will be taken on

questions about the relative weight of consequences of well-being versus justice, or justice versus autonomy, or consequences of well-being versus autonomy. Each of these ethical considerations is supposed to carry some moral weight.

1.1 Empirical suppositions

As will be seen below, the issue of insurance companies' and other third parties' access to genetic information puts the ethics of genetic testing in an even more complicated context. To make the discussion more manageable, it is therefore expedient to assume some fairly plausible empirical hypotheses as valid. In the following, I will make two such assumptions. The *first* is that the use of presymptomatic genetic testing will become more widespread, and that more diseases will be detectable before onset through genetic testing. As we have seen, the extent to which meaningful presymptomatic genetic testing will be developed for more diseases is controversial (I.4.2). Most of the people initiated seem to hold that this will happen to some extent, however. This supposition is, then, not very controversial.

The *second* assumption is that the systems of publicly funded social insurance in the welfare states around the North Atlantic are, since the 1990's, the subject of a partial and ongoing dismantling. In the following discussion, I will follow the general debate and concentrate on these countries (members of the EU) and the USA. The conclusions, however, will be valid for any developed country. Publicly funded social insurance, built up during the first half of the 20th century, is collective and mandatory, and one important goal for its establishment has been to insure against the cost of treatment in the event of illness, loss of income due to illness, premature death, or during old age. Some main reasons for the dismantling of these systems are the fast expansion of public financial obligations and a desire to make the provision of the insurance services more economically efficient. The reforms of the 1990s have comprised (a) partial individualization and commercialisation of public arrangements; (b) lesser generosity towards those publicly insured; and (c) active encouragement to seek private supplements to the remaining public arrangements. The supply of personal insurance by private insurance companies operating in competitive markets has been strongly stimulated by these reforms (Radetzki, Radetzki and Juth, 2003, p 2). Unlike collectively financed social insurance, private insurance companies have a desire, as far as possible, to adjust the premiums charged to their customers to the risk

represented by each individual engagement. That is why they are interested in genetic information, just as they seek and obtain other information of relevance for individual risk assessment.

Because of ethical considerations, use of and access to the results of genetic testing, and genetic information in general, has been regulated in various ways in the countries mentioned above. In some cases, the choice has been something close to total regulation (Norway and some states in USA). Many European countries have chosen a middle position between total and partial regulation, where insurers are allowed to ask for the results of tests already performed when the insurance fall out above a certain specified amount (in Sweden about 50.000€), but never to demand new tests to be performed. The question is then, if these forms of regulation are defensible from an ethical point of view, or if there are good reasons to abandon or strengthen them. In other words, which forms of regulation are defensible under which circumstances?

1.3 Things to come

The following discussion will unfortunately not lead to any neat and straightforward solutions. Suggestions will be given, but no definite answers. One important conclusion is that the questions must be answered against the background of how the basic institutions of society are constructed more generally. Another important conclusion is that emergence and continued evolvement of genetic testing provides a reason for society to reverse the trend of dismantling collective social insurance systems. This is not, of course, a direct answer to the question of how insurance companies' access to genetic information should be regulated. However, it is an interesting result in its own right that suggests that the question of regulation may be of secondary importance, provided that the basic institutions of society are arranged in a certain way. However, regardless of this, ethical arguments in conjunction with reasonable empirical hypotheses seem to argue against both complete absence of regulation as well as against total regulation. The result then seems to be that the solution to the problems that arise as a result of the growing importance of private insurance, in conjunction with the increasing possibility of determining risk on the basis of genetic information, is a resurrection of collective financed insurance combined with some sort of partial regulation. This is not to categorically to say that such a resurrection should take place. There may well be other important reasons to not do so, e.g. reasons of

economic efficiency that in the end can affect people's welfare considerably. But the developments in genetics present additional arguments for a welfare state in the classical sense of the word. After the discussion of insurance companies, I will use the findings of that discussion in order to say something very brief about two other parties' (alleged) right to genetic information: employers and researchers.

2. Consequentialism

Consequentialism is the position that the moral status of actions is determined solely by the value of their consequences compared to available alternatives (II.4.2). I will here focus exclusively on the value of subjective well-being (II.4.1.4) or as I will sometimes call it below, welfare. Consequentialist considerations could, of course, also be applied to societal institutions and laws, that is, one can hold that a reason to implement certain institutions and laws is that such an implementation is conducive to general well-being. As already stated, I will assume that consequentialist considerations carry some moral weight, that is, the consequences in terms of the well-being of people have some relevance for evaluating whether or not a certain regulation should be implemented.

In this context, a more disturbing problem with consequentialism is nevertheless actualised: the problem of knowing what consequences a certain regulation will have. I will sidestep rather than tackle this obvious problem by concentrating on the mostly discussed consequences of well-being of different forms of regulation, which almost exclusively concern negative consequences. These consequences are so salient that a consequentialist cannot ignore them. Moreover, the fact that we cannot say everything should not prevent us from saying something, especially given the obvious importance to people's well-being that the discussed consequences could have.[7]

2.1 Negative consequences of absence of regulation: uninsured population

An obvious negative consequence in terms of welfare that probably will result from absence of regulation is that people with high enough risk of contracting genetic disease will become uninsurable. Presymptomatic genetic testing

[7] Furthermore, the problem of having enough knowledge to make the ethical theory action-guiding is not a unique one for consequentialism (see VII.3.2 and VII.5.2.2). See Gren, 2004, p 137-144, for a fuller argument of this regarding several ethical theories.

makes it possible to differentiate individuals at high risk of developing conditions that will result in illness or death. Insurance companies will want to charge higher premiums from these people in order to compensate for the higher risk of paying the compensation, or maybe deny them insurance altogether if the risk is considered too great. Whether these people are denied insurance altogether or just charged very high premiums will in many cases amount to the same result (since many people cannot afford the high premiums): an uninsured high-risk population.

This need not be a great problem if private insurance is not vital for people's welfare (e.g. their access to health care, or their possibility to guarantee provision for their children in case of death). However, if the above described dismantling of the social insurance systems keeps going, private insurance will eventually become vital to most people's welfare. This, I have claimed, is what is in fact happening. A way to avoid the problem of an uninsured high-risk population, then, is to regulate insurance companies' access to genetic information, so that it cannot be used to identify the high-risk population. Total regulation thus may look as a swift solution to the problem at hand. As always, however, things are more complicated.

2.2 Negative consequences of total regulation: adverse selection

The problem of adverse selection is one of the most discussed in relation to the question of insurance companies' access to genetic information. It is often considered to be the strongest argument in favour of insurance companies' right to genetic information and, thereby, against total regulation (Sandberg, 1995, p 1555). To explain what the argument of adverse selection amounts to, we have to move further into the issue of what kind of entity insurance is.

A private insurance is a contract between an insurer and an insured, which says that the insurer in exchange for a premium from the insured will pay a benefit or compensation to the insured given the occurrence of a specified event that is more or less probable. The events relevant in this context are, then, health problems or premature death. The size of the premium is calculated on the basis of a risk assessment regarding the occurrence of this event and the size of the compensation. Higher risks and compensations mean higher premiums, since the insurance would otherwise be a bad deal for the insurer. Even given a considerable size of the compensation, if the risk is low, the premiums might still not be very high. However, if the risk is higher, the insurer needs to raise the premiums proportionally. And at some magnitude of

elevated risk, it becomes a bad deal altogether to grant insurance at all. To be able to set the size of the premium, or to decide whether or not to establish a contract at all, it is therefore essential for the insurer to estimate the probability of the event; that is, how great the risk is that the insurer will in fact have to pay the compensation.

This risk assessment is made on the basis of particular information about the applicant and general statistical information about the health-significance of various factors. In the standard case of health and life insurance the assessment is done on the basis of the applicant's age, health status and other information considered material. Information is material *"if it would influence the judgement of a prudent insurer in fixing the premium; or in determining whether she/he will take the risk."* (Chadwick & Ngwena, 1995, p 120) This may include information about the applicant's sex, choice of life style (e.g. smoking or not smoking) etc. Clearly, genetic information of the type produced by presymptomatic tests for Huntington's disease or cancer is material in this sense and is also considered so by insurance companies.

The international standard is a legal obligation of the applicant to reveal material information to the insurer, if the applicant knows about it.[8] Typically, this is implemented through a right of insurers to effect a reduction or elimination of compensation in the event of incomplete or erroneous information. However, it is in the interest of the insured to be able to withhold this kind of information from the insurer without the threat of sanctions. If an individual knows about her genetic predisposition for disease and is allowed to withhold this information (as would be the case if total regulation was to be implemented), it is possible for her to purchase insurance with a very high benefit without the premium reflecting her inflated chance of receiving the compensation. There is no reason in general to believe that people with genetic predispositions to disease are more altruistically inclined than others. Should this be an open course of action we can therefore assume that many of those who suspect themselves to be so disposed would take tests and, in the case of a positive result, buy insurances because they know that the benefit (probably) will befall them.

Since the insurance company cannot raise the premium especially for this group (they cannot be identified), the premium must be raised for everyone in

[8] Ibid. This is sometimes called the applicants informational duty, and is regulated through law in Sweden (Försäkringsavtalslagen 1927:77).

order to cover for the increased expenses for these benefits. But generally raised premiums will lead to a reduction of customers, especially among those who know themselves to be low-risk.

The fear of the insurance companies is, then, that the increased opportunities of individuals to attain knowledge about their genetic risks without a corresponding legal duty to reveal this knowledge will lead to *adverse selection*, i.e. that high-risk people become more likely to seek insurance, while low-risk people become less so inclined. In a worst case scenario from the insurance companies' point of view, this process may eventually make it altogether unprofitable to run insurance business in the areas of health and life. This, then, is why insurance companies argue that there should be a duty to reveal this kind of information.

It is important to keep in mind that the obligation is to reveal the information *if had by the applicant*, since only this can give rise to adverse selection. The problem then arises when there is *asymmetric information*, that is, when one part has information relevant to the value of a transaction that the other part is lacking.

How likely is this scenario? What reasons are there to expect that the absence of a right to genetic information will lead to an adverse selection so severe that it will threaten the existence of personal private insurance?

The answer to this question is dependent on at least three other factors, assuming that total regulation is implemented: (i) the extent to which persons at high risk of genetic disease will use information about this to purchase insurances with high benefits without revealing the risk (that is, if the phenomenon of adverse selection really is a phenomenon); (ii) how many of this sort of persons there are, and (iii) to what extent raised premiums for other insurance customers will make them take their business elsewhere or altogether refrain from insurance. Let us discuss these factors one at the time.

As concerns the first factor, I have already remarked that there are no reasons in general to think that people who know themselves to be at high risk of developing some genetic disease would be reluctant to engage in profitable transactions. General remarks of this kind do not settle the matter, however. The question is an empirical one and must therefore be settled by empirical means. Unfortunately, data about the phenomenon of adverse selection are difficult to interpret and, in the case of genetic diseases, scarce.

If we allow generalization from other diseases than genetic ones, perhaps some weaker conclusions can be supported. There seems to be certain evidence indicating that HIV has led to adverse selection (Oppenheimer & Padgug, 1991). However, this discounts for the problems of providing any evidence at all for the putative fact of adverse selection (Brown, 1992). Nevertheless, there are known cases of persons positively tested for Huntington's disease who have applied for life insurance with very high benefits, and this may be taken as being proof enough (Geller *et al*, 1996, p 82). However, research on females tested positive for BRCA1 shows very weak support for a correlation between positive tests and number of life insurance policies.[9] To conclude, empirical evidence seems inconclusive.

As concerns the second factor, it is dependent on the actual scope of presymptomatic genetic testing: how many conditions can be tested for, how common are they and how many people potentially at risk of such conditions will choose to test themselves? These matters are obviously empirical too. It depends partly on which of the two scenarios adumbrated in I.4.2 are realized: the cautious or the bold. If the bold scenario is realized, there will be genetic testing for more disorders, including reliable and informative testing for multifactorial diseases. Then, naturally, there will be many more persons aware of their genetic susceptibility for diseases than today and, consequently, the problem of adverse selection will be much more accentuated. However, even if the cautious scenario turns out to be the real one, the economic viability of insurance business can be threatened, given total regulation.[10] It is enough that sufficiently many high-risk persons are tested.[11] And I have made the, not too controversial, empirical supposition that more genetic high-risk people than today will be identified.

As concerns the third factor, and I am afraid I am starting to be repetitive, the matter is again empirical and far from settled. Whether or not low risk people will take their business elsewhere or not engage in them at all will

---

[9] Smith et al, 1999. They conclude that they "view with some scepticism the insurance industry's contention that denial of access to genetic test results... will threaten the industry's economic viability" (p 68). However, the authors themselves have reservations concerning this conclusion, e.g.: "the reason we observe little evidence of adverse selection could be because our follow-up period of four months is too short" (p 68).

[10] For more specific evidence to this effect, see Radetzki, Radetzki and Juth, 2003, p 76-77.

[11] Approximately 3% identified high-risk persons of the total population seem to be enough, at least if the argumentation below about offshore companies is correct (Ibid).

depend on several, to some degree, correlated variables. These include, for instance, the size of the premium raise (which is dependent on the already mentioned factors), the access of lower cost premiums (which is dependent on the presence or absence of monopolies and cartels, among other things) and to what extent public insurance is available.

There are, however, powers at work that give us good reasons to believe that adverse selection can become a problem in the long run.[12] The economic integration of the world has increased strongly during the post-war era, and the pace at which this is happening seems to be increasing. This is obvious if one examines the increasing flow of goods, capital and information across national borders, and the growing strength and significance of multinational corporations. Single nations' attempts to reverse this trend through legislation have often been futile. This also means existing and increasing possibilities to obtain private insurance in another country than your own.

It is very likely that some countries will not regulate insurance companies' access to and use of genetic information. This paves the way for insurance companies to establish themselves in these countries *offshore*. From this base of operation they may offer lower premiums to genetic low-risk individuals all over the world. Since use of genetic information to differentiate premiums is an efficient tool in market competition, establishment offshore is likely to take place for insurance companies in countries implementing total regulation.

The possibility of buying insurance offshore to a lower premium if you are an identified low-risk person, will force domestic insurance companies to raise premiums to cover increased expenditures that will result from a smaller portion of low-risk persons. This will give people more motivation to find out if they are low-risk, and use that information to buy cheaper insurance offshore, which will further raise the domestic premiums etc. This reasoning indicates a dynamic process that constantly makes the situation worse for insurance companies that are under total regulation. The prospect of getting run out of business suddenly seems more probable. Even on relatively cautious premises regarding the actual use of presymptomatic genetic testing and willingness to buy insurance offshore, personal insurance will be made unprofitable in countries with total regulation.

---

12 The following is a summary of the argumentation in Radetzki, Radetzki and Juth, 2003, chapter 5.

There are some important reasons to believe, then, that adverse selection can become a serious problem for insurance companies in countries where total regulation is implemented. But, one may ask, why bother? Let them scorch under the regulation fire. There are too important values, such as privacy, at stake to give in to the business interest of insurance companies, one reaction to this scenario may be.

Unfortunately, there are more interests at stake than the profit of a few insurance companies. Insurance companies contribute to the economy of the society and, therefore, indirectly to the welfare of the society. Moreover, and more important, insurance is a service in demand, and all those demanding it will be without matching supply if insurance companies are run out of business. This may not be a serious problem if the demand is a demand for a luxury good one can do well without. The problem here is that the scenario just adumbrated can be expected to be combined with a dismantling of the social insurance system. If so, these two processes taken together will leave the same people uninsured as in the scenario of absence of regulation. A dilemma is rising to the surface.

The dilemma is that regardless of whether insurance companies are allowed or forbidden to use genetic information the result may be an uninsured high-risk population – a "genetic proletariat" (Billings *et al*, 1992). In the case of absence of regulation, it is because of insurance companies' possibility to differentiate premiums to the detriment of genetic high-risk persons. In the case of prohibition, it is because insurance companies are unable to differentiate premiums, which can make it bad business. This dilemma has been called "the Genetic Catch-22" and is concisely summarized with these words: "If insurers act, or are forced to act, generously by not using genetic testing, then they produce disastrous consequences; if they act selfishly and exclude clients on the basis of testing, then again, they produce disastrous consequences." (Hedgecoe, 1996, p 76-77)

A swift way out of this dilemma is to implement partial regulation, that is, to allow insurance companies to ask for the results of already made tests, but not to demand new ones. That would limit the uninsured population to those who have already taken genetic tests that show increased risk of disease. In order to avoid that fate, individuals only need to abstain from taking such tests. And it would prevent adverse selection, since it would make it illegal for the insurance seeker to withhold relevant genetic information if the insurance company asks for it (failure to disclose such information would make the

contract invalid and leave the insurance company without obligation to pay its due) and thus undermine the problem of asymmetric information necessary for adverse selection.

