**SUMMARY:** Below is a summary of this 258 page report which can be downloaded in full as a pdf here: [http://www.nuffieldbioethics.org/filelibrary/pdf/nuffieldgeneticsrep.pdf](http://www.nuffieldbioethics.org/filelibrary/pdf/nuffieldgeneticsrep.pdf)

Alternatively it can be viewed online in an easy-to-access chapter format here: [http://www.nuffieldbioethics.org/publications/geneticsandhb/rep00000001098.asp](http://www.nuffieldbioethics.org/publications/geneticsandhb/rep00000001098.asp)

The aim of this report was to identify and define ethical questions raised by recent advances in human genetics, specifically as they relate to human behaviour. The council aims to anticipate public concern and act accordingly by promoting public understanding and discussion.

Armed with a healthy degree of scepticism, drawn from the “ugly history” of a “perverted science,” the council aims to avoid the mistakes of the past. Of particular relevance to the Constructive Conversations research project is Part IV: Ethical, legal, social and policy issues, (chapters 12-15).

**THE COUNCIL’S TERMS OF REFERENCE:**

- “To define and consider ethical, social and legal issues arising from the study of the genetics variation within the normal range of behavioural characteristics.”
- To consider the ethics of undertaking such studies.
- To consider the implications of applying the findings of such studies through the development of genetic tests.
- To consider the impact of the results of such genetic tests on individuals.
- To consider the broader social impact of genetic knowledge, particularly the potential for social stigma.

**SOME DEFINITIONS:**

**Quantitative genetics:** mostly this sort of research involves twins, siblings, adopted children and families, and uses estimates of heritability and other statistical techniques to distinguish the effects of genetic and environmental factors on variation in certain behavioural traits. The estimates generated refer to groups of people, not to individuals, and do not lead to predictive information regarding individuals. The bulk of research in behavioural genetics has used these methods.

**Molecular genetics:** this research examines the DNA of individuals with the aim of identifying variation in particular genes that influences behaviour. Because there are usually many genes involved, such research is very unreliable, as the results are not often repeated by other researchers.

**Research Involving Animals:** techniques involve selective breeding and the direct manipulation of specific genes in order to understand how genes effect the organism. It is difficult to apply such findings to complex human traits such as intelligence and personality, however, hence such research is limited.

**Therapy:** therapies aim to treat, cure or prevent diseased and to alleviate pathological conditions which place someone outside the normal range.
Enhancements: enhancements, as opposed to therapies, aim to improve already healthy systems and to advance capacities which already fall within the normal range. The distinction between therapy and enhancement is often used to justify a distinction between interventions which merit public support and those that don’t.

Germline Gene Therapy: involves modifying the germline cells (those cells that are transmitted to children by their parents), hence this type of gene therapy would change both the characteristics of the individual receiving the therapy and also the characteristics of their children and future generations.

Somatic Gene Therapy: the process of changing the genotype of an individual by modifying the DNA in the cells of their body. It is unlikely the genetic changes will be passed on to the individual’s children because this type of therapy does not affect the cells that are important to reproduction.

Preimplantation Genetic Diagnosis (PGD): a technique which enables embryos created by in vitro fertilisation programmes to be tested for genetic disorders before they are implanted. This is often referred to in the popular press as a quest for ‘designer babies,’ but the council believes such terms are misleading.


Diagnostic Spread: the tendency for disorders to be broadly defined so that more and more individuals are caught in the diagnostic net.

CONCLUSIONS ON THE IMPLICATIONS OF GENETIC TESTING:

- Even though genetic tests may have a low predictive capacity because of the many other factors that influence behaviour, hence making it impossible to make any robust predictions based on the results or to design any effective interventions, this does not exempt us from considering the ethical implications.

