Summary and recommendations

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Human behaviour is influenced both by the genes that we inherit and the environment in which we live. With the significant advances in our knowledge of genetics and publication of the draft sequence of the human genome, the focus of research has moved once again towards understanding the biological contribution to behaviour.[1] Some researchers are attempting to locate specific genes, or groups of genes, associated with behavioural traits and to understand the complex relationship between genes and the environment. This is called research in behavioural genetics. In contrast to research into the genetic basis of diseases and disorders, researchers in behavioural genetics investigate aspects of our personalities such as intelligence, sexual orientation, susceptibility to aggression and other antisocial conduct, and tendencies towards extraversion and novelty-seeking.

If genes that influence particular behavioural traits are identified, it could become possible to test for the presence of variations in these genes in individual people. No such tests currently exist. Moreover, there is disagreement about whether tests that predict human behaviour accurately could ever be developed. But even if genetic tests could not yield predictions of a *definite* outcome, it may nonetheless be possible that tests that suggest an individual will have an *increased chance* of possessing a particular trait to a greater or lesser degree might be developed. Such hypothetical tests might be undertaken for a variety of purposes. One purpose would be simply to gain more knowledge about the influence of genes on behaviour. Another purpose might be that of intervention or treatment, for example to prevent aggressive behaviour by using medicines, or by attempts to change relevant aspects of the environment. A further purpose might be that of selection. This encompasses, for instance, prenatal testing, the streaming of children in schools on the basis of intelligence and aptitude, the screening of employees and jobseekers to exclude those with traits that employers consider undesirable, and the use by insurers of genetic information about behaviour and personality traits in order to estimate risk. Yet another purpose might be to claim diminished legal responsibility for one's actions or to mitigate punishment for criminal behaviour.

In 1999, the Nuffield Council on Bioethics agreed that it was important to anticipate the ethical, legal and social implications raised by research in behavioural genetics. Previous work by the Council and other groups has focused on inherited disease and susceptibility to clinical disorders. This Report is intended to fill that gap and to draw attention to the implications of research in genetics which falls outside the medical sphere. The objectives of the Working Party established by the Council in 2000 were to define and consider the ethical, legal and social issues arising from the study of the genetics of variation within the normal range of behaviour characteristics.

The subject of this Report is human behaviour within the normal range, as opposed to traits that are defined as illnesses or diseases. An important preliminary question is whether it is actually feasible to talk about a 'normal range' of behavioural traits. There is a danger that, in speaking of the 'normal' range, this Report may be misunderstood as stigmatising certain kinds of behaviour, namely those that are at the extremes of variation. It therefore needs to be emphasised that when we use the phrases 'normal variation' or 'behaviour in the normal range', no moral evaluation or judgement is implied. In these phrases, 'normal' has a statistical meaning – it refers to the range of variation, usually that which includes about 95% of the population, and

[1] See for example Duster, T. (1990). *Backdoor to Eugenics.* New York: Routledge. This account reports a substantial rise, during the 1980s, in the publication of scientific articles that attempt to explain the genetic basis of behavioural traits.

which is thought not to contain any individuals with clinical disorders or diseases. There are other approaches to defining normal behaviour. They include the theory that abnormal behaviour is that which results in impaired function in society for the individual, either from the individual's own perspective, or from an objective standpoint, regardless of whether the behaviour is statistically rare or not. We take the statistical approach merely as our starting point, using it to limit the field of inquiry. We have focused on traits, such as intelligence, that are continuously distributed measures, displayed by each individual in the population to a greater or lesser extent, and which are not commonly viewed as disorders.

The Report is divided into three parts. The first part of the Report explains the historical and scientific background to research in the field of behavioural genetics. Chapter 2 outlines the history of the eugenics movement and its profound effect on the development of clinical genetics and developmental psychology since the Second World War. Chapter 3 attempts to explain what is meant by the suggestion that genes influence or affect human behaviour. There are different ways in which one can study the contribution that genetic factors make to human behaviour. Chapters 4-6 explain the different methods used by researchers in behavioural genetics.

The second part of the Report, Chapters 7–11, contains reviews of the findings that have been obtained to date in each of these methods of research, with respect to the following behavioural traits: intelligence, personality, antisocial behaviour and sexual orientation. The principal themes that emerge from the reviews of the evidence are summarised in Chapter 11. The Report has been written so that readers not wishing to digest the scientific information contained in the reviews of the evidence can refer to Chapter 11 instead, without compromising their understanding of the Report.

The third part of the Report examines the ethical, legal and policy issues and offers a series of conclusions and recommendations. Chapter 12 begins by discussing whether there is an inherent conflict between understanding the genetic influences on behaviour and human dignity, as it is expressed in the concepts of free will and moral responsibility. Chapter 13 then addresses some of the potential applications of the research including genetic, medical and environmental interventions aimed at changing behavioural traits, as well as prenatal selection. Chapter 14 is concerned with the implications of research in behavioural genetics for the criminal justice system, in relation to attributions of legal responsibility and sentencing, and in predicting antisocial behaviour. Chapter 15 considers genetic testing and selection with regard to education, employment and insurance. The conclusions and recommendations from the Report are summarised in the remainder of this section.

Behavioural genetics and eugenics

Eugenics has been a major social and political force in the twentieth century. Aspects of eugenic policies and practices, in particular, the violation of reproductive freedoms through the segregation and sterilisation of tens of thousands of people in the US, Europe and elsewhere, and the horrors of the 'euthanasia' programmes in Nazi Germany, have been widely, and correctly, condemned.