2.3 Negative consequences of partial regulation: deterrence

Partial regulation, alas, probably will have adverse consequences too, namely for those with reason to perform genetic testing but who have not done so yet. We have already discussed the many reasons there can be to go through genetic testing (chapter II). In some cases, it may make the difference between life and death for the individual who take the test.

However, some may prefer to remain ignorant concerning their genetic constitution, even if such knowledge is of vital importance to their health and life, due to the possibility of being denied insurance (or forced to pay premiums one cannot afford) if the test reveals risk for disease. This deterrence to testing is a negative consequence, of course, for those individuals who would benefit from genetic testing themselves in terms of well-being and/or autonomy (II.2.4).

What is the extent of this problem of deterrence? This, obviously, is an empirical matter. No systematic scientific investigations have been made. Some anecdotal evidence for the occurrence of the phenomenon seems to be at hand, however. A reasonable conjecture is that the severity of the deterrence problem is dependent on the extent and generosity of public social insurance systems. The more generous the public system is, the less people will have to rely on private insurance to guard against misfortunes. In such a society, private personal insurances will be an expendable form of luxury commodity, with limited impact on general welfare. But where social insurance systems are not so generous (as in the USA), and where access to private insurance is a necessary means for access to other vital goods, such as health care, reluctance to gather genetic information that can leave you uninsured is probably greater. In other words, the more important private insurance is to the well-being of people, the greater the problem of deterrence will be. And how important private insurance is to people's well-being is heavily dependent upon the presence of social insurance systems.[13]

---

[13] Not even generous social insurance systems, such as the Swedish, seems to avoid the deterrence problem altogether, however. So the problem is not to be underestimated. Genetic counsellors have claimed that genetic testing has been aborted on several occasions, because of fears concerning lack of private personal insurance (personal information from Christian Munthe who

To avoid the problem of deterrence, then, two different institutional arrangements are possible: to implement (or resurrect or sustain) generous social insurance systems or to implement total regulation, that is, ban the access to genetic information altogether. The first possibility runs counter to what seems to be the trend in western countries (the second empirical supposition, see VII.1.1). That will lead to increasing problems with the second solution: the more people that depend upon private insurance, the more acute the problem of adverse selection will be if total regulation is applied. But still, a combination of dismantling collective social insurance systems and stern regulation is the policy many of these countries have chosen. We have seen the problems in terms of well-being this may lead to.

It might be argued that the compromise between partial and total regulation chosen by countries like Sweden and the Netherlands might solve the problem of adverse selection and deterrence simultaneously. As I have already mentioned (see 1.1), this system allows a person to keep genetic information to herself if the insurance benefit is below a pre-specified amount and insurance companies are never allowed to demand new tests. The problem is that this solution also creates a dilemma. The higher the pre-specified amount, the less the problem of deterrence, but the greater the problem of adverse selection. The lower the pre-specified amount, the less the problem of adverse selection, but the greater the problem of deterrence. If the pre-specified amount is not high enough, the compensation may not be high enough to cover the costs of health care and the loss of income of the sick person. All this, again, given the ongoing dismantling of collective insurance. To make this solution into a sustainable policy in the light of the dismantling of collective social security systems is therefore trickier than might be thought at first glance.

2.4 Consequentialist arguments: Summary

To summarize: there are reasons to believe that all types of regulation will lead to severe adverse consequences for high-risk persons. The form of regulation that seems to avoid the problem of an uninsured high-risk population more than any alternative regulation is partial regulation (that both avoids adverse selection and allows non-tested high-risk persons to buy insurance at a normal

---

is currently investigating the matter). In the USA there are even stronger evidence that fears for lack of insurance protection makes people reluctant to take genetic testing, which supports the argumentation above ("Bush Administration Backs Genetic Discrimination Ban". PM from US government administration 2002-02-13).

premium). However, partial regulation may lead to deterrence to perform genetic testing, which can be a great loss. Moreover, it can still lead to certain people being unable to insure themselves. A public social security system that is generous enough to make access to private insurance superfluous to basic welfare will, however, lessen these negative consequences of partial regulation.

3. Autonomy

Autonomy has already been thoroughly discussed in this book. A conception of autonomy was developed that can be used to formulate various conflicting ideals of autonomy, ascribing differing normative significance to facts of autonomy (e.g. if it is a restriction to what others may do to you, a value to be promoted or a duty to fulfil), different views on how "basic" it is (whether it is an intrinsic value of some sort - a positive to promote or a negative to respect - or an instrumental value), why it is a value, and so on (see chapter III).

In the context of insurance companies' access to and value of genetic information, there is one recurring opinion of autonomy that is so widespread that it demands attention. It is the following: considerations of autonomy provides a strong argument for the right to remain ignorant about ones genetic constitution, and this provides a strong case against insurance companies *demanding* genetic testing on previously untested persons as a term of insurance (Chadwick, 1997, p 17 ff; McGleenan, 1997, p 47; Sandberg, 1995, p 1555; Takala, 2000, p 97). That is, autonomy at least speaks against absence of regulation.

In chapter IV and V, we saw that autonomy has been referred to in order to defend both the right to know and the right not to know about ones genetic constitution (Husted, 1997, p 63), as well as the duty to know about it (Rhodes, 1998, p 18). Since we limit ourselves to the question about regulation of insurance companies in this context, there is no need to repeat this discussion. Instead, I will focus upon two important ideals of autonomy that seem to lurk in the background of many arguments in this particular context. On this basis I will investigate to what extent they really support the alleged conclusion that autonomy provides a reason against absence of regulation (and thus indirectly supports partial regulation).

3.1 Mill's ideal of autonomy

Mill's famous ideal is that the autonomy of the individual should be respected, that is, she should not be prevented from acting according to her decisions and decide according to her wishes, at least as long as the actions do not harm

anyone else (Mill, 1859, p 68). For our autonomy to be violated according to this ideal someone thus actively has to prevent us from making the decisions we want or from acting as we have decided. Would a demand for genetic testing from insurance companies constitute such a violation?

The following example suggests that it would not. Jack makes a voluntary decision to obtain a life insurance. This insurance is sold on a market in which every insurance company demand genetic testing from the applicant as a condition for establishing such an insurance contract. Jack, however, does not want to know about his genetic constitution. He has Huntington's disease in his family, and he believes for good reasons that if he was to learn that he is a carrier of that hereditary disease, he would not be able to complete the great novel he is writing (one of his most important projects), due to the emotional paralysis that this knowledge would bring on him. Does this mean that the insurance companies are violating Jack's autonomy in a Millian sense?

The argumentation that suggests this not to be the case goes something like this. The right to have your decisions respected does not imply a right to get whatever you want on your own terms. The important point, according to this ideal of autonomy, is that you decide for yourself *given* the options you have. In the situation just mentioned, Jack can independently decide *either* to obtain a life insurance, *or* to remain ignorant about his genetic constitution. Granted, he cannot decide to satisfy both these wishes. That, however, does not imply that the insurance companies violate his autonomy, according to this ideal. Jack is violated no more than Jill is violated, when she is prevented from getting all fishing tackle she wants, having already spent her money on those rare Beatles-records she also wants. Considering market prices, Jill cannot get all she wants; yet this does not mean that the salesmen of the city have violated her autonomy.

In analogy with Jill, Jack's autonomy is neither violated as a result of the obstacles he is subject to. To buy insurance is an economic transaction, where the buyer chooses to accept or reject the terms of the seller (Borna and Avila, 1999, p 357). As long as these choices are respected, there is no violation of autonomy, according to Mill. It would be strange to claim that insurance companies actively prevent Jack from deciding what he wants and to do what he decides, just by providing terms Jack does not accept. Even if Jack then chooses not to obtain something he would have obtained if the terms had been more beneficial (that is, if insurance companies had not demanded genetic testing), we cannot say that insurance companies thereby actively harms

Jack (which could have motivated regulating insurance companies terms, according to Mill). Because of this, Mill's famous ideal of autonomy cannot be used as an argument against absence of regulation.[14]

3.2 The ideal of self-realization

Mill's ideal of autonomy is not so much a question about degrees. Our autonomy is violated when someone actively prevents us from acting on our own decisions, although no harm to others results from us doing so. If we are not so prevented, our autonomy is respected. The purpose of this ideal is to stake out the limits of a private sphere, within which no one may interfere, which ideally gives us the possibility to realize our plans.

However, this may seem insufficient. Most people are interested in real, and not just formal, opportunities to realize (from their point of view) important plans and wishes. For that to be true at least some people may need more than non-interference; they may need active help from someone else. If autonomy is of value, it therefore seems as though people, in such situations, have at least a prima facie claim on others to receive such help (if they so wish). This ideal of autonomy can of course come in many variations (depending on the status and weight assigned to the value of autonomy), but the basic idea is easy enough to state: to the extent the individual is leading her life according to her basic ideals and plans (or projects or goals), she is autonomous. In other words: to be autonomous is to live the life according to one's own standards. Therefore, we all have reasons, not only to abstain from "active" infringements of people's autonomy, but to actively *promote* the autonomy of people as well. That is, we have moral reasons to take active measures to ensure that people have real opportunities to live their lives according to their own standards (at least as long as living such a life does not prevent anyone else from doing the same). This amounts to the ideal of self-realization, presented earlier (III.3.1.1). This ideal of course says something more than that a persons decisions should be respected (at least if they really track her wants and the realization does not actively harm anyone else) – it says that it is of value to be autonomous and that this value should be promoted by others than the individual himself (of course, only the individual herself can

[14] At least if Mill is interpreted in this way, relying heavily on the distinction between action and omission (i.e. it is not harm not to help someone). If the reader finds this to be an unfavourable interpretation of Mill, she is free to change label on the position I am presenting to something she can accept.

ultimately decide to live autonomously, but others can help her to make that a real possibility). As we have seen earlier, this idea of autonomy is often discussed by medical ethicists (Glover, 1984, p 160; Harris, 1998, p 148; Munthe, 1999, p 198) and we have also seen that the idea plays a crucial role when it comes to justifying the value of genetic testing (II.2.3). The ideal of self–realisation takes autonomy to be a question of degrees to greater extent than Mill's ideal. We can be more or less autonomous depending on our competence to make our own decisions and our ability to implement them (see III.2.3 and III.2.4). As we have seen, genetic information can enhance our capacity to lead more autonomous lives and, according to this ideal, then, this constitutes a reason for providing such testing (II.2.3).

It is more reasonable to claim that insurance companies' demand on applicants to take genetic tests is detrimental to autonomy interpreted in accordance with the ideal of self-realization, than interpreted in accordance with Mill's ideal. Let us once more turn to the case of Jack in order to demonstrate that this is so. Although it still is reasonable to claim that insurance companies do not *force* Jack to take a genetic test by demanding this as a term of contract, this demand nevertheless limits Jack's possibilities of realizing his important plans. The gravity of the limitation depends on what Jack's plans are and the circumstances under which Jack makes his choice. If the circumstances are such that there is an asymmetry of power to Jack's disadvantage, the gravity increases. For example, if he needs the insurance more than the insurance company needs him as a customer (his position of bargaining is then weaker than that of the company), the demand that he has to perform a genetic test in order to be able to obtain insurance limits his ability to realize his own plans to a greater extent than if the balance of power had been the opposite. This is more likely to be the case if there are very meagre collective social insurance systems. Let us picture a society where Jack's children are dependent on him obtaining life insurance to be able to continue school in the case of his premature death. If one of his most important plans are to provide for his children *and* finish the great novel, given such circumstances, his possibilities to live autonomously is severely limited by the insurance companies' demands. If private life insurance on the other hand is an expendable commodity, obtained merely to make his children rich in the case of premature death, then the severity of the limitation is much less.

What is valid for Jack, is also valid on a general level: the extent to which insurance companies' demands for genetic testing limit people's autonomy,

depends on people's values and plans and the circumstances under which they choose. To what extent are the demands of the insurance companies incompatible with the plans of people in general? To be able to answer this, we must be familiar with society's basic social institutions, the values and projects most important and widespread among the population (which requires intimate knowledge about the culture), and so on. If it is shown that insurance companies' demand to use genetic information really limits individuals' possibilities to self-realization to a great extent, does this mean that they should be forbidden to demand such information? That depends on what value we ascribe to autonomy as self-realization; the greater value it has, the more reason do we have to restrict demands from insurance companies (or anyone else) that will impede the realization of this value.

How great is the value of living your life according to your own basic values and wishes, then? I think no one would say that this is of no value whatsoever, but different ethical theories, of course, will provide different answers to how great this value is and what determines this magnitude. Classic forms of consequentialism that typically do not include autonomy as a value in itself, gives self-realization an instrumental value:[15] the value of self-realization depends on the contribution of self-realization to well-being. For example, according to the hedonistic version of consequentialism, the value of self-realization partly depends on how bad people would feel towards the prospect of not being able to live according to their own values and plans. In western societies, this agony is probably worse than in societies with less or other expectations on life. To cut a long story short, a consequentialist must know about all sorts of things in order to determine the value of self-realisation.

Another theory assigns intrinsic value to autonomy in the sense of self-realization. Especially modern liberals seem to be inclined to do so.[16] If self-realization is of intrinsic value, it must be of value to all individuals that can achieve it. Due to this fact, the ideal provides reasons to contribute to other people's self-realization. Unlike Mill's ideal of autonomy, this ideal will thus naturally actualise typical questions of justice: who should contribute, how

---

[15] To some extent, the preferentialistic version of consequentialism (II.4.1.2) will be coextensive to this ideal of autonomy (to the extent that living according to your values and plans is satisfying your intrinsic preferences, namely). The difference between these two ideas is discussed in III.2.4.

[16] The most obvious example is Rawls, 1972, but also Nozick, 1974, p 50, and Dworkin, 1985, chapters 8 and 9.

much, and to whom? I will return to these questions later in this chapter (section VII.5).

3.3 Autonomy: Summary

Different ideals of autonomy support different conclusions concerning regulation of insurance companies' access to and use of genetic information. Mill's ideal of autonomy cannot be used to defend any kind of regulation.[17] Autonomy interpreted as an ideal of self-realization seems more promising as a basis for a defence of regulation. To use this ideal to support that conclusion, we need to know a great deal: we need to know about societal circumstances, people's plans and values, what kind and how great the value is. What kind of regulation it speaks in favour of is therefore uncertain. The ideal speaks in favour of partial regulation to the extent that a right to demand genetic testing undermines individuals' possibilities to realize important plans and values. The argument could even be used in favour of total regulation, for instance, if the problem of deterrence becomes so severe that people's possibilities to live the lives they choose are gravely limited as a result. I must once again stress the significance of societal circumstances to address this issue. If society is so arranged that people are not in need of private insurance in order to gain access to important goods, vital to possibilities in society (such as health care, education, etc.), then people will be able to realize important plans regardless of regulation on private insurance.

4. Privacy

The right to privacy refers to a protected zone around the individual – a private sphere where the individual is especially entitled to non-interference from others as well as control over what is happening (see also VI.2.2). This sphere can be broad and general or just concern certain aspects of the individual (for instance the physical body), certain information or some kinds of decisions. The defence for such a private sphere has a long tradition in the legislation of the western civilisation (McGleenan, 1997, p 43-44). For instance, it is common to refer to privacy to claim the right to control information about oneself (e.g. information about ones sexual orientation or genetic constitution), to avoid interference concerning certain decisions (e.g. about

[17] This does not imply that it supports absence of regulation. The correct conclusion is that it does not directly support any kind of regulation, nothing more.

abortion), to avoid supervision (e.g. of public places), or to claim the right not to answer certain questions (e.g. to your employer about political opinions, recreational activities or reproductive plans).

Privacy is not equivalent to autonomy; the right to sometimes be "left alone" does not in it self imply any right to self-determination. But the right to privacy can be justified with reference to autonomy: to be able to practice self-determination it can be necessary to be left alone. Mill's ideal of autonomy can be seen as an attempt to defend privacy with reference to the value of autonomy (which in turn can be defended with reference to general welfare, according to Mill): to be autonomous in any interesting sense we must demarcate a sphere in which others in general, and society in particular, must not interfere.

The question in this context is if genetic information should belong to such a protected sphere. Is there a *genetic* privacy? Is there anything special about genetic information about individuals that makes it especially worthy of protection?

First let me say something more about privacy. How protected should some piece of information be to be counted as belonging to a persons privacy? When is your privacy protected? The common understanding of privacy seems to require a great deal of protection. I will join this received opinion and say that genetic privacy is protected when the person herself has full control over her genetic information, without the risk of adverse consequences to herself, whatever she chooses to do with it (at least as long as she does not use it to harm others). If she can be excluded from insurance because of negligence to disclose genetic information to insurance companies, her genetic privacy is not being fully respected, according to this understanding of privacy. A successful argumentation in favour of this strong kind of privacy thus speaks in favour of total regulation.