- “A standard view is that since the state does not have an obligation to provide techniques for improving intelligence or athleticism or changing behaviours, these interventions should not normally be provided as part of a public healthcare system. Nonetheless, it may also be argued, that within a free society and a free market, these techniques should be available for purchase. The anxiety, however is that if such tests and interventions were available for private purchase, the result could be that only the more affluent members of society would have access to them…this could lead to even greater inequalities” (p.xxvii).

- The council believes “equality of opportunity is a fundamental social value” (p. xxvii).

- Individuals may be able to use genetic tests without the involvement of health professionals, and this has important implications for the regulation and monitoring of tests and interventions. Without appropriate safeguards, consumers may be at risk of exploitation through misleading marketing practices.

- “The inherent inequality of bargaining position and power between the employer and the individual employee means that the employer is likely to initiate the tests and to decide how they are to be administered and used. A ‘right to refuse’ to take a test to disclose genetic information or a ‘right to know’ the outcome, is likely to be of little practical value where the employee has to choose between exercising the right or waiving it in order to secure a livelihood” (p.xxxii).
In 1997, the Advisory Committee on Genetic Testing (ACGT), a non-statutory committee that reported to the Department of Health, produced a *Code of Practice and Guidance on Human Genetic Testing Services Supplied Direct to the Public*. The code of practice was a voluntary one, and suppliers of genetic tests were expected to submit their proposed tests to the ACGT for consideration before introducing them to the public. Some of the code’s requirements are highly relevant, including the need for external quality control of laboratories conducting the tests, and the importance of protecting the confidentiality of the data obtained.

The questions addressed by genetic tests include very sensitive areas of personal and family vulnerability, and there is considerable potential for exploitation of these anxieties. This danger is particularly important since both tests and interventions might be applied to children without their consent. Therefore the Council believes it is not adequate in this area to rely on the same mechanisms that apply to non-genetic or non-medical enhancement to prevent misleading claims being made and ineffective tests from being sold.

**GENERAL CONCLUSIONS ON THE ETHICS OF BEHAVIOURAL GENETICS:**

- Human behaviour is influenced both by the genes that we inherit and the environment in which we live.
- The connection between genes and diseases is far from straightforward.
- Media coverage often conveys an inaccurate and misleading impression of the state of genetics research.
- “There is no inherent conflict between a greater understanding of genetic contributions to behaviour and due regard for human dignity…There is no reason for adherents of behavioural genetics, or critics, to regard it as offering a radically new way of understanding human life which threatens to undermine the dignity of humanity. It complements, and does not displace, the familiar social sciences, the humanities and indeed our ordinary understanding of behaviour” (p.xxiv).
- ‘Fatalism’ about genetics is a misconception, as the existence of genetic influences does not mean we are powerless to change or modify our character.
- Research in behavioural genetics could potentially contribute to the existing phenomenon of ‘medicalisation’.
- This could lead to the creation of more “unwell” categories of people hence more medication and unnecessary expenditure by the health service.
- There are five features of any intervention that may provide moral reasons for accepting or rejecting their use:
  - Effectiveness
  - Safety
  - Reversibility
  - Extent to which one can make choices about its use.
  - Implications for individuality.
- The use of genetic information in conjunction with information about other, non-genetic influences on behaviour may be justified if the aim is to benefit the individual, and in doing so, to benefit society also.
- “Setting aside the contested issue of the ethics of abortion on social grounds, which is outside the scope of this Report, we take the view that the use of selective termination following PND to abort a foetus merely on the basis of information about behavioural traits in the normal range is morally unacceptable” (p.152).

**RECOMMENDATIONS:**

* Regulation and Quality Control:
  - Health service providers should charge a named agency with monitoring the medicalisation of normal populations.
  - Both the public and private provision of direct to the public genetic tests for behavioural traits should be stringently monitored and regulated.
Discrimination:

- Employers should not demand that an individual take a genetic test for a behavioural trait as a condition on employment.
- More research needs to be done regarding the ethical and social implications of using genetic information about behavioural traits in the context of education.
- The use of genetic information about behavioural traits in the normal range should fall under the scope of the five-year moratorium agreed in the UK in 2001, and should therefore not be used by insurance companies in setting premiums.