4.1 Is there anything special about genetic information?

We have already discussed this matter from various angles (see e.g. chapter I.4.3). The important question in this context is the following: is there something special about genetic information that makes it an object for special concern in legislation and regulation aimed at protecting privacy? This is to ask once again for the ethical significance of genetic information, but now given the assumption made about there being ethical reasons for laws and other formal societal rules.

Four main characteristics has been used to argue that genetic information is different from other (medical) information in morally relevant ways: Genetic information is: (i) predictive about disease before onset; (ii) transmittable to offspring; (iii) revealing about other persons than the one tested (namely the persons' blood relatives); and (iv) especially personal and intimate.

The received wisdom in today's discussion is that none of these characteristics single out genetic information as deserving special treatment compared to other medical information, not even together (Holm, 1999; Launis, 2000; Sandberg, 1995, p 1550 ff). This is so, since other kinds of non-genetic information are claimed to be relevantly similar (see I.4.3 for an argument to this effect). This does not show that genetic information should not be protected in the name of privacy, but then so should other information relevantly similar too.[18]

The most debated characteristic concerns the personal and intimate nature of genetic information. The argument should not rely on the very controversial idea that there is something very personal about genetic information as such, since this claim would draw on a form of genetic essentialism already refuted (I.4.1). However, no one should deny that genetic information is *considered* very personal and intimate in our culture, as is information about sexual preference, private relations and so on. However, what people consider being very personal and intimate, what they feel is of nobody else's business so to say, changes over time (think about discussing one's sexual orientation, for instance). Maybe genetic information will cease to be considered especially sensitive, when this information becomes more frequently used and widespread.

The fact that genetic information is considered personal and intimate can be used to argue that it should be protected. Laws of integrity are often justified with reference to the value of respecting peoples' feelings that this information is of no other's business. These laws are then justified against a broader consequentialist background. People feel distressed and worried about the fact that others may gain access to information they think of as very personal and intimate. This is one explanation of the fact that many are reluctant to share genetic information to third parties (Borna and Avila, 1999; Mayer et al, 1999). Regulation of access to genetic information can thus be

---

[18] This is the motivation in Norwegian legislation to prohibit insurance companies from using all sorts of medical information. See Radetzki, Radetzki and Juth, 2003, p 37-38.

justified on the ground that it helps people to protect them from the distress they may experience if genetic information were not thus protected. To put things simpler: why genetic privacy? In order to avoid distress and worry.

If there is nothing inherent in genetic information that makes it especially worthy of protection, and the reasons to protect genetic privacy are general consequentialist ones, then the question arises of how efficient a means to consequentialist ends regulation of insurance companies' access to genetic information is. Is regulation to protect genetic privacy an efficient instrument for handling peoples' distress? Some have claimed that such legislation can be counterproductive (McGleenan, 1997; Wolf, 1995). Regulation can contribute to the opinion that genetic information is a strange and potentially dangerous substance that we better keep secret, and thus reinforce the false ideology of genetic essentialism. Furthermore, if genetic conditions get special treatment in regulation, we risk stigmatising those affected by them further. There is an analogy to restrictive policy on immigration. Such a policy can be motivated by a concern for the distress caused by facing foreign cultures. The result is fewer encounters with foreign cultures, which contributes to cultural prejudices, which increases distress caused by facing foreign cultures.

There are other ways to take measures against the distress caused by third parties access to genetic information. One way is to make it more optional to reveal such information to third parties. In the case of insurance companies, this can be accomplished through public social security systems with a widened scope. With such a system, the individual can choose not to disclose the information, without the risk of loosing access to important basic goods, such as health care and economic compensation in case of disease.

One important explanation for the great reluctance in many states in the USA to accept insurance companies' access to genetic information probably is the fear of being left without insurance vital for health care and other important goods. Regulation may not be an efficient means to solve this problem. First, there is a problem of defining genetic information and genetic testing in such a way that regulation prevents use of these (Rothstein, 1997, p 457-459). Even if we focus on monogenetic diseases, which are genetic in a straightforward way, these may be tested for with other means than straightforward molecular genetic testing on DNA. For instance, cystic fibrosis (see I.4.1) may be detected by a chloride test on perspiration and many other monogenetic conditions may be tested for by biochemical analysis of proteins

or detected by access to family history. It may be difficult to formulate legislation as to include all the conditions one is interested in and exclude all the rest.

Second, there are other properties than genetic ones that insurance companies can and do use to demarcate genetic high-risk populations.[19] An illuminating analogy is the problem in the USA of using legislation to prevent discrimination by insurance companies of HIV-positives. When use of HIV-tests was banned, other medical tests (of T-cells) were used instead. When this was prohibited, insurance companies used sexual orientation to identify the relevant high-risk population. When this was regulated against, insurance companies began to differentiate between occupations where homosexuals were over-represented. Insurance companies are not interested in causal relations, but in statistical correlations, and some features have to be singled out if private insurance is to be economically sustainable. The genetic case, of course, is even more problematic to regulate, because of the numerous ways such regulation can be sidestepped due to the great variation of diseases that are genetic.

However, the force of this last line of reasoning should not be overestimated. If true, there cannot be a serious problem of adverse selection in general, since the thrust of the argument is that insurance companies always can find a way to sidestep regulation in order to identify high-risk persons.[20] Nonetheless, it does not matter which of these arguments that are most plausible in the end, since they both supports the same conclusions: that regulation may not be the most efficient way to protect the interest of insurance-holders.

4.2 Privacy: Summary

Genetic privacy can be protected by total regulation. The primary motivation to protect genetic information is to avoid the distress felt if it were not

---

[19] One way is to use ethnic groups, as in the much debated testing programs for sickle-cell anaemia among the black population of USA in the 1960s (Gostin, 1991, p 118).

[20] My own inclination is to think that regulation can sometimes be effective, making the problem of adverse selection worse than the problem of impotence of regulation. However, this cannot be settled without more empirical investigations. It should perhaps also be noted that the argument of adverse selection and the argument of impotence of regulation corresponds to two classic conservative arguments: the argument of jeopardy and the argument of futility (Hirschman, 1991).

protected, because genetic information is considered personal and intimate. There are, however, problems with using regulation as a means to protect genetic information. First, regulation may strengthen ill-informed fear of genetic information and consequently stigmatisation of people with genetic disorders. Second, regulation may be an inefficient means to eliminate distress due to fear of being left without insurance, since insurance companies can use other ways than genetic to single out genetic high-risk populations. Privacy can be protected to a certain extent by other means than regulation, however. There is the possibility to, through a social insurance system, guarantee access to vital goods without access to private insurance. The fact that one can avoid to reveal genetic information without loss of vital goods provides the protection of privacy in this system. Such system could also "play down" the importance of genetic information, and thus counteracting the belief in genetic essentialism, which would be a gain.

5. Justice

Justice is one of the basic concepts of ethics in general and political philosophy in particular. In the discussion about insurance companies' right to genetic information it is probably the most common consideration of a normative character brought to stand, and we have repeatedly seen that questions of justice arise in the discussion of the value of and right to genetic information (see e.g. II.3.3.1, II.3.3.2, and VII.3.3). Like autonomy, the concept of justice has a controversial meaning, but is always positively valued. That is to say, everyone agrees that justice is a good thing, but there is fierce disagreement on what is just.

Sometimes it has been claimed that there are various ideals of justice, but one basic concept of justice on which the various ideals agree. This has been stated in numerous ways, with small differences in substance.[21] It is, however, hard to find anything that is both unique and common to different ideas of justice. It has been claimed that all ideas of justice are ideas of equality (Dworkin, 1977, p 179). This is true, on a very loose definition on equality, which says something like *relevantly similar cases should be treated similarly* (the so-called formal principle of justice). That means, for instance, that if some

[21] See e.g. Hart, 1961, p 156, who claims justice has a core of meaning that is constant between different users; Rawls, 1972, p 5, who differs between a common concept of justice and different conceptions of justice; and Ohlsson, 1998, p 45 who differs between the formal principle of justice (relevantly similar cases should be treated similarly) and different substantial principles of justice.

dividable good is to be distributed between two persons, and there is no relevant difference between them from the point of view of justice, they should receive (or have) the same amount of the good.[22] However, this is unsatisfactory as a unique characteristic of justice. First, the suggestion is close to empty as long as one has not defined "relevantly similar". Second, this claim may not differentiate principles of justice from other ethical principles: some would claim that this is nothing more than the principle of universalizability that all plausible ethical judgements have to satisfy (see e.g. Hare, 1981).

Something more is thus required to differentiate questions of justice from other normative issues. One such proposed characteristic is that questions of justice are question of distribution of benefits and burdens.[23] There is no unanimity on this point,[24] but in this context it is a reasonable prerequisite. From the point of view of the insured, insurance policies can be considered as benefits or *goods*, and the premiums charged by insurance companies a burden. The situation is the other way around for insurance companies.[25] The question of justice, then, is how these goods and burdens should be distributed. The question in no way implies anything about there being a distributor (for private insurance, the market does the distribution according to the principles of supply and demand) or about the method of distribution. To some theories of justice, the method of distribution is relevant for the justice of the distribution and these theories should not be excluded without a hearing.

If we concentrate on goods (which is customary in discussions of justice), how are they to be distributed? The proposals on what kind of distributions that are just are legio and (often) incompatible: distribution should be according to desert (Rachels, 1991), according to need (Miller, 1976), such that

---

22 To this both Nozick and utilitarian can agree, since "relevantly similar" in Nozick's terminology would mean "equal entitlement" and if two people have entitlements to an equal amount of a dividable good, they should receive the same amount. A similar reasoning is applicable to utilitarianism, which would say that "relevantly similar" amounts to something like "has equal interest of" or "makes the first person as happy as the other".

23 What are the relevant benefits and burdens to be distributed is a controversial question, but one we fortunately enough have to address in this context, since they are defined by the subject matter.

24 See Young, 1990, p 13 ff.

25 Strictly speaking, insurance does not have to be a burden to insurance companies (it is the commodity they are selling and want to sell, since that gives them their profit). But paying compensation to the insured, of course, is a burden to the insurance companies.

situation of the worst off cannot be improved further (Rawls, 1972), such that the welfare is maximised (the total: Hare, 1991; the average: Harsanyi, 1977),[26] the result of an unforced trade on a free market (Nozick, 1974), or the result of negotiation between the involved parties (Gauthier, 1986). To further complicate matters, propositions have been made that different principles should be applied to different goods (Walzer, 1983).

Considering this multitude of principles, can there be any hope of saying anything about what is just? In most cases it is difficult. In the case of personal insurance, however, a grouping of principles along two major lines is feasible, as disagreement in theory does not necessarily preclude agreement in practice. This I will try to demonstrate in the following. *On the one hand* there are the principle of desert and various principles in favour of a far-reaching equality in the distribution of the recourses of society; principles therefore called principles of equality (of which I will discuss three: the difference principle, the priority principle and the principle of need).[27] These are sometimes used to argue against insurance companies right to genetic information, and in favour of total regulation. *On the other hand* there are principles that defends the right to keep things acquired through fair transactions and negotiations. These will be called principles of voluntariness. These are used to argue for insurance companies' right to ask for and use genetic information.

I will also discuss a third type of theory of justice with relevance to this issue – theories that claim different principles of justice to be applicable in different circumstances. I will discuss the most elaborated version of such theories, namely Walzer's theory of "complex equality" (Walzer, 1983, p 17). This theory can be described as an attempted compromise between principles of equality and principles of voluntariness.

These are the main conclusions I want to defend in the following: contrary to what has been claimed in the debate, the principle of desert and the principles of equality do not directly support total regulation. Rather, they support a more general conclusion, which is not committed to any particular view regarding more specific practical arrangements, namely the claim that no one should suffer excessive burdens because of her genetic constitution. Rather, genetic susceptibility to disease is a ground for compensation,

---

[26] These principles amounts to consequentialism, and will not be discussed as separate theories of justice.

[27] I will not address the form of egalitarianism, which states that equality is of intrinsic value. This would require a book of its own. See Temkin, 1993, for a thorough exposition of this position.

according to these views. This conclusion is neutral on the method through which this should be accomplished. Principles of voluntariness, on the other hand, are either implausible (which is shown for instance by the application to this case) or do not support the libertarian conclusions they are claimed to support. The most reasonable application of Walzer's theory of justice will reach conclusions similar to the principles of equality, since private personal insurance increasingly is becoming a good necessary to security and welfare. Because of some assumptions made by the theory, this is unclear, however. This presents difficulties for the theory, I will argue. This application will therefore teach us something about the theory of justice, namely that the most reasonable theories are the theories of equality (and desert). Consequently, no one should be burdened only because of her genetic constitution.

5.1 Desert and equality

One argument that seems to tell against the justice of an arrangement where insurance companies are allowed to ask for genetic information is that no one should have to be exposed to additional burdens due to factors one reasonably cannot be held responsible for (Dworkin, 1985, p 207; Rawls, 1972, p 47-48; Roemer, 1995, p 4-5). On the basis of this *principle of desert* the following can be argued (Holtug, 1999, p 284 ff). We can only be held responsible for that which we ourselves choose (or for foreseeable consequences of such choices). No one chooses her own genetic constitution. It is therefore not a just arrangement that someone who has suffered bad luck in the natural lottery through inheriting an increased susceptibility to disease, because of this should suffer from the additional burden of limited access to or denial of other goods, such as insurance. On the contrary, such a person rather should be compensated for those burdens that are due to bad luck.[28] If insurance companies are allowed access to genetic information, they will exclude from insurance people already burdened due to bad luck, and this precisely because of this bad luck (i.e. their increased susceptibility to disease). Therefore the companies should not have access to this information. It might seem, then, that the principle of desert speaks in favour of total regulation (Johnston, 1999, p 80, 83-84).

---

[28] Holtug, 1999, however, argues that we need an extra premise (such as a principle of equality) to reach the conclusion that undeserved burdens should be compensated (p 287). He does not claim that the principle of desert implies that regulation should be implemented.

The principle of desert is often connected to the ideal of equal opportunities. The reasoning behind this ideal goes something along the following lines. In modern societies of the Western type, there is a competition for favoured positions – favoured in that they mean an advantageous allocation of basic goods, such as income and social status. In order for this competition to be just, we must all have equal opportunities to succeed in it; circumstances must not unfairly disfavour anyone. There are basically four different views on how equal circumstances has to be in order to make the opportunities equal: (a) absence of legal barriers for favoured positions (e.g. no nobles; formal equal opportunities. Nozick, 1974); (b) elimination of informal barriers based on sex, ethnicity, sexual orientation and so on (Fishkin, 1987); (c) elimination of all social circumstances that have consequences for the competition, but that is not the result of the competitors' own choices, i.e., elimination of the social lottery (Goldman, 1987); (d) elimination of all circumstances, natural and social, that have consequences for the competition, but that are not the result of the competitors' own choices (Roemer, 1995).[29]

It has been claimed that we have *fair* equal opportunities only when we have reached step (d) (Rawls, 1972, p 74; Roemer, 1995, p 2-3). Then people's positions are determined by their own choices, rather than circumstances they cannot do anything about. When we have eliminated the effects of such natural and social circumstances, what we have left is what the individual herself contributes with. This is what the person is entitled to, is justified to claim or deserves. Interpreted in this way, the principle of desert leads to far-reaching equality: no one should have to suffer detrimental consequences because of things they cannot do anything about themselves. However, this leaves open for interpretation, first, what should be counted as "detrimental consequences" (who are to be compensated), and, second, how this compensation should be accomplished in a society with scarce resources. Here, more substantial theories of equality come into play. Of such theories, I will in the following consider three main streaks: the difference principle, the priority principle and the principle of need.

---

[29] The three first steps can be found in Buchanan et al, 2000, p 65. Including the fourth step we have the view on equal opportunity they call the brute luck-view.

Rawls' difference principle is so widely discussed that a closer presentation than the following is superfluous: "social primary goods... are to be distributed equally unless an unequal distribution... is to the advantage of the least favoured." (1972, p 303) I will not account for the argumentation that leads to this principle or explicate the principle further, since that is not needed for my purposes. Only the application of Rawls' conception or ideal of justice to the question of insurance companies' right to genetic information is of primary interest here. This brings the focus on the basic moral intuition that this ideal of justice expresses: the claim that we have special obligation towards those worst or, at least, worse off.

Rawls' theory of justice has many inherent problems that nevertheless should not be concealed. One problem is the difficulty of identifying the worst off group (is it comprised of a small destitute minority or everyone but the best off, or something in between?).[30] Besides that, the privileged position that Rawls gives this group have troubling consequences, in that the least improvement to the worst off always outweigh an improvement of the second worst off group, no matter the size of the improvement of this group, the size of the groups and even if the difference between the groups is very small to start with (Holtug, 1999, p 288). These consequences are to some extent the result of Rawls' concentration on groups instead of individuals, but also his stern deontological reluctance to balance the interest of the worst off against the interest of those better off.

The more general moral intuition reflected by Rawls' theory of justice does not have to solve that kind of technicalities, however. It is enough to claim that the worse off someone is, the stronger the obligation of others to help her. This general idea is summed up by the *priority principle*: "[b]enefiting people matters more [morally] the worse off these people are" (Parfit, 1997, p 213). This principle can be used to argue against insurance companies' right to genetic information, since this right would often be used to the disadvantages of the already bad off individual (Holtug, 1999, p 290).[31] People who already suffer from natural disadvantage (the increased risk of developing disease), is further burdened by reduced possibilities to insure themselves against the bad effects of this. That seems to be contrary to the priority principle.

---

[30] However, Rawls does have some, not very elaborated, suggestions on how this should be done (but not so very much about why it should be done in the way he proposes), 1972, p 98.

[31] To argue this point a minimal priority principle, stating that people who are worse off should not get their situation worsened to the benefit of those better of, is sufficient.

A similar line of reasoning seems applicable to the *principle of need*: goods should be allotted according to need. What need is, when someone is in need and what determines the extent of a need, is notoriously hard to define (Kymlicka, 1994, p 183-186). The spirit of the principle of need is, however, congenial to the priority principle; to be worse off is often to be needy in the way this word is commonly used. If insurance companies are allowed to access genetic information, those in most need of insurance will be the ones suffering the greatest difficulties of getting it. Any reasonable interpretation of the principle of need therefore might seem to favour the same conclusion as the priority principle: total regulation.

In spite of the apparent force of these lines of reasoning, however, the conclusion is premature. Indeed, it does seem to follow that those suffering from misfortunes, such as genetic disease, should be compensated as far as is possible. The more fortunate have an obligation to give up some of their goods to help those worse off, *even if this causes a decrease in the net balance of goods.* All this speaks in favour of a redistribution to the benefit of these unfortunate individuals. But it does not tell us that insurance companies are the party obligated to perform this redistribution. Rather, it seems more congenial to the principles of equality to claim that all of those better off should contribute.

Moreover, as we have seen, the effect of forcing insurance companies to provide for genetically worse off by prohibiting insurance companies' use of genetic information may be the collapse of private personal insurance. Then the very problem that the regulation was intended to solve will resurface, and this as a result of this regulation. This is also problematic on the principles of equality, since it would further burden an already burdened group.

There is a further problem with letting private insurance and regulation solve the problem of compensating the genetically worse off, namely the problem of overcompensation. You might purchase a health insurance to guarantee access to proper care in case of disease or injury. You may also purchase it to save money or to acquire wealth. The worry of insurance companies is that persons allowed to withhold genetic risk will enter insurance contracts with very high benefits, not to guarantee a decent level of welfare, but to strike exceedingly rich. The same thing goes for life insurance, maybe even to a greater extent (Chadwick & Ngwena, 1995, p 123). And constructing such special opportunities seems difficult to defend with

reference to considerations of justice. We may have an obligation to help people in need or to compensate for arbitrary inequalities, but we surely do not have any obligation to make persons with genetic disorders vastly richer than the average person. To this the consequentialist argument that such policy might also undermine solidarity with this group can be added.

All of these problems speak in favour of another solution to the problem of achieving justice (according to the principle of desert and the principles of equality) for the genetic high-risk group. The solution favoured should be familiar by now: a generous collective social insurance system, which guarantees that no one stands helpless in case of disease.

This does not mean that private insurers are without responsibilities. Private personal insurance is a highly valued commodity, and there are few of us who would feel comfortable to be shut out from this market because of our genes. To be unable to purchase the commodities you want, just because of your genetic constitution, is also an undeserved loss. To avoid this, and at the same time avoid adverse selection and overcompensation, a system of partial regulation similar to that in Sweden and the Netherlands can be implemented (see VII.1.1). The level below which one can buy insurance without revealing genetic information, then has to be decided on several grounds: the severity of the problem of adverse selection is maybe the most important, since the solving of this problem is necessary for the existence of private personal insurance. However, if the existence of a social security system of the type proposed is a fact, then private personal insurance is somewhat of a luxury commodity, probably primarily of interest to the wealthier part of the population (if there is such a population in a just society). And there is something to the following claim: "there is nothing wrong with applying a libertarian view to the distribution of benefits between members of a privileged group in society" (Tamburrini, 2000, p 119) – at least if the privileged position of this group is not a result of unjust social arrangements.

5.2 Voluntariness and rights

5.2.1 Actuarial fairness

Principles of justice also have been used as arguments in favour of insurance companies' right to genetic information. The most frequent argument refers to actuarial assessment of risk (Sandberg, 1995, p 1554; Wortham, 1986, p 361). The whole idea of private insurance is based on the assumption that people pay premiums in proportion to the risk of payment of the compensation taken by

the company. With access to genetic information, insurance companies can take the higher risk of those with damaged genes into consideration, and differentiate premiums accordingly. The idea of actuarial fairness is that, in correspondence with the spirit of private insurance, everyone should pay premiums according to her own risk, or to phrase it in negative terms, no one should have to pay higher premium than the risk she actually represents. Justice according to actuarial fairness rests on "the *moral* judgement that *fair underwriting* practices must reflect the division of people according to the *actuarially accurate* determination of their risks" (Daniels, 1990, p 500).

The concept of actuarial risk is problematic, however. As far as I know, no one has explicitly defended that the calculations of risk undertaken by insurance companies aim at reflecting any kind of "objective" risk or probability. Since it is highly controversial if there are any objective probabilities (Resnik, 1987, p 61), a defence of actuarial fairness would therefore profit from not relying on any such assumption. A more promising interpretation of the concept of actuarial risk is to refer to the accurate calculation of risk, given the known factors relevant to the risk in question (Harper, 1993, s 224).

However, insurance companies do not use all known factors relevant to the risk in question when they differentiate premiums. Calculation of risk and differentiation of premiums are based on a limited numbers of factors. To use all the factors known relevant for estimation of risk for disease and premature death, would simply make the investigation of potential customers too expensive to bear its own costs. The customary procedure is, therefore, to use some factors traditionally seen as highly relevant, for which statistics are already available. Because of this, all risk-assessments are more or less arbitrary in light of the actuarial ideal. The problem is not just that insurance companies defend a practice with reference to an ideal (actuarial fairness) that they do not reach. Worse than that, insurance companies do not even try to reach the ideal. They have other more important (economical) considerations that stand in the way. Therefore, if the actuarial ideal can be so outweighed by these sorts of considerations from the point of view of the insurance companies, reason dictates that claims from actuarial fairness can be similarly outweighed by *all* considerations of a similar kind. For example, it may be outweighed by economic factors on behalf of potential customers – such as the economic risk of revealing the results of genetic testing.

All of this is, of course, compatible with the claim that actuarial fairness can in fact not be outweighed in this way, and that insurance companies should sacrifice the economic gains of applying cheap and simple methods of risk-assessment for the sake of actuarial fairness. However, such a suggestion presupposes the actuarial ideal to express a basic tenet of justice and actuarial fairness, seen as an independent principle of justice, has inherent problems. The ideal is namely based on a dubious moral principle: individuals should be able to gain from their natural advantages, even when others stand to loose because of this (we will later discuss libertarianism, which defends this). That is contrary to the principles of equality previously discussed, according to which natural disadvantages are grounds for compensation rather than further burdens. If one finds such principles of justice plausible, one cannot consequently embrace actuarial fairness as a basic tenet of justice.

Against this one may object that it is reasonable that we at least sometimes should be allowed to gain benefits because of our natural advantages. That seems to be necessary in a market economy of the Western type. To this theories of equality can agree, however: it may be the case that everybody in a society, including the worst or worse off, stands to loose from blocking incentives to talents. In this particular case, however, the question is not whether we should prevent talents to gain from their capacities. Instead, the question is if those who have suffered the bad luck of being genetically susceptible to disease should be further burdened through exclusion from other goods, such as health care. Since that is a consequence of actuarial fairness taken as a basic principle of justice, most people probably will be reluctant to accept this as a reasonable principle.

A perhaps more convincing argument in favour of actuarial fairness instead refers to the fact that allowing the withholding of genetic information to insurance companies will make low-risk individuals subsidize high-risk individuals, which is unjust towards low-risk individuals. This is not very convincing, however, since everybody will have to pay the higher premiums such an allowance would result in, including the high-risk individuals. Low-risk individuals are therefore not discriminated against in this respect.

To gain further support against regulation, one thus has to leave purely actuarial concerns and instead refer to more general intuitions of justice. Then one can claim that all those more fortunate and better off should carry the cost of compensation of genetic high-risk individuals, and not just those who have

chosen to invest in private personal insurance. This speaks in favour of generally subsidized compensation from society, where people pay according to capacity and receive according to need.

The line of reasoning above shows, perhaps not surprisingly, that the actuarial ideal is best seen as internal to the business of private insurance – not a general principle of justice. This suggestion is further strengthened by its actual use within insurance business: it is one consideration of many that can be balanced out in case of conflict with e.g. economic factors. Because of this, the actuarial ideal leaves plenty of room for people to abstain from genetic testing or the sharing of information from such tests in connection with applying for private insurance.

If, instead, actuarial fairness is interpreted as a *strict* ideal that insurance companies *should* do their best to comply to, the actual procedures of risk-assessment of insurance companies would have to undergo rather far-reaching revisions. It seems rather difficult to predict what the result of such revisions would be for the business of private insurance, as well as society on the whole. Therefore, to describe what a strict ideal of actuarial fairness would have to say about genetic testing in connection with insurance is difficult, to say the least.

5.2.2 Libertarianism

Even if ideals of actuarial fairness will not do the job, there are *basic* ideas of justice that appear to support the right of insurance companies both to ask for information from old tests and to demand new tests to be made; i.e. absence of regulation. These are the *libertarian* theories of justice, of which the most famous is Robert Nozick's theory of entitlement.[32] Libertarian theories are united by backing up a strong kind of free market system without taxation and (stricter) regulation. My criticism will partly extend to all these libertarian theories, when it comes to criticizing the libertarian conclusions they allegedly reach, but I will concentrate most of my criticism to Nozick's particular theory.

The basic assumption of Nozick's theory is that we have certain absolute negative rights, foremost to our body and acquired property. In virtue of this, no one may prevent the individual from using his body, psychological

---

[32] Although this will not be systematically demonstrated, other theories in this family support the same conclusions in this respect as Nozick's, e.g. Gauthier's theory of morals by agreement (see instead Gauthier, 1986; Kymlicka, 1990, p 132 ff; Holtug, 1999, p 288).

capacities and justly acquired property in the way she seem fit herself, as long as the individual does not violate the same rights of anyone else (I may destroy my justly acquired car if I want to do so, but not by crashing into your porch). If all property is justly acquired, every voluntary transaction that does not violate anyone's rights will result in a just distribution, no matter what the pattern of distribution looks like. "A distribution is just if it arises from another just distribution by legitimate means" (1974, P 151) is Nozick's concise statement of this idea.

According to libertarianism, each one is free to choose the terms she herself wants when engaging in transaction with property she is entitled to, just as she is free to accept or reject the terms of the other party of the transaction. This implies that insurance companies may demand information about the insurance applicant's genetic constitution as a term of insurance contract, if they choose to do so. If the insured deliberately withholds such information, the insurance company has the right to be compensated by the insured, and the state has an obligation to force the insured to pay compensation. Justice on behalf of the insured is constituted by the fact that she could have rejected the contract and chosen not to engage in the transaction, if she had found the terms unacceptable.

One basic problem facing anyone who tries to apply these assumptions to reality is that it is unclear, to say the least, to what extent people's material belongings are in fact justly acquired property (Nozick, 1974, p 231). This due to the vast amount of force, violence and robbery that can be found throughout human history - not least the history of Western affluence. I will sidestep this difficulty, assuming (implausibly) that people's belongings are in fact theirs in the moral sense of libertarianism. I will argue that there are still serious problems involved in supporting absence of regulation on libertarian grounds.

The major problem with libertarianism is its normatively unacceptable consequences, which are clear in this case. According to libertarianism, taxation is a violation of the right to property,[33] even if tax-money saves lives or

[33] This holds given the implausible assumption that the libertarian rights extend to our actual material belongings. I will question this assumption shortly. However, regardless of whether one rejects libertarianism due to its (alleged) moral implications or because it does not have these implications, the conclusion will be the same: that absence of regulation cannot be defended on libertarian grounds.

reduces extensive suffering (Kymlicka, 1990, p 96-97). People in dire conditions instead have to rely on the voluntary beneficence of others. If private personal insurance companies demand genetic information and use this to differentiate premiums, which they most certainly will if they are allowed to, those suffering from genetic disease may be left totally without means to provide for the most basic material necessities for survival. This consequence should be enough to make most people reject libertarianism.

The basis of libertarianism seems sound, however. It is an appealing thought that each individual should be the sovereign ruler of what happens to her own body with its attributes and capacities, and that we should be allowed to use this as we our selves choose, as long as we respect the corresponding rights of others. Perhaps, then, the consequences just mentioned is the price we have to pay in order to uphold this fine ideal of personal liberty. However, these consequences follow only if Nozick's further claim that "self-ownership" implies the absolute right to justly acquired external property is accepted. Property, according to Nozick, can be justly acquired either through original acquisition of previously un-owned nature, or through voluntary transactions between autonomous individuals. We have the right to acquire parts of the external world, as long as they are not previously acquired, and we leave "enough and as good" parts to others (Nozick, 1974, p 202).[34] This last condition on legitimate original acquisition has been called "Locke's proviso"[35] and has been the subject of much debate. The outcome of the debate shows that the basis of Nozick's theory does not imply the general resistance to taxation or regulation of the market as easily as he thought.

Hillel Steiner, 1997, has argued that a reasonable interpretation of the basis of libertarianism leads to non-libertarian conclusions. According to Steiner, each individual, on the basis of each person's right to use her body and talents to achieve prosperity, has an original justified claim of access to an *equal* part of (the value of) natural resources. If natural resources already have been acquired by earlier generations, then these generations has a duty to share the (value of) natural resources with the new individuals. Steiner continues his argument by

---

[34] How the acquisition should be done in order to legitimate is unclear. Do I have to "mix labour" with that which I acquire (which seems to have been the position of Locke)? In that case what exactly do I acquire (if I use part of a tree to make a chair, do I acquire the whole tree, the parts I am using or just the product)? Is it enough to fence a thing in or "call for" it in order to acquire it? I will ignore these difficulties.

[35] From Locke, who originally formulated this in Two Treatise of Government, 1689, II:27.

claiming that if everyone has such an equal right to natural resources, then we also share an obligation to carry the costs for whims of nature. The genes of an individual are a result of such whims of nature.[36] This seems to favour an obligation to compensate those who suffer adverse consequences as a result of their genes. It is an issue of appropriateness how this compensation should be implemented – through a regulation that limits insurance companies rights to use genetic information, or through a social insurance system. It is important to notice that the compensation cannot be left to voluntary beneficence, since there is a *right* to compensation if Steiner is right.

Further arguments can be brought to bear on the idea that Nozick cannot deduce the conclusions he does. Nozick claims that Locke's proviso is compatible with individuals acquiring a larger part of natural resources than the part each one would have acquired through equal distribution. On the other hand, Nozick claims that an acquisition of a part of natural resources that makes others worse off materially than they would have been had that part of nature never been acquired is illegitimate. This interpretation of Locke's proviso has been widely criticized. The background of the criticism is that Nozick defends the principle of self-ownership with reference to the ideal – vital to all forms of liberal ideals - that each individuals right to live his life according to his own ideas of what is valuable should be respected (Nozick, 1974, p 50).

This raises the question of why Nozick emphasises making others worse off *materially* and not worse of in the ability to lead the life the individual herself finds valuable (Cohen, 1986). If the ability to lead the life the individual herself finds valuable is the basic tenet underlying Nozick's theory, why is there according to him no obligation to support those who cannot do this without the help of others (Holtug, 1999, p 289)? Many of those suffering from genetic disease obviously belong to this group and this may imply far-reaching obligations of others to help these people. For instance, Kymlicka (1990, p 113) has shown that if libertarianism in this way is interpreted in line with its most basic moral tenet, the resulting demands on redistribution of resources may be extensive.

---

[36] To an increasing extent, this can be questioned. Preimplantation and prenatal genetic diagnosis make it possible to choose the genetic make-up of their children. The responsibility for the consequences of that make-up could then be claimed to belong to the parents, thus making them the party that should provide compensation, according to Steiner.

5.3 A compromise

Even if libertarianism is hard to defend generally, it may be defensible partially. A dominating opinion in Western societies is that market transaction is an appropriate and efficient method of distribution of a wide variety of goods. Very few become morally indignant by the fact that e.g. golf-equipment and Beatles-records are distributed according to supply and demand. Most people lead good lives without the right to support for the purchase of such expendable commodities. On the contrary, most people think that a right to receive support is limited to some goods, of vital concern to welfare, such as health care, education and food. These vital goods should be accessible to all, and, if necessary, we are justified in implementing some mechanism of redistribution to provide these goods for those unable to purchase them on the market.