Reproductive Issues:

- Although law and clinical practice support the use of genetic information to provide informed choice for prospective parents, the council takes the view that the use of selective termination following PND to abort a foetus merely on the basis of information about behavioural traits in the normal range is morally unacceptable.

Research:

- UNESCO states: ‘Research, treatment or diagnosis affecting an individual’s genome shall be undertaken only after rigorous and prior assessment of the potential risks and benefits pertaining thereto and in accordance with any other requirement of the national law.’
- The Gene Therapy Advisory Committee and other relevant bodies should develop guidelines for research into gene therapy for normal behavioural traits before such research takes place, especially regarding germline gene therapy as the far-reaching effects for future generations cannot be predicted.
- The council believes that research in behavioural genetics has the potential to advance our understanding of human behaviour, and that the research can therefore be justified. However, it is noted that those who fund research in this area should continue to fund research of a high calibre, should be transparent about their funding practices and should be aware of the potential for the abuse and misinterpretation of results.

Legal Issues:

- With regard to the sentencing of convicted offenders, the criminal law should be receptive to whatever valid psychiatric and behavioural evidence is available.
- Research in behavioural genetics does not pose a fundamental challenge to our notions of responsibility as they are applied in the legal context.

SUMMARY OF CHAPTER 12:

**GENETICS, FREEDOM AND HUMAN DIGNITY**

- Outlines different theories about how behavioural genetics affects our conception of people as rational, responsible moral beings with free will.
- If it turns out that people are no longer responsible for their behaviour, and that these things are genetically determined instead, the whole basis for treating each other as worthy, moral subjects deserving of respect would be undermined.
- If research were to reveal that individual character and personal identity have a genetic basis, this could undermine people’s sense of identity.
- If, however, behavioural genetics does not threaten the conception of a person as a rational, responsible being, “then it ought to be possible to welcome the deeper understanding of the springs of human motivation which behavioural genetics promises, without feeling that there is thereby a threat to the inherent dignity of humanity” (p.121).
The conception of ‘free will’ is threatened by behavioural genetics in so far as it implies that (material) genes affect the motivations of the (immaterial) self.

“The aspect of human dignity that has been central to this chapter is the conception of oneself as a free responsible agent, capable of acting for reasons and directing the course of one’s life in accordance with one’s own values and understandings of the world…It has been argued that when the issues are correctly understood, there is no inherent conflict between a greater understanding of genetic contributions to behaviour and due regard for human dignity” (p.130).

SUMMARY OF CHAPTER 13:
SELECTING AND CHANGING BEHAVIOURAL TRAITS

The fact that findings from research concerning the biological basis of addiction to alcohol, and of autism, helped to liberate individuals and parents from the charges previously laid against them of moral weakness and of neglecting their children respectively, reveals that in some cases genetic research may indicate that a behavioural trait is one for which medical interventions are appropriate and welcome.

The role of genetic factors could be over-estimated, hence taking away focus from the social and economic environments which are also likely to play a vital role.

The use of genetic tests might increase social stigma and tendencies towards the labelling of people who display the traits being tested.

On the other hand, knowledge of a genetic predisposition may also help to reduce the stigma associated with a trait by leading to acceptance of it as ‘natural’.

The ‘expressivist’ argument opposes selection for traits in the normal range because of the signals it might send about the value of different types of people and different forms of life. Termination of pregnancies affected by disability signals that disability is unacceptable or that disabled people are inferior.