Given the second empirical supposition of this chapter, private personal insurance is to an increasing extent becoming such a vital good. The social role of insurance companies is thereby changing. This has lead some to claim that insurance companies have other obligations than profit-maximising business in general – obligations of a social kind (Chadwick & Ngwena, 1995, p 122). The fact that access to private personal insurance is increasingly becoming necessary for the security and welfare of the individual makes it reasonable to apply stricter regulations on such insurance than on goods such as golf-equipment and Beatles-records. Such, at least, is the general idea.

This kind of argumentation of justice is of a communitarian kind, and can be supported with reference to considerations of principle. The most obvious candidate is Michael Walzer and his primus opus on justice: *Spheres of Justice* (Walzer, 1983). I will look closer into this in the following.

Walzer's point of departure is that a society, or, more generally, a culture, has shared, important values and ways of seeing social relations. Different societies regard different things as goods, depending on these values (Walzer, 1983, p 8-9). The term 'goods' have a wide meaning and should be understood as everything positively valued and distributed according to societal norms, including public offices and social relations. Whether some thing is a good or not is partially determined by the function this thing fulfils in people's relations, or its *role*. Money is an example: it is of value in our society because it functions as a means of exchanging commodities and services. Some things are valued in several cultures, but often to different degrees and for different

reasons. For instance, cattle are considered valuable due to its function as food in one culture, while another culture values cattle for its religious significance.

These examples illustrate that different goods have different *social meanings*. This term refers to the common evaluation and understanding of a certain thing in a certain society. The following claim is crucial to understand Walzer's theory of justice: what principle of distribution that should be applied to a certain good is determined by or a part of the social meaning of this good (Walzer, 1983, p 20). For Western societies of the type that are of concern here, Walzer discern three basic principles of distribution (Walzer, 1983, p 21-26): the principle of desert, the principle of need (resembling the principles of equality discussed above) and free exchange (resembling libertarian principles discussed above). For instance, it is part of the social meaning of punishment in Western societies, that it should be distributed according to guilt (negative desert). The favoured positions, such as jobs, should befall the person with best merits (positive desert) and health care should be distributed according to need. Non-vital material commodities, however, are to be distributed on the basis of free exchange. That all this has a banal ring is because we have a common understanding of the social meanings of these goods, which also tells us how they should be distributed.

Following this, a just society is a society of "complex equality" (Walzer, 1983, p 17), as opposed to simple equality (where everyone has the same amount of every good). Complex equality means absence of dominance (Walzer, 1983, p 16-20), which means that we should not be allowed to use one type of good to acquire goods that have another social meaning. In our society, the commonly agreed injustice of being able to use money to avoid legal punishment is an obvious example. Walzer states this thought by saying that different goods demarcate different spheres, and that justice prevails when spheres do not impose on one another.

With this theory of justice as our point of departure the question thus becomes: what is the social meaning of personal insurance? Attempts have been made to answer this question in the spirit of Walzer, but this has proved to be a rather difficult task (Lemmens, 1999). Partly, this difficulty is due to the fact that the social meaning of a good is to some extent determined by its relation to other goods. The task is further complicated by the dynamics of history, in which the social meaning of some goods gradually change. That is, a type of good which resides in one sphere and to which one type of

distributive ideal is applicable may, due to social change, move into the area of another sphere, thereby making other distributive ideals more appropriate regarding this type of good. This is, I claim, what seems to be happening with personal insurance.

At least traditionally, private insurance has been considered a good among others to be exchanged on a free market according to supply and demand: they are bought to satisfy "private desires of certainty" (Lemmens, 1999, p 34). As mentioned, this role of private insurance is changing. Since we are in a situation where public social insurance systems are weakened, private insurance has a tendency of becoming more vital for basic welfare. Private insurance is developing into a necessary means of compensating for loss of income or providing for health care in case of disease and of compensating for loss of income in case of the premature death of family providers.

Walzer argues that health care is a typical example of a good that should be distributed according to need. No one should have to be left without access to health care in our society. The principles of the market should therefore not interfere with the sphere of health care. This does not imply that private personal insurance should be banned. But if health care should be distributed according to need, it should be accessible for the individual regardless of her success in the competitive market.

The obligations of insurance companies therefore must be judged with consideration taken to the rest of society. In the EU of today, the major part of health care is funded by taxes (Nys et al, 1993), and is distributed according to some vaguely formulated criterion of need (SOU 1995:5, p 22). There are reasons to believe that this situation is about to change (it is, I have claimed, in fact already changing). If health care should be distributed according to need, the following assertion seems reasonable from a "walzerian" point of view: insurance companies' obligations to make personal health insurance accessible for everyone is proportional to the absence of social insurance systems. Someone has to see to it that the needy get the care they are entitled to, and if the state does not provide for this redistribution, insurance companies must do this. For this to be accomplished, some sort of rather strict regulation is probably necessary.

We have seen, however, that it is a risky business to leave this responsibility to private insurance, because of the problem of adverse selection. For Walzer, it makes no difference in itself how we regulate insurance companies use of genetic information. The important thing according to his theory in this

regard, is that no one is left without the goods that are part of the sphere of "Security and Welfare" (Walzer, 1983, p 64) that should be distributed according to need. Health care, education and commodities such as food and housing belong to this sphere (Walzer, 1983, p 64-94). If we are to allow private personal insurance, it must not threaten anyone's access to these goods. But such a threat is exactly what is posed by the problem of adverse selection. For this reason, the suggestion to force insurance companies to provide health insurance according to need does not seem as a stable solution. Remaining, then, is the solution of reversing the weakening of social security systems. The conclusion supported by Walzer's theory in this regard is similar to those supported by the principles of equality and the principle of desert, then.

However, even if one is inclined to accept this conclusion (as I am), there are good reasons to avoid building it on Walzer's theory.[37] This is so, since the theory has several serious problems of a general kind. One such problem is that it is unclear how the theory should deal with disagreements on or vagueness of the social meaning of a good. This is so, since the idea that goods should be distributed in accordance with their social meaning presupposes that each good has one such meaning,[38] which rules out disagreement, and that the meaning is clear enough so as to yield an answer to what kind of distribution that is implied by it, which rules out vagueness (in this sense). However, from the debate of the proper distribution of insurance, it is obvious that there are disagreements on its just distribution. For instance, a libertarian would disagree to the claim that health insurance and, thus, health care should be distributed according to need (or something of the kind). Even if one thinks that the actual number of libertarians in a society is too small as to be able to determine the social meaning of goods, the problem of vagueness remains: it is not obvious that the distribution of health care according to need is a part of, or implied by, the *meaning* of health care (even if most people probably think that health care should be distributed according to need or something of the like).

True, Walzer has a general answer to solve problems like these: it is the task of the democratic political sphere to determine the borders of different

---

[37] Some of the points of this criticism can be found in Dworkin, 1985, p 214-220.

[38] Otherwise, the problem of which meaning that is the relevant one emerges. I will return to this shortly.

spheres (Walzer, 1983, p 281-282). However, this solution seems to dodge rather than address the fundamental question of how social goods should be distributed. Democratic political procedures is a way of reaching a practical solution on what distribution to implement in the face of disagreements of how we should distribute goods, procedures that most of us consider legitimate even if we do not agree to the solution reached, and not an answer to how one should distribute goods (this is what the disagreement concerns).

Of course, one could claim that the outcome of such a democratic procedure is just, due to the process, whatever the outcome may be. However, besides being at odds with moral intuitions (for instance: "So a distribution is just even if the majority robs a minority of all its means of survival?") it seems to be at odds with the plausible idea that one cannot infer moral conclusions from strictly empirical premises, that is, infer an ought from an is.[39] This is another general problem for Walzer's theory: even if there were no disagreements on or vagueness of the social meanings of goods, so that it were evident what distribution their meaning implied, it still seems problematic to infer from the fact that a good actually *has* a social meaning that it *ought* to be distributed according to it.

I will not elaborate the problem of the ought/is-distinction.[40] Perhaps this problem can be solved. However, this problem points towards another problem that is, I think, even graver: Walzer's theory seems to have morally implausible implications. For instance, if it were a part of the social meaning of health care insurance and health care that it should be distributed according to free exchange, then you should not get it if you cannot pay for it. However, Walzer's theory implies that it must be just to apply this view in these circumstances. However, this would clearly be unjust, so Walzer's theory must be wrong.

Of course, someone might disagree with my claim that this is morally appalling. Perhaps you are a libertarian. But even if you are, you should be reluctant to claim that the social meaning of a good determines the just distribution of it, even if you agree that the distribution is right. Otherwise you would deprive yourself of the possibility of rationally questioning the distribution of a certain good when it is in accordance with the social meaning

---

[39] This is the famous Hume's law, most famously formulated in Hume, 1740, Book III, Part I, Section I, p 469-470.

[40] See instead Salwén, 2003, for a discussion of Hume's law.

of the good, but not according to the distribution you favour, since the question of just distribution is settled by the social meaning of the good in question. And a theory that closes the possibility of rational criticism in such a way is problematic, to say the least. So even if Walzer's theory reaches the correct solution, it seems to do so in the wrong way.

6. Other third parties

Up till now, this chapter has dwelled on the question of insurance companies' right to genetic information. I have argued that this right should be limited somehow, but that the morally defensible way to provide insurance for disease and premature death is through public insurance. However, as we have seen, insurance companies is just one of many parties interested in genetic information. In this section, I will address the question of two other parties alleged right to genetic information: employers and researchers. While doing this, the findings from the previous discussion will prove useful, especially regarding employers, although limited, especially regarding researchers. This is so, since the case of employers is more relevantly similar to the case of insurance companies than is the case of researchers, not least since employers and insurance companies share the economic interest in genetic information. This indicates that the previous discussion of insurance companies can be useful to illuminate all relevantly similar questions, that is questions regarding economically interested third parties' legal right to genetic information. I will thus start off with employers.

6.1 Employers

Employers may also have an interest in receiving genetic information from the presymptomatic genetic testing of an individual. The interest of employers in receiving this information is primarily economic, just like the case with insurance companies. Employers can avoid or reduce various costs by receiving information that someone has an increased risk of (genetic) disease by using this information to avoid having such an individual on the staff. This may reduce costs for the disruption of work and compensation due to sick leave (in countries where such compensation is to some extent financed by employers). The reduction of cost will of course be greater when employers can avoid *job applicants* rather than firing an already employed person. This is so, since firing an employee on the basis of genetic testing, even if legally permissible in the country in question, may be connected with severance

payment and hiring and training a replacement employee.[41] Another way to reduce cost in the light of genetic information about increased risk of disease is to adapt the work environment so as to remove or reduce the risk in question. However, this is also likely to be a cost. So the most obvious economic advantage for employers of receiving genetic information is to receive it from job applicants, i.e. prospective employees, who they then can abstain from employing if the risk of increased costs they might impose is considered to be too high.

In light of these interests of employers in receiving genetic information from presymptomatic genetic testing, should they be allowed to demand this information from the individual? That is, should employers have a legal right to obtain this information or should this be regulated in any way? My primary aim in this subsection will not be to argue in favour of any specific answer to this question (even though I will indicate in which direction the arguments point), but only try to demonstrate how the previous argument concerning insurance companies can serve to illuminate also this question.

First, it should be noted that the separation between total, partial, and absence of regulation, could be used regarding employers as well: they may be prohibited from using any kind of genetic information at all (total regulation), they may be allowed to use only information that the (prospective) employee already has (partial regulation), and they may also be allowed to demand genetic testing as a prerequisite of employment (absence of regulation).

Realising that the same types of regulations are applicable in the case of employers as in the case of insurance, it also becomes easier to see that much of the same arguments are applicable, albeit with some important exceptions. First, with regard to consequentialistic arguments, just like partial regulation may lead to deterrence from testing in the case of insurance companies, it may have the same consequences in the case of employers. And just like anything less than total regulation may leave some people without insurance due to their genetic risk, it may leave the same people without employment. However, there is no parallel to the argument of adverse selection in the case of employment, since increased risk of genetic disease does not provide an increased incentive to look for employment, whereas such increased risk

[41] In fact, the economic gain of receiving genetic information about someone who is already an employee can be questioned altogether, partly due to the factors already mentioned, but also due to the fact that sick leave may increase as a result of the person receiving information about her increased risk for disease (Laurie, 2002, p 155).

provides an increased incentive to seek for life- and health insurance. Thus, genetic high-risk persons getting work will not threaten the work supply. Thereby, the strongest argument in favour of giving insurance companies some access to genetic information is absent in the case of employers.

Second, arguments of autonomy apply. Just as the autonomy of the individual, in the sense of her (possibilities of) self-realization, may be reduced by partial regulation as compared to total regulation, and even more so by absence of regulation, in the case of insurance companies, the same goes for the case of employers: if employers are allowed to turn down an employee on the basis of her genetic risk, this can severely limit the autonomy of the individual. For instance, absence of regulation may make it difficult for an individual to remain ignorant about her genetic constitution even if she so desires, since it allows for employers to demand new tests of the individual. And turning down a job opportunity in order to remain in ignorance might be too burdensome for the individual to be a live option.

Third, arguments of privacy apply. Privacy is threatened if anything less than total regulation is implemented, since giving the employer a right to obtain genetic information will mean that the individual can suffer adverse consequences (be out of employment) if she refuses to give up control of this information.

Fourth, arguments of justice apply. This is so, since employment can be considered to be a good, and it is a good that (the structure of) society determines the distribution of. Of course, *work* does not have to be a good. At least some types of work, sometimes, are more plausibly seen as a burden. However, employment, and thus work, is tied to the distribution of several other goods: most obviously money, but also social status and, thus, self-respect. And questions of the proper distribution of societal goods are questions of justice.

However, there is one important difference between the distribution of care and compensation of ill-health on the one hand and work on the other: in the former case, a publicly financed system may secure a just distribution just as well as regulation, if not better. However, in the latter case, this solution does not seem to be feasible, at least not to the same extent. To be sure, society does offer employment and could offer employment to those shut out of the work market due to their genes. But in the case of absence of regulation, there is reason to believe that the number of people without work due to their genes can become too great in order for society to be able to bear the long-

term costs. Still, the general point remains that all ethical considerations that are relevant regarding insurance companies are relevant regarding employers.

As already mentioned, I will not try to figure out what specific answer to the question of employers' right to genetic information these arguments would lead to. I think, however, that already these brief remarks points towards a stricter regiment of regulation than regarding insurance companies. As already noted, the most important argument in favour of partial, rather than total, regulation of insurance companies, namely the argument of adverse selection, is irrelevant regarding employers. And to this may be added that publicly financed alternatives in order to secure justice do not seem as feasible in this case as in the case of insurance.

However, this may be to take matters too far. Even if one concurs that the economic interest of avoiding costs relating to sick leave should not matter for decisions of employment,[42] there are other parties than the employers whose interest is at stake. For instance, one can refer to the fact that it can be in the interest of the (prospective) employee to have the information too. The following might be an example: one may be especially vulnerable to certain environments due to one's genetic constitution. For instance, one may have an increased genetic susceptibility for developing a certain disease if exposed to certain chemicals and substances compared to others. In such cases, it can certainly be in the interest of employees to test themselves in order to be able to avoid such work environments. However, despite initial appearance, this argument does not speak in favour of allowing employers to demand genetic testing or genetic information that the person has as a term of employment. It merely supports the right of the employee to obtain testing if she is concerned that she might get sick due to her work environment.

However, in rare cases, the interest of others, like the general public, might be at stake. Thus, it has been suggested that "the legislation be drafted so as to forbid employers testing for genetic conditions other than those which might put the public at direct and substantial risk."[43] An example might be genetic tests for Huntington's disease performed on airline pilots. However, it is questionable if testing should be performed by the employer and before

---

[42] The opinion that this should be irrelevant for the question of whether or not one employs someone seems to be widespread (Laurie, 2002, p 154-155). Rather, "decisions on employment should be based on current ability to do the job" (Ibid.).

[43] The suggestion is made by the Science and Technology Committee in UK (Laurie, 2002, p 154).

symptoms. There are alternative and established ways of ensuring the safety of the public in this case, like regular testing of ability to work the plane and the presence of co-pilots in the cockpit.

This relates to another problem with genetic testing for employment purposes: allowing employers to use genetic information can discourage them to take steps to ensure a safe work environment. It may sometimes be easier and cheaper to do a genetic test than to try to implement measures that reduces risks. This also relates to the case of insurance companies, since it relates to the question of the point of regulation. The point of regulating insurance companies use of genetic information is to protect the interest of the prospective insurance holder. It is problematic if some people become uninsured due to their genes and thus looses out on important social goods necessary to lead a good life, like health care and compensation in case of disease or premature death. Similarly, the point of regulating employers use of genetic information is to protect the interest of the prospective employee. It is problematic if some people become unemployed due to their genes and thus loose out on important social goods necessary to lead a good life, like employment. However, unlike the case of insurance companies, regulation does not seem to be counterproductive in the case of employers. Rather, it seems to be an efficient mean to realize the society that, I guess, most of us want: a society where no one is excluded from the possibility of living a good life due to her genes.[44] A reasonable and just measure to achieve this in the case of insurance is through collectively financed insurance distributed according to need, or so I have argued. And a reasonable way of achieving this in the case of employment is to improve work environment so that potential genetic disease does not have to become a problem. And letting employers use genetic information can, then, be a disincentive to strive for this. So the argument that speaks against (total) regulation in the case of insurance companies (it is counterproductive to its aim) seems to speak in favour of regulation in the case of employers (it contributes to its aim).

The question of employers' use of genetic information, thus, just like the question of insurance companies', ultimately boils down to the quesion of what constitutes a good society. And, somewhat rhetorically, the queston can be asked, what society is most desirable: a society where parts of the

---

[44] This relates to the notion of "the morality of inclusion", discussed by Buchanan et a, 2000, p 258-303.

population are excluded due to their genes, or a society where people make an effort to create an environment that enable for as many as possible to be included?

6.2 Researchers

Finally, I will say something brief about another third party that can have an interest in the genetic information of a person: researchers. The interest of this party is somewhat different to the cases of insurance companies and employers, since they do not have to be economically motivated.[45] They also perform research that can be beneficent to people, for instance, that might lead to cures for diseases. This gives rise to questions about the individuals' obligations to further good causes in a more obvious way than is the case with insurance companies and employers. Presenting this problem will thus serve the purpose of pointing out that different third party interest gives rise to different kinds of moral questions.

Do researchers have a right to genetic information? They may, in a sense, if someone has an obligation to participate in a genetic study. Then the researchers have a right towards that person regarding her participation. However, I have never heard of anyone claiming that such a right should be legally enforced or otherwise institutionalised in any way. That is, the question is not whether anyone ought in any way be coerced into participating in genetic research. I take it for granted that arguing this point is superfluous. Furthermore, there are very good reasons for the confidentiality of scientific research on genes to be rigorous, since otherwise the possibility of getting people to participate voluntarily would be bleak. So I also take it for granted that genetic information from genetic research ought never to be released to other third party interests.[46]

Still, then, researchers may have a right in the sense that someone else has a moral reason to participate, and perhaps a moral reason so strong that it supports a duty to do so: one *ought* to participate. Recall the case of Tom (V.3.2): "Tom has to decide whether to participate in a population study which would provide scientists with a more accurate picture of Huntington's

---

[45] This is not to deny that biomedical researchers often have substantial economic interest in their research, e.g. regarding the possibilities of patenting prospective pharmaceuticals.

[46] The question becomes different if the research-subject finds out this information herself. Then it might be the case that she has obligations to others, e.g. relatives (see chapter VI). However, also in that case, to *legislate* the obligation seems a bad idea.

disease." (Takala & Häyry, 2000, p 109). Does Tom, or any one else in his situation, has a duty to participate in the scientific study? "Because the information can be a significant good to them [some unspecified others that can benefit from the research] and because we are morally required to render service to our brethren, Tom has a duty to participate in the study." (Rhodes, 1998, p 23) Is there such a duty? Let us suppose, like Rhodes seems to do, that the only ground for participation is the possibility of doing good and avoiding harm for some others. Is there a duty for Tom (or anyone in a relevantly similar situation) to participate?

This depends on the importance of the investigation and on the importance of Tom's participation. Let us for now assume that the failure of the investigation would indeed harm someone to an extent that is morally relevant. We still have to know how important Tom's contribution is in order to establish *his* duty to participate. I would thus concur to the following claim: if, and only if, Tom's participation is necessary in order for the study to be successful, he has a duty (based on beneficence and/or non-harm) to participate. That is, Tom has no duty if his participation is not necessary for the success of the study. That can happen in two ways. 1) Too few are participating in the study in order for it to be successful. 2) There are enough people participating in the study, so the participation of Tom is not necessary for the study to be successful. In other words, Tom only has a duty to participate if he tips the scale.[47]

To this, the following might be retorted. The claim just made implies that if enough people participate, no single individual of those who participate has a duty to participate. But the participation of these individuals taken together is necessary for the success of the study. Thus, no individual who could participate but does not do so does anything wrong, even if the result of this is that there are not enough people participating to make the study successful (with the exception of the case where it is true of every individual that her participation would tip the scale).

This is only as it should be, however. In the case when more people than necessary for the success of study are participating, it is just because of this that no one in particular among these people is obliged to participate. It is a good thing that they do, but since no one of them is necessary for the success

[47] Or if he is part of a group of people who tips the scale, if the number of persons tipping the scale is vague. This proviso will be implicitly assumed in the following.

of the enterprise, it is hard to see that *they* have a *duty* to do so. Not only is the affirmation of such duties counterintuitive. If we had such duties, we would drown in them. This is so, since we would then have a duty to participate in every study that has beneficiary consequences, even when our contribution is of no consequence. In the case of participating in a study with too few participants, it seems odd to claim that we have a duty to participate in every enterprise that would have beneficiary consequences if enough people participated, when they in fact do not.

What lurks in the background is, of course, the question of how to generate individual duties from (what seems to be) collective ones. It is tempting to think that an individual should participate on the ground that at least someone would be harmed if a collective that can comprise of the individual in question fails to participate. One way to reach such a conclusion is to refer to rule-oriented versions of consequentialism. The general idea of rule utilitarianism[48] is that the rightness of an action is determined by whether it is in accordance with a rule such that, if people were generally adhering to it, the world, on the whole, would better than if they were adhering to another rule (Tännsjö, 1998b, p 49).

Rule utilitarianism could be used to underpin the duty of an individual to participate, even if that individual is not necessary for the success of an enterprise. However, this idea has general problems, of which a few were previously suggested. Firstly, it has normative implications that are hard to accept. The most salient is perhaps the following. Rule utilitarianism implies that I should do some things that would have optimal consequences if everyone did it, even when everyone is not doing it and my doing it would have disastrous consequences. This is not only troubling in itself, but also seems to be at odds with the spirit of consequentialistic thinking.

Take the following example. An old house is burning. Inside the house there is a beautiful and rare antique bookcase, a true piece of art. In order to save it before burning down and without getting hurt, we would have to be at least five persons. If there were four others gathering around to do this, I would indeed have a duty to participate in the rescuing operation. The danger to myself is then minimal and an old treasure that brings a lot of joy to others would be saved. But no one is gathering to save it. Do I have a duty to go in

---

[48] On the use of consequentialism and utilitarianism, see II.4.2.

myself and try to save it, even if this means that I will become unconscious by the gases and burned to death in the futile process of trying? It seems hard to accept. Yet, this seems to be the implication of rule utilitarianism.

To this it might be retorted that this is a scurrilous portrait of rule utilitarianism. No one thinks that this is the rule to follow in the situation. But then another, more devastating, problem rises to the surface. What exactly is the rule? How general or specific is it to be? This is, of course, the problem of relevant act descriptions. Kant can avoid the problem by referring to the actual motive of the agent. The act-oriented version of utilitarianism can avoid it by referring to the actual consequences of the action. But rule utilitarianism is essentially referring to something *de dicto*, namely a rule. Any answer in order to avoid examples like the above mentioned only runs the risk of making rule utilitarianism collapse into act-oriented version of utilitarianism.[49]

Another way to get to an individual duty on consequentialist grounds is to say that the moral responsibility for bad consequences due to failure of a collective to act in a certain way somehow distributes to the individuals of the collective (Glover, 1975). However, this move is not available in this case, since it is reasonable to hold that the distribution of responsibility to any particular individual, for instance Tom, is proportional to the contribution Tom would do to the collective action in question, for instance the (collective) action of performing a useful population study. This implies that Tom has a reason to participate, in virtue of the collective having a reason to participate, only to the extent that Tom contributes to this action. Since Tom only contributes to this if he actually tips the scale, he has no reason to participate unless he actually can tip the scale.

However, all of this is of course compatible with claiming that, generally, one should participate in scientific studies that may bring good to others. One reason is, of course, that there is often insecurity on whether enough people will participate – I might just be the one that tips the scale over. More generally, act-oriented versions of utilitarianism are quite compatible with encouraging strategies and character traits that are conducive to general welfare, such as the strategy to participate in beneficiary studies every now and then.

The conclusion of this is that Tom probably has no duty to participate in the study based on non-harm. This is so, since it is unlikely that the success of

---

[49] Lyons, 1965, has convincingly argued this, so I will not go through the tedious process of repeating the argument. See also Nell, 1975, chap. 2 and Kagan, 1998, p 226-227.

the study is dependent on his participation. So, in general, researchers have no corresponding rights towards individuals.[50] However, maybe he should participate in some studies sometimes. This might be justifiable from a consequentialistic framework. And the same that goes for Tom goes for all individuals who can participate in beneficial research-programs.

7. Conclusions

This chapter has addressed some questions regarding third parties rights to genetic information. The question that has received most attention is whether insurance companies should be legally allowed to gain access to and use genetic information or if this should be regulated somehow. I have used four types of ethical arguments when addressing this question: arguments of consequences of well-being, autonomy, privacy and justice respectively.

More specifically, I have argued that there are reasons to believe that all types of regulation will lead to severe adverse consequences for high-risk persons. The form of regulation that seems to avoid the problem of an uninsured high-risk population more than any alternative regulation is partial regulation. However, partial regulation may lead to deterrence to perform genetic testing, which can be a great loss. A public social security system that is generous enough to make access to private insurance superfluous to basic welfare will, however, lessen these negative consequences of partial regulation. Regarding autonomy, different ideals of autonomy support different conclusions. I argued that the ideal of self-realization seems most promising as a basis for a defence of regulation, since insurance companies demands to gain access to genetic information can limit people's possibilities to live the lives they choose. However, once again, this can be at least partly remedied by a public social security system, which would be preferable to total regulation if the problem of adverse selection becomes so grave as to make such regulation counterproductive. Regarding privacy, I argued that the general rationale of such arguments is consequentialist in spirit, which once again gives rise to the question of what type of regulation is a good instrument for achieving consequentialist goals. Regarding justice, I argued that libertarian and Walzerian theories are flawed, while more plausible theories of equality speak in favour of relieving the burdens of those worse off, including those who have

[50] An interesting theoretical possibility, that I will not enter, is that they have these rights towards collectives.

increased risk of suffering from genetic disease. However, this does not imply that private insurance are the party obliged to contribute. Rather, all those better off should contribute. This, taken together, suggests that it has been a mistake to dismantle collective social insurance and let private insurance take over. Rather, social insurance, a key component of the welfare state, should be resurrected. This, together with some form of partial regulation, is what the arguments seem to support in the end.

I then briefly tackled the same question regarding employers: should they be legally allowed to gain access to and use genetic information? I argued that the same ethical considerations that are relevant in the case of insurance companies are relevant in the case of employers. However, some of these considerations point in another direction in the latter case: while total regulation is likely to be counterproductive to protect the interest of insurance holders, total regulation is likely to contribute to the protection of (prospective) employees, since the problem of adverse selection is absent in this case and such regulation will provide an incentive to improve the working environment. Lastly, I briefly discussed the question of a duty to participate in genetic research programs on consequentialist grounds. I argued that one only has such a duty in very rare circumstances, and that alternative ways of arguing in favour of such a duty on this ground are unsuccessful.

Chapter VIII
Summary

This book has addressed two main questions:

(i) What is the value of genetic information from presymptomatic genetic testing for first, second, and third parties?

(ii) Do any of these parties have some kind of right to genetic information from presymptomatic genetic testing?

And, as a consequence, the following question has received some attention:

(iii) How should conflicts of interests/rights between various parties be handled?

More specifically, I have discussed presymptomatic genetic testing performed on normal adults, which may reveal information about risk of disease.

Regarding the question of the value for the individual that goes through with testing, I have argued that the value of presymptomatic genetic testing lies in the possible uses of the information such tests can result in. For instance, such information can be used to implement preventive measures, reduce anxiety, and make plans for the future. I argued that these particular values ultimately rest on two basic values: subjective well-being and autonomy. Although these values may be both promoted by genetic testing, I have also argued that they may be reduced, or even damaged, by receiving the result from presymptomatic genetic testing. I have also argued that, generally, these values show the basis for some types of testing weaker than for others. For instance, this goes for testing for diseases for which there are no preventive measures, since these cannot lead to the realization of health-related values, and testing that are uncertain (testing with low reliability or predictability), since they are less likely to reduce anxiety and promote autonomy. I also argued that the

situation of the test, for instance, the way in which the test result is disclosed, is crucial for the realization of the values of well-being and autonomy. Perhaps most notably, ensuring proper understanding of the test result, as well as of the possible psychological and societal consequences, and providing support, is of importance for promoting the values in question. This renders some support for genetic counselling, a practice which aims at understanding and emotional support. Accepting that the two values of both presymptomatic genetic testing and genetic counselling basically are well-being and autonomy provides us with a coherent account of more specific values in these practices, as well as a standard of evaluation for the practices based on these basic values. For instance, the norm of non-directiveness and the requirement of pre-test counselling are thus evaluated. However, the idea of autonomy as a value to promote often presupposed in this context is somewhat of a novelty in biomedical ethics, in which autonomy is usually considered to be a right that should be respected. This called for a closer analysis of autonomy. This analysis consisted of developing a conception of autonomy, useful for formulating ideas of autonomy conceived of as a value, as well as a right, and a discussion of the theoretical problems that arise in relation to the conceptions and moral ideals of autonomy.

Regarding the question of the values for the blood relatives, whose genetic constitution can be inferred from testing the individual, I argued that their possible value of receiving that information is the same as for the individual. The values for third parties of receiving genetic information depend on the interest they have in the information. For instance, the interest for insurance companies is to receive information in order to adjust premiums accordingly, since this is necessary for their economic viability.

Regarding the question of the individual's right to genetic information from presymptomatic genetic testing, I have argued that the proper basis for any right to genetic information, both positive and negative, is the values that can be promoted as a result of societal recognition of these rights. The values I have in mind are the values I argued provide the possible justification for presymptomatic genetic testing in the first place, namely well-being and autonomy. If this is correct, which I have argued that it is, the moral landscape of presymptomatic genetic testing will become much easier to survey, since the rights in this area ultimately will boil down to considerations of the values in it. As mentioned, I have also argued that given this basis, the recognition of

some rights of the individual seems reasonable, both positive and negative ones. However, these rights will be special (holding under the circumstances in which the values that are the basis for the rights really are promoted), derived (from these values), and prima facie (since they may be overridden by the values they are based on). Furthermore, I have argued that, even if there in very rare cases may be a moral duty to know, negative, and even positive, rights to ignorance should be recognized. At least, the legal right not to be forced to genetic testing or to be informed about one's genetic constitution without one's consent should be recognized. Although such a right has its limitations, e.g. due to the fact that it seems unreasonable to enforce sanctions on relatives who choose to reveal such facts and that, at times, consent cannot be obtained without revealing some information one is asking for consent to reveal, the legal right to ignorance should be rather extensive. This is not undermined by alleged general moral duties to know based on arguments of Kantian ethics or considerations of autonomy, arguments that are irrelevant in this context or sometimes just plain false. Or so I have argued.

Regarding the question of blood relatives' rights to genetic information, I argued that there are moral reasons to inform relatives that vary in strength with the value for the relatives of being informed, but that practical considerations make it plausible to leave the decision of whether or not to inform relatives to the tested person, except perhaps in very rare cases. I also argued that the consent of relatives should not be a requirement for testing.

Regarding the question of third parties' right to genetic information, I almost exclusively focused on the question of insurance companies' rights. I argued that regulation is insufficient to protect the interest of those in need of being insured against the financial burdens of genetic risk for disease, but that, at least very stern, regulation may be counterproductive to this effect. Instead I argued that considerations of well-being and justice speak in favour of the protection or resurrection of social insurance, a key component in the welfare state. I then used the findings in this discussion to very briefly address the question of employers' right to genetic information, where a more restrictive stance seems plausible. I finally added some remarks on researchers right to genetic information, which brought the plausibility of different versions of consequentialism to the stand.