“A society divided between those possessing enhanced abilities as a result of prenatal selection and those conceived naturally with the ordinary range of abilities might well develop consequential divisions which make life more difficult for ordinary people. But much depends here on the rest of the assumed social and political context. If we assume a democratic context whose political institutions and culture are organised in such a way that the public as a whole, and in particular those who are less talented, benefit from the exceptional abilities of a few, especially talented individuals, then there seems no good reason for thinking that things will get worse, in ways that are unfair, if such people are created. By contrast, if the society is one in which a talented elite enjoy their good fortune without any commensurate benefits for the rest of society, then there is no reason why the latter should welcome the creation of a larger and correspondingly more powerful elite” (p.154).

As far as the argument that genetic testing is ‘interfering with nature’ there is no argument because all medical interventions involve some such interference.

“The challenge for conservative opponents of prenatal selection is to convert this kind of intuitive reaction against prenatal selection into arguments that are robust enough to defeat the liberal proponents of a ‘right to procreative autonomy’” (p.154).

SUMMARY OF CHAPTER 15:
TESTING AND SELECTION IN EMPLOYMENT, EDUCATION AND INSURANCE

Outlines the guiding legal principles behind policy and regulation of the use of genetic information: the 1997 Convention, the 1997 Declaration and the 2000 Charter, all of which prohibit the use of genetic information to discriminate against people; but none have legal force.
Because tests for the genetic components of behaviour in the normal range are not yet accurate and reliable, they cannot be used as the basis for fair and efficient decisions in relation to education, employment or insurance.

“At present there is no legislation in the UK that directly regulates genetic testing or the use of genetic information in employment. At common law, an employer may lawfully require an applicant to undertake genetic testing in order to be appointed to a particular job” (p.177).

“The employer can justify its actions on the grounds that the specific test is accurate and reliable and that the use of the information is ‘appropriate and necessary’ to the requirements of the job. Effectively, discrimination law leaves the control of genetic testing in the employer’s hands and is not primarily concerned with its effect on the dignity or autonomy of the employee” (p.179).

Key Principles for policy regarding the use of genetic testing in EMPLOYMENT:
1. An individual’s ‘right not to know’ their genetic constitution ought to be upheld.
2. An individual should not be required to disclose the results of a previous genetic test.
3. For certain jobs where issues of public safety arise, an employer should be able to refuse to employ a person who refuses to take a relevant genetic test.
4. Accuracy and reliability of results must be assured.
5. Considering the uncertainties of genetic testing and screening, it would be more appropriate to monitor the health of a person by existing medical and screening procedures.
6. The aim should be to remove hazards from the workplace, not to remove employees on the basis of inherited characteristics.
7. Employers should not demand that an individual take a genetic test for a behavioural trait as a condition of employment.

Key Issues regarding the use of genetic testing in EDUCATION:
1. The use of such tests in the educational context may lead to stigmatisation or a tendency towards ‘genetic self-fulfilling prophecies’ that constrain a child’s self-image.
2. It may be argued that in relation to education, the predictive use of genetic information could be justified, if the aim of such an approach was to provide better and more appropriate schooling for children.

Key Issues regarding the use of genetic testing in INSURANCE:
1. The Association of British Insurers (ABI) has stated that behavioural genetics is unlikely to be of relevance to insurers, because it would not be possible to demonstrate a clear link between genetic information regarding susceptibilities to particular behavioural traits and a change in the risk of an individual claiming on an insurance policy.
2. “The change in the role of insurance strongly suggests that access to insurance should more properly be viewed in terms of an essential social right rather than an option for the few with appropriate financial resources. This change requires one to ensure that unreasonable discrimination on the basis of genetic information as to behaviour is prevented by strict regulation. Without such regulation, there is a real risk that scientific developments in the future will lead to the creation of a group on individuals whose genetic characteristics make them either uninsurable in the commercial judgement of the insurance industry, or insurable only at a level of prohibitively high premiums” (p.186).
3. The council agrees with the HGC that “where insurance is linked to important public goods such as house ownership or life insurance and persons are restricted from obtaining these goods because of personal genetic qualities, it is not unreasonable to balance the costs to these individuals and to society against the costs to the insurance industry” (p.186).