Thus, the question of this book has been discussed and, in some instances, I have argued in favour of specific answers to them. However, some questions

have received more attention than others. Perhaps most notably, the question of first parties' value of and right to genetic information has been most thoroughly discussed. This is partly due to the fact that much of the basis of the discussion of other parties was laid when discussing first parties. However, it is also partly due to the fact that the discussion of other parties is almost never ending, since there are so many parties at stake. I have merely made a selection based on previous debates and own interest. Furthermore, some answers have been more specific than others. This is partly due to my own interests as well, but also partly because of my shortcomings due to being a moral philosopher: I can argue in favour of some features being morally relevant while others are not, but I often lack the knowledge and experience necessary in order to take a more definite stand on what to do in practice in order to meet (what I argue to be) reasonable moral standards. So, for instance, I have taken a more definite stand on the moral irrelevance of genetic relatedness than on what practice to implement in order to look after the interest of relatives (although I have indicated some answer to this as well). As I said in the outset of the book, this is not the first or the last word on the subject. It is a contribution to an ongoing debate, in which the voice of empirical researchers and practitioners is crucial in order to reach more specific and determinate answers on what to do. Moral philosophy in general, and applied ethics in particular, cannot be performed in isolation from the subject matter it addresses.

But also many philosophical questions that have arisen in the course of this book have been left for future investigation. For instance, although I have argued that the most straightforward and coherent account of what has been said about the justifiability of presymptomatic genetic testing presupposes that autonomy is a value that should be promoted, I have not taken a stand on whether this is a reasonable ideal in general and for health care in particular. So, should promotion of autonomy really be a goal of health care practices? To what extent should this goal be prioritised in relation to other goals? This last question obviously actualises the underlying philosophical question: is autonomy a value in itself? This is obviously a crucial question for anyone interested in the justification of presymptomatic genetic question. Similarly, many broader questions relating to the good and just society has been posed, but not answered: How should the values that presymptomatic genetic testing can realize be distributed?

These questions call for further investigation, both of what we can do and what we should do. So, like many long investigations' journey into summary, this one ends with even more questions.

Bibliography

Adelswärd, V, Sachs, L (2002), *Framtida skuggor: Samtal om risk, prevention och den genetiska familjen* (*Future shadows: conversations on risk, prevention and the genetic family*), Arkiv förlag, Lund.

Adler-Karlsson, G (1969), *Functional Socialism: A Swedish Theory for Democratic Socialization*, Prisma, Stockholm.

Andrews, L B *et al* (eds.) (1994), *Assessing Genetic Risks: Implications for Health and Social Policy*, National Academy Press, Washington D.C.

Aristotle, *The Nicomachean Ethics*, Ross, D (translation and introduction), Oxford University Press, Oxford, 1991.

Arthur, J, Shaw, W (eds.) (1991), *Justice and Economic Distribution*, Prentice-Hall, New Jersey.

Baker, D L *et al* (eds.) (1998), *A Guide to Genetic Counselling*, Wiley-Liss Inc, ORT.

Beauchamp, T L, Childress, J F (2001), *Principles of Biomedical Ethics*, Fifth edition, Oxford University Press, New York.

Bennett, R (2001), "Antenatal Genetic Testing and the Right to Remain in Ignorance", *Theoretical Medicine and Bioethics*, 22, p 461 ff.

Bergström, L (1966), *The Alternatives and Consequences of Actions*, Almqvist & Wiksell International, Stockholm.

Bergström, L (1982), "Interpersonal Utility Comparisons", *Grazer Philosophische Studien*, Vol. 16/17, p 283 ff.

Billings, P *et al* (1992), "Discrimination as a Consequence of Genetic Testing", *American Journal of Human Genetics*, vol. 50, p 476 ff.

Borna, S, Avila, S (1999), "Genetic Information: Consumers' Right to Privacy Versus Insurance Companies Right to Know: a Public Opinion Survey", *Journal of Business Ethics*, p 19 ff.

Brandberg, Y (2003), "Psykosociala aspekter: Att förstå gendiagnostik" (Psychosocial aspects: To understand genetic diagnosis), *Gendiagnostik i sjukvården* (*Genetic Diagnosis in Health Care*), Vetenskapsrådet (The Swedish Research Council), Stockholm.

Brandt, R (1979), *A Theory of the Good and the Right*, Oxford University Press, Oxford.

Brower, V (1997), "Testing, Testing... Testing?", Nature Medicine, 3, p 131 f.

Brown, M J (1992), "Evidence of Adverse Selection in the Individual Health Insurance Market", *Journal of Risk and Insurance*, vol. 59.

Brülde, B (1998), *The Human Good*, Acta Universitatis Gothoburgensis, Gothenburg.

Brülde, B (2003), *Teorier om livskvalitet* (*Theories on quality of life*), Studentlitteratur, Lund.

Brülde, B, Tengland, P A (2003), *Hälsa och sjukdom – en begreppslig utredning* (*Health and malady – a conceptual inquiry*), Studentlitteratur, Lund.

Brännmark, J (2002), *Morality and the Pursuit of Happiness: A Study in Kantian Ethics*, Department of Philosophy, Lund University, Lund.

Buchanan, A *et al* (2000), *From Chance to Choice - Genetics and Justice*, Cambridge University Press, Cambridge, UK.

Burley, J, Harris, J (eds.) (2002), *A Companion to Genetics*, Blackwell Publishing Ltd, Oxford.

Capron, A M (2000), "Genetics and Insurance: Accessing and Using Private Information", *Social Philosophy and Policy*, Vol. 17, s. 235 ff.

Carlson, E (1995), *Consequentialism Reconsidered*, Kluwer Academic Publishers, Dordrecht.

Chadwick, R (1997), "The Philosophy of the Right to Know and the Right not to Know", Chadwick, R *et al* (eds.), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot, 17 ff.

Chadwick, R, *et al* (eds.) (1997), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot.

Chadwick, R, *et al* (eds.) (1999), *The Ethics of Genetic Screening*, Kluwer Academic Publishers, Dordrecht.

Chadwick, R, Ngwena, C (1995), "The Human Genome Project, Predictive Testing and Insurance Contracts: Ethical and Legal Responses", *Res Publica*, Vol. 1, p 115 ff.

Christman, J (1988), "Constructing the Inner Citadel: Recent Work on the Concept of Autonomy", *Ethics*, Vol. 99, No. 1, p 109 ff.

Clarke, A (1991) "Is Non-Directive Counseling Possible?", *Lancet*, 338, p 998 ff.

Clarke, A (ed.) (1994), *Genetic Counselling: Practice and Principles*, Routledge, London.

Clarke, A (1998) "Genetic Counselling", *Encyclopaedia of Applied Ethics (Vol. 2)*, Academic Press, San Diego.

Clarke, A (2003) "Commentary", in "Balancing Autonomy and Responsibility: the Ethics of Generating and Disclosing Genetic Information", by Hallowell *et al*, Journal of Medical Ethics, Vol. 29, 2, p 74 ff.

Cohen, G A (1986), "Selfownership, Worldownership and Equality" in Lucash, F (ed.), *Justice and Equality Here and Now*, Cornell University Press, New York, p 108 ff.

Connor, M, Ferguson-Smith, M (1997), *Essential Medical Genetics*, Blackwell Science Ltd, Oxford.

Council of Europe (1997), *Convention of Human Rights and Biomedicine*, Oviedo, 4.IV.

Daniels, N (1990), "Insurability and the HIV Epidemic: Ethical Issues in Underwriting", *The Milbank Quarterly*, 68, p 497 ff.

Diamond, J (1999), *Guns, Germs and Steel – The Fates of Human Societies*, Norton, New York.

Dillon, R S (ed.) (1995), *Dignity, Character, and Self-respect*, Routledge, London.

Doukas, D J, Berg, J W (2001), "The Family Covenant and Genetic Testing", American Journal of Bioethics, Vol. 1, No. 3, p 2 ff.

Dworkin, G (1981), "The Concept of Autonomy", Haller, R (ed.), *Science and Ethics*, Ropodi, Amsterdam, p 203 ff.

Dworkin, G (1988), *The Theory and Practice of Autonomy*, Cambridge University Press, Cambridge, Illinois.

Dworkin, R (1977), *Taking Rights Seriously*, Duckworth, London.

Dworkin, R (1985), *A Matter of Principle*, Harvard University Press, London.

Elster, J (1982), "Sour Grapes – Utilitarianism and the Genesis of Wants", Sen, A, Williams, B (eds.), *Utilitarianism and Beyond*, Cambridge University Press, Cambridge, p 219 ff.

Elster, J (1983) *Sour Grapes: Studies in the Subversion of Rationality*, Cambridge University Press, Cambridge.

Elster, J (1990), *Vetenskapliga förklaringar* (*Scientific explanations*), Korpen, Gothenburg.

Feinberg, J (1986), *Harm to Self*, Vol. 3 of *The Moral Limits of the Criminal Law*, Oxford University Press, New York.

Feldman, F (1975), "World Utilitarianism", Lehrer, K (ed.), *Analysis and Metaphysics*, Kluwer, Dordrecht.

Fishkin, J S (1987), "Liberty vs Equal Opportunity", Paul, E F et al (ed.), *Equal Opportunity*, Blackwell, New York.

Francén, R, Gren, J, Juth, N (2003), "Om ojämlikhet" (On inequality), *Tidskrift för politisk filosofi*, no. 2, p 5 ff.

Frankfurt, H (1971), "Freedom of the Will and the Concept of the Person", *Journal of Philosophy*, 68, p 829 ff.

Fraser, F C (1974), "Genetic Counseling", *American Journal of Human Genetics*, 26, p 636 ff.

Friedman, M (1986), "Autonomy and the Split-Level Self", *Southern Journal of Philosophy*, 24, p 19 ff.

Försäkringsavtalslag (1927:77), Nationell lagstiftning, Sverige.

Gauthier, D (1986), *Morals by Agreement*, Clarendon Press, Oxford.

Geller, L N *et al* (1996), "Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis", *Science and Engineering Ethics*, 2, p 71 ff.

Glover, J (1975), "It Makes no Difference Whether or not I Do it", *Proceedings of the Aristotelian Society*, vol. 49.

Glover, J (1977), *Causing Death and Saving Lives*, Penguin Books, London.

Glover, J (1984), *What Sort of People Should There Be? Genetic Engineering, Brain Control and their Impact on our Future*, Penguin Books, Suffolk.

Goldman, A (1987), "The Justification of Equal Opportunity", *Social Philosophy & Policy*, Vol. 5, Issue 1, pp 88 ff.

Gostin, L (1991), "Genetic Discrimination: The Use of Genetically Based Diagnosis and Prognosis Tests by Employers and Insurers", *American Journal of Law and Medicine*, Vol. XVII, p 109 ff.

Gren, J (2004), *Applying Utilitarianism: The Problem of Practical Action-guidance*, Acta Universitatis Gothoburgensis, Gothenburg.

Griffin, J (1986), *Well-being: Its Meaning, Measurement and Moral Importance*, Clarendon Paperbacks, Oxford.

Göring, H H, *et al* (2001), "Large Upward Bias in Estimation of Locus-Specific Effects from Genomewide Scans", *American Journal of Human Genetics*, 6, p 1357 ff.

Hallowell *et al* (2003), "Balancing Autonomy and Responsibility: the Ethics of Generating and Disclosing Genetic Information", *Journal of Medical Ethics*, Vol. 29, 2, p 74 ff.

Hare, R (1981), *Moral Thinking*, Oxford University Press, Oxford.

Hare, R (1991), "Justice and Equality" in Arthur, J, W Shaw (eds.) (1991), *Justice and Economic Distribution*, Prentice-Hall, New Jersey, p 118 ff.

Harper, P S (1993), "Insurance and Genetic Testing", *The Lancet*, Vol. 341, p 224.

Harper, P S, (1996), "Personal Experiences of Genetic Diseases: A Clinical Geneticist's Reaction", Marteau, T, Richards, M (eds.), *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, Cambridge University Press, Cambridge.

Harper, P S (2001), *Practical Genetic Counselling*, Fifth edition, Arnold, London.

Harris, J (1998), *Clones, Genes, and Immortality: Ethics and the Genetic Revolution*, Oxford University Press, Oxford.

Harris, J, Keywood, K (2001), "Ignorance, Information, and Autonomy", *Theoretical Medicine and Bioethics*, 22, p 415 ff.

Harsanyi, J (1977), *Rational Behaviour and Bargaining Equilibrium in Games and Social Situations*, Cambridge University Press, Cambridge.

Harsanyi, J C (1982), "Morality and the Theory of Rational Behaviour", Sen, A, Williams, B (eds.), *Utilitarianism and Beyond*, Cambridge University Press, Cambridge, p 39 ff.

Hart, H L A (1961), *The Concept of Law*, Clarendon Law Series, Oxford.

Hedgecoe, A (1996), "Genetic Catch-22: Testing, Risk and Private Health Insurance", *Business & Professional Ethics Journal*, Vol. 15, p 69 ff.

Helgesson, P (2001), "DNA-chips på löpande band" (DNA chips off the assembly line), *Dagens Nyheter*, 13 Nov.

Hermerén, G (1999), "The Right to Know and not to Know", *"Who Owns Our Genes?" Proceedings of an International Congress*, Nordic, Tallinn.

Hirschman, A O (1991), *The Rhetoric of Reaction*, Belknap Press, Cambridge (Massachusetts).

Hoedemaekers, R, Have, ten H (1998), "Commercialisation of Genetic Diagnostic Services", *Medicine, Healthcare and Philosophy*, 1, p 217 ff.

Hoedemaekers, R (1999), "Genetic Screening and Testing. A Moral Map", Chadwick, R, *et al* (eds.), *The Ethics of Genetic Screening*, Kluwer Academic Publishers, Dordrecht.

Hohfeld, W N (1919), *Fundamental Legal Conceptions as Applied in Judicial Reasoning*, Yale University Press, New Haven, 1964.

Holm, S (1999), "There Is Nothing Special about Genetic Information", Thompson, A, R Chadwick (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York, p 97 ff.

Holtug, N (1999), "Genetic Knowledge in a just Society", in Thompson, A, R Chadwick (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York, p 283 ff.

Hume, D (1740), *A Treatise of Human Nature*, Selby-Bigge, L A, Nidditch, P H (eds.), Second edition, Oxford University Press, Oxford, 1978.

Husted, J (1997), "Autonomy and a Right not to Know", Chadwick *et al* (eds.), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot, p 55 ff.

Häyry, M, Takala, T (2000), "Genetic Ignorance, Moral Obligations and Social Duties", *Journal of Medicine and Philosophy*, Vol. 25, No. 1, p 107 ff.

Häyry, M, Takala, T (2001), "Genetic Information, Rights, and Autonomy", *Theoretical Medicine and Bioethics*, 22, p 403 ff.

Johnston, M (1999), "Selling Souls: Ethical Theory and the Commercialisation of Genetic Information", Thompson A and Chadwick R (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York, p 79 ff.

Juth, N (2003), "Insurance Companies' Access to Genetic Information: Why Regulation Alone Is Not Enough", *Monash Bioethics Review*, Vol. 22, No. 1, p 25 ff.

Kagan, S (1989), *The Limits of Morality*, Oxford University Press Inc, New York.

Kagan, S (1998), *Normative Ethics*, Westview Press, Oxford.

Kant, I (1785), *Groundwork of the Metaphysics of Morals*, Paton, H J (ed.), Routledge, New York, 1991.

Kant, I (1797), *The Metaphysics of Morals*, *The Cambridge Edition of the Works of Immanuel Kant: Practical Philosophy*, Gregor, M J (ed.), Cambridge University Press, Cambridge, 1996.

Kessler, S (1997), "Psychological Aspects of Genetic Counseling. XI. Nondirectiveness Revisited", *American journal of Medical Genetics*, 72, p 164 ff.

Knoppers, B M (2002), "Genetic Information and the Family: Are We Our Brother's Keeper?", *Trends in Biotechnology*, Vol. 20, No. 2, p 85 f.

Kristoffersson, U (2000), "Kommer genetiken att revolutionera sjukvården? Skepsis mot överdrivna förväntningar" (Will genetic technology revolutionise health care? Scepticism in the face of exaggerated expectations), *Läkartidningen*, no. 47, p 5499 ff.

Kymlicka, W (1990) *Contemporary Political Philosophy*, Oxford University Press, New York.

Lannfelt, L *et al* (1995), "Genetic Counseling in a Swedish Alzheimer Family with Amyloid Precursor Protein Mutation", *American Journal of Human Genetics*, 56, p 332 ff.

Launis, V (2000), "The Use of Genetic Test Information in Insurance: The Argument from Indistinguishability Reconsidered", *Science and Engineering Ethics*, Vol. 6, p 299 ff.

Laurie, G T (1999) "In Defence of Ignorance: Genetic Information and the Right not to Know", *European Journal of Health Law*, 6, p 119 ff.

Laurie, G T (2002), *Genetic Privacy: A Challenge to Medico-Legal Norms*, Cambridge University Press, Cambridge.

Lemmens, T (1999), "Private Parties, Public Duties? The Shifting Role of Insurance Companies in the Genetic Era", in Thompson, A, R Chadwick (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York, 31 ff.

Lindahl, L (1977), *Position and Change: A Study in Law and Logic*, D. Reidel Publishing Company, Dordrecht.

Lindley, R (1986), *Autonomy*, Macmillan Education Ltd, London.

Lippman, A (1991), "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities", *American Journal of law and Medicine*, 17, p 15 ff. Reprinted in Clarke, A (ed.) (1994), *Genetic Counselling: Practice and Principles*, Routledge, London, p 142 ff.

Locke, J (1689), *Two Treaties of Government*, Laslett, P (ed.), Cambridge University Press, New York, 1988.

Lucassen, R P (1999), *Practical Genetics for Primary Care*, Oxford University Press, Oxford.

Lyons, D (1965), *Forms and Limits on Utilitarianism*, Oxford University Press, Oxford.

Marc-Wogau, K (ed.) (1970), *Filosofin genom tiderna: Antiken, Medeltiden, Renässansen (Philosophy Through the Ages: Antique, Medieval, Renaissance)*, Thales, Stockholm.

Marteau, T, Anionwu, E (1996), "Evaluating Carrier Testing: Objectives and Outcomes", Marteau, T, Richards, M (eds.), *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, Cambridge University Press, Cambridge.

Marteau, T, Richards, M (eds.) (1996), *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, Cambridge University Press, Cambridge.

Mayer, N R *et al* (1999), "Coercion, Control, and Consequence in Genetic Testing: Views on Insurance among Tested Individuals and the General Public", Thompson, A, Chadwick R, (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York.

McGleenan, T (1997), "Rights to Know and not to Know: Is There a Need for a Genetic Privacy Law", in Chadwick, R *et al* (eds.), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot, p 43 ff.

Michie, S, Marteau, T (1996), "Genetic Counselling: Some Issues of Theory and Practice", Marteau, T, Richards, M (eds.), *The Troubled Helix: Social and*

Psychological Implications of the New Human Genetics, Cambridge University Press, Cambridge.

Michie, S *et al* (1997), ""Nondirectiveness in Genetic Counseling: An Empirical Study", *American Journal of Human Genetics*, 60, p 40 ff.

Mill, J S (1859), *On Liberty*, Penguin Books, Suffolk, 1974.

Miller, D (1976), *Social Justice*, Clarendon Press, Oxford.

Moore, G E (1903), *Principia Ethica*, Cambridge University Press, Cambridge, 1993.

Munthe, C (1996), *The Moral Roots of Prenatal Diagnosis: Ethical Aspects of the Early Introduction and Presentation of Prenatal Diagnosis in Sweden*, Studies in Research Ethics, Gothenburg.

Munthe, C (1998), "Kunskap för vem? Gentestningens etik och politik" (Knowledge for whom? The ethics and politics of genetic testing), *Gentest för vem? Forskare kommenterar genetisk diagnostik (Genetic testing for whom? Researchers comment on genetic diagnostics)*, Källa 50, FRN, Solna, Sweden.

Munthe, C (1999), *Pure Selection: The Ethics of Preimplantation Genetic Diagnosis and Choosing Children Without Abortion*, Acta Universitatis Gothoburgensis, Gothenburg.

Munthe, C (2002), "Genetisk testning och vägledning i sjukvården – etiska aspekter på genetisk screening" (Genetic Testing and Counselling in Health Care – Ethical Aspects of Genetic Screening), *Genetic Screening – om hälsa och ärftlig sjukdomsrisk*, (*Genetic Screening – about Health and Risk of Genetic Disease*), Statens Medicinsk-Etiska råd, Stockholm.

Nell (O'Neill), O (1975), *Acting on Principle: An Essay on Kantian Ethics*, Colombia University Press, New York.

Nozick, R (1974), *Anarchy, State and Utopia*, Basic Books, New York.

Nozick, R (1981), *Philosophical Explanations*, The Belknap Press of Harvard University Press, Cambridge (Massachusetts).

Nys, H et al (1993), Predictive Genetic Information and Life Insurance: Legal Aspects: Towards a European Policy?, University of Limburg, Department of Health Law, Maastricht.

Oduncu, F S (2002), "The Role of Non-directiveness in Genetic Counseling", *Medicine, Health Care and Philosophy*, 5, p 53 ff.

Ohlsson, R (1998), "Rättvis lön" (Just wage), *Tidskrift för politisk filosofi*, Nr 2.

Oppenheimer, G M and Padgug, R A (1991) "Aids and the Crisis of Health Insurance", Reamer, F G (ed.) *Aids and Ethics*, Colombia University Press, New York, chap. 5.

Ost, D E (1984), "The 'right' not to know", *The Journal of Medicine and philosophy*, 9, p 301 ff.

Parfit, D (1984), *Reasons and Persons*, Oxford University Press, Oxford.

Parfit, D (1997), "Equality and Priority", *Ratio*, 10, p 202 ff.

Parker, M (2001), "Genetics and the Interpersonal Elaboration of Ethics", *Theoretical Medicine and Bioethics*, 22, p 451 ff.

Parker, M, Lucassen, A (2003), "Concern for Families and Individuals in Clinical Genetics", *Journal of Medical Ethics*, 2003, Vol. 29, 2, p 70 ff.

Platt Walker, A (1998), "The Practice of Genetic Counselling", Baker, D L *et al*, *A Guide to Genetic Counselling*, Wiley-Liss Inc, ORT, p 1 ff.

Pörn, I (1997), "The Meaning of 'Rights' in the Right to Know Debate", Chadwick, R *et al* (eds.), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot, p 37 ff.

Rachels, J (1991), "What People Deserve", in Arthur, J, W Shaw (eds.) (1991), *Justice and Economic Distribution*, Prentice-Hall, New Jersey, p 136 ff.

Radetzki, M, Radetzki M and Juth N (2003), *Genes and Insurance: Ethical, Legal and Economic Issues*, Cambridge University Press, Cambridge.

Rasmusson, M (2001), "Kan ett långt liv gå i arv?" (Can longevity be inherited?), *Svenska Dagbladet*, 3 Aug.

Rawls, J (1972), *A Theory of Justice*, Oxford University Press, London.

Resnik, M D (1987), *Choices: An Introduction to Decision Theory*, Minnesota University Press, Minneapolis.

Resta, R G (1997), "Eugenics and Nondirectiveness in Genetic Counseling", *Journal of Genetic Counselling*, Vol. 6, No. 2, p 255 ff.

Rhodes, R (1998), "Genetic Links, Family Ties and Social Bonds: Rights and Responsibilities in the Face of Genetic Knowledge", *Journal of Medicine and Philosophy*, 23, p 10 ff.

Rhodes, R (2000), "Autonomy, Respect, and Genetic Information Policy: A Reply to Tuija Takala and Matti Häyry", *Journal of Medicine and Philosophy*, 25, p 114 ff.

Roemer, J (1995), *Equality of Opportunity: Theories and Examples*, University of California, Davis.

Rothstein, M A (ed.) (1997), *Genetic Secrets: Protecting Privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven.

Rothstein, M A (1997), "Genetic Secrets: A Policy Framework", Rothstein, M A (ed.), *Genetic Secrets: Protecting privacy and Confidentiality in the Genetic Era*, Yale University Press, New Haven, p 451 ff.

Räikkä, J (1998), "Freedom and a Right (Not) to Know", *Bioethics*, Vol. 12, No. 1, p 49 ff.

Salwén, H (2003), *Hume's Law: An Essay on Moral Reasoning*, Almqvist & Wiksell International, Stockholm.

Sandberg, P (1995), "Genetic Information and Life Insurance: A Proposal for an Ethical European Policy", *Social Sciences and Medicine*, Vol. 40, p 1549 ff.

Sandman, L (2001), *A Good Death: On the Value of Death and Dying*, Acta Universitatis Gothoburgensis, Gothenburg.

Schneewind, J B (1998) *The Invention of Autonomy: A History of Modern Moral Philosophy*, Cambridge University Press, Cambridge.

Sen, A, Williams, B (eds.) (1982), *Utilitarianism and Beyond*, Cambridge University Press, Cambridge.

Shattuck-Eidens, D et al (1997), "BRCA1 Sequence Analysis in Women at High Risk for Susceptibility Mutations", Journal of the American Medical Association, 15, p 1242 ff.

Shickle, D (1997), " Do 'All Men Desire to Know'? A Right of Society to Choose not to Know about the Genetics of personal Traits", Chadwick, R *et al* (eds.), *The Right to Know and the Right not to Know*, Ashgate Publishing Company, Aldershot, 69 ff.

Shickle, D (1999), "The Wilson and Jungner Principles of Screening and Genetic Testing", Chadwick, R, *et al* (eds.), *The Ethics of Genetic Screening*, Kluwer Academic Publishers, Dordrecht.

Shiloh, S (1996), "Decision-making in the Context of Genetic Risk", Marteau, T, Richards, M (eds.), *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, Cambridge University Press, Cambridge, p 82 ff.

Silver, L M (1997), *Remaking Eden, Cloning and Beyond in a Brave New World*, Avon Books, New York.

Smith, K R *et al* (1999), "Genetic Testing and Adverse Selection in the Market for Life Insurance", Thompson, A, R Chadwick (eds.), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York, p 57 ff.

Smith, M (1994), *The Moral Problem*, Blackwell Publishers Inc, Cambridge (Massachusetts).

Slote, M (1985), *Common-sense Morality and Consequentialism*, Routledge & Kegan Paul, London.

Sobel, S K, Cowan, D B (2000), "Impact of Genetic Testing for Huntington Disease on the Family System", *American Journal of Medical Genetics*, 90, p 49 ff.

SOU 1995:5, Vårdens svåra val (The difficult choice facing health services)

Steiner, H (1997), "Choice and Circumstance", *Ratio*, 10, p 296 ff.

Takala, T (2000), *Genes, Sense and Sensibility: Philosophical Studies on the Ethics of Modern Biotechnologies*, Reports from the Department of Philosophy, University of Turku, Helsinki.

Takala, T (2001), "Genetic Ignorance and Reasonable Paternalism", *Theoretical Medicine and Bioethics*, 22, p 485 ff.

Tamburrini, C M (2000), *The 'Hand of God'? Essays in the Philosophy of Sports*, Acta Universitatis Gothoburgensis, Gothenburg.

Temkin, L S (1993), *Inequality*, Oxford University Press, New York.

Tersman, T (1993), *Reflective Equilibrium*, Almqvist & Wiksell, Stockholm.

Thomas, L (1995), "Self-respect: Theory and Practice", Dillon, R S, *Dignity, Character, and Self-respect*, Routledge, London, p 251 ff.

Thomson, J J (1990), *The Realm of Rights*, Harvard University Press, London.

Thompson, A, Chadwick, R (eds.) (1999), *Genetic Information: Acquisition, Access and Control*, Kluwer Academics/Plenum Publishers, New York.

Tännsjö, T (1998a), *Vårdetik* (*Health Care Ethics*), Third Edition, Thales, Stockholm.

Tännsjö, T (1998b), *Hedonistic Utilitarianism*, Edinburgh University Press, Edinburgh.

Tännsjö, T (1999), *Coercive Care: The Ethics of Choice in Health and Medicine*, Routledge, London & New York.

Tännsjö, T (2000), *Grundbok i normativ etik* (*Introduction to normative ethics*), Thales, Stockholm.

UNESCO (1997), Universal *Declaration on the Human Genome and Human Rights*, Paris, November 11.

Wahlström, J (2002a), "Folkets oro är befogad" (People are right to be worried), *Dagens Nyheter*, 19 februari.

Wahlström, J (2002b), "Hälsa, ärftlighet och genetiska undersökningar – medicinska bakgrundsfakta" (Health, Heritance and Genetic Investigations – Medical Background), *Genetic Screening – om hälsa och ärftlig sjukdomsrisk*, (*Genetic Screening – about Health and Risk of Genetic Disease*), Statens Medicinsk-Etiska råd, Stockholm.

Walzer, M (1983) *Spheres of Justice: A Defence of Pluralism and Equality*, Blackwell Publishers, Oxford.

Vehmas, S (2001), "Just Ignore It? Parents and Genetic Information", *Theoretical Medicine and Bioethics*, 22, p 473 ff.

Wertz, D C et al (1995), *Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services*, Unofficial WHO document, WHO/HDP/GL/ETH/95.11

WHO (1998), *Proposed International Guidelines on Ethical Issues in Medical Genetics and the Provision of Genetic Services*, Geneva, 15-16 December, 1997.

Widmer, P (1994), "Human Rights Issues in Research on Medical Genetics", *Ethics and Human Genetics*, Council of Europe, Strasbourg, p 175 ff.

Wilkinson, S (2003), *Bodies For Sale. Ethics and Exploitation in the Human Body Trade*, Routledge, London.

Williams, B (1981), "Persons, Character and Morality", *Moral Luck*, Cambridge University Press, Cambridge, 197ff.

Wolf, S (1995), "Beyond Genetic Discrimination: Towards the Broader Harm of Geneticism", *Journal of Law, Medicine and Ethics*, 23, p 345 ff.

Wolff, J (1991), Robert Nozick: Property, Justice and the Minimal State, Polity Press, Cambridge.

Wood-Harper, J, Harris, J (1996), "Ethics of Human Genome Analysis: Some Virtues and Vices", Marteau, T, Richards, M (eds.), *The Troubled Helix: Social and Psychological Implications of the New Human Genetics*, Cambridge University Press, Cambridge, p 274 ff.

Wortham, L (1986), "Insurance Classifications: Too Important to Be Left to Actuaries", *University of Michigan Journal of Law Reform*, 19, p 349 ff.

Young, I M (1990), *Justice and the Politics of Difference*, Princeton University Press, Princeton, New Jersey.

Young, R (1982), "The Value of Autonomy", *The Philosophical Quarterly*, Vol. 32, no. 132, 35 ff.

Öberg, I (2002) "I skuggan av arvet – om behovet av kunskap, stöd och integritet" (In the shadow of heredity – on the need of knowledge, support and integrity), *Genetic Screening – om hälsa och ärftlig sjukdomsrisk*, (*Genetic Screening – about Health and Risk of Genetic Disease*), Statens Medicinsk-Etiska råd, Stockholm.

Index

ACTA PHILOSOPHICA GOTHOBURGENSIA
ISSN 0283-2380

Editors: Ingmar Persson and Dag Westerståhl

Published by the Department of Philosophy of the University of Göteborg

Subscription to the series and orders for single volumes should be addressed to:
ACTA UNIVERSITATIS GOTHOBURGENSIS
Box 222, SE-405 30 Göteborg, Sweden

VOLUMES PUBLISHED

1. MATS FURBERG, THOMAS WETTERSTRÖM and CLAES ÅBERG (editors): Logic and Abstraction. Esays dedicated to Per Lindström on his fiftieth birthday. 1986. 347 pp.

2. STAFFAN CARLSHAMRE: Language and Time. An Attempt to Arrest the Thought of Jacques Derrida. 1986. 253 pp.

3. CLAES ÅBERG (editor): Cum Grano Salis. Essays dedicated to Dick A. R. Haglund. 1989. 263 pp.

4. ANDERS TOLLAND: Epistemological Relativism and Relativistic Epistemology. Richard Rorty and the pos sibility of a Philosophical Theory of Knowledge. 1991. 156 pp.

5. CLAES STRANNEGÅRD: Arithmetical realizations of modal formulas. 1997. 100 pp.

6. BENGT BRÜLDE: The Human Good. 1998. 490 pp.

7. EVA MARK: Självbilder och jagkonstitution. 1998. 236 pp.

8. MAY THORSETH: Legitimate and Illegitimate Paternalism in Polyethnic Conflicts. 1999. 214 pp.

9. CHRISTIAN MUNTHE: Pure Selection. The Ethics of Preimplantation Genetic Diagnosis and Choosing Children without Abortion. 1999. 310 pp.

10. JOHAN MÅRTENSSON: Subjunctive Conditionals and Time. A Defense of a Weak Classical Approach. 1999. 212 pp.

11. CLAUDIO M. TAMBURRINI: The 'Hand of God'? Essays in the Philosophy of Sports. 2000. 167 pp.

12. LARS SANDMAN: A Good Death: On the Value of Death and Dying. 2001. 346 pp.

13. KENT GUSTAVSSON: Emergent Consciousness. Themes in C.D. Broad's Philosophy of Mind. 2002. 204 pp

14. FRANK LORENTZON: Fri vilja? 2002. 175 pp.

15. JAN LIF: Can a Consequentialist Be a Real Friend? (Who Cares?). 2003. 167 pp.

16. FREDRIK SUNDQUIST: Perceptual Dynamics. Theoretical Foundations and Philosophical Implications of Gestalt Psychology. 2003. 261 pp.

17. JONAS GREN: Applying Utilitarianism. The Problem of Practical Action-guidance. 2004. 160 pp.

18. NIKLAS JUTH: Genetic Information – Values and Rights. The Morality of Presymptomatic Genetic Testing. 2005. 459 pp.

ISBN 91-7346-534-8