Behavioural genetics formed a major part of the scientific foundations on which eugenic policies were claimed to be based and the development of behavioural genetics was itself shaped by eugenic concerns. However, this does not necessarily imply that contemporary research on the genetics of behaviour is in any sense eugenic or is driven by considerations that could be considered eugenic. In fact, as we have pointed out, part of the reason for the decline in the support of eugenic policies in many countries from the 1930s onward was scientific research which demonstrated that the policies of segregation and sterilisation of those deemed to be unfit

would not achieve their stated goals. However, as a number of respondents to our consultation have suggested, there remains a view that research on the genetics of human behaviour, particularly in the area of intelligence, is necessarily eugenic or will lead to the re-establishment of eugenic policies. It is possible that contemporary understanding of the heritability of IQ and other behavioural characteristics, and increasing knowledge of the processes of inheritance of other traits, could provide a scientific foundation for a programme of positive or negative eugenics, were there to be the political will or power to construct and implement such a policy (paragraph 2.19).

We conclude that historical and philosophical studies of eugenic practices and policies should be encouraged so that it may be clearly understood what was, and was not, unacceptable about the past and the ways in which this may, or may not, be distinguished from contemporary genetic policies and practices (paragraph 2.20).

The science of behavioural genetics

There are different ways in which researchers can study the contribution that genetic factors make to human behaviour. First, there are observational studies, which involve assessing and comparing relatives such as twins or siblings, families and adopted children. This type of research is called quantitative genetics because it aims to examine the extent to which variation in a trait is influenced by genetic factors in a population. It uses statistical methods to examine and compare groups of people, without focusing on particular genes (Chapter 4). Secondly, researchers can try to identify differences in genes that contribute to trait variation in characteristics or traits between individuals. This type of research is called molecular genetics (Chapter 5). Thirdly, researchers can use animals to try and examine the effects of particular genes on behaviour (Chapter 6).

It is common to hear of research that claims to identify a ‘gene for aggression’ or a ‘gene for homosexuality’. But how could our genes *cause* us to act in a particular way? What is really meant by saying ‘a gene for X’? The connection between genes and diseases is far from straightforward, and the relationship between genes and behaviour is even more complicated. It is often difficult to establish which genes contribute to a trait and how they do so because:

- More than one genetic factor usually contributes to a particular trait.
- These multiple genetic factors may interact with each other and have different effects depending on which other factors are present in the individual’s genotype.
- As well as genetic factors, many non-genetic (environmental) factors may contribute to the manifestation of a trait.
- These environmental factors may also interact with each other.
- The genetic factors may affect which environmental factors have an effect. (This is called gene–environment interaction.)
- Conversely, environmental factors may affect which genetic factors have an effect.
- Certain genetic and environmental factors may go hand in hand. (This is called gene–environment correlation.)
- A protein may be modified after it has been produced from a gene, and this can alter its function.
- Genes do not have a continuous effect in our bodies. They may be turned on and off, both during our overall development and within the lifetime of an individual cell.

So, while it might be correct to say that a particular genetic variant is part of the cause of a particular trait, or that it is one causal factor, it will seldom be the only cause, nor is it likely to be either a necessary or sufficient condition for the trait to be manifested. Furthermore, even if particular genes that contribute to a trait can be identified, this is only a small part of the story. There is still a need to understand the very indirect pathway between a gene, a particular protein and an individual scoring highly on an IQ test or having an aggressive personality. Our understanding of these causal pathways is at an even earlier stage than our understanding of which genes influence behavioural traits, which is itself extremely limited (paragraphs 3.9 – 3.14).[2]

The complexity of human behaviour and the difficulties in understanding how genes are involved may seem overwhelming. There is wide agreement that genes do have an indirect effect on behaviour. However, some commentators have suggested that any attempt to understand the processes by which genes influence behaviour will certainly fail. We disagree. We consider that it is neither a theoretical nor a practical impossibility to identify genes that contribute to behavioural traits and to understand some of the mechanisms by which they do so. However, we note that terminology such as 'a gene for X' or 'a set of genes for X' is very misleading because it fails to convey the complexity of the role of genetic factors in causal explanations of human behaviour. Genes determine which proteins are made. They do not determine which behavioural or personality traits an individual possesses. Furthermore, the product of an individual gene will only very rarely be directly related to a complex behavioural characteristic. It will normally interact with many other genes and with many non-genetic factors, which means that the predictive capability of tests for any single or small number of genes will in general probably be quite limited. Nonetheless, the proteins that genes make and the way these affect our bodies and brains will be one part of an explanation of human behaviour (paragraph 3.20).

Reporting research in behavioural genetics

Research which claims to show an association between particular genetic variants and particular traits tends to receive considerable attention in the scientific and lay media. The various methods of research in this field are not infallible, and the reviews of the evidence in Chapters 7–10 show that few findings have been replicated successfully to date. Thus, reports of such things as 'gay genes' or 'smart mice' convey a highly inaccurate impression of the state of the research. The lack of reporting of negative or contradictory findings exacerbates this problem. These difficulties are not unique to research in behavioural genetics. However, it does seem that such research is, at present, particularly susceptible to reporting which, whether strictly accurate or not, is misleading in the impression it gives to the reader. The potential for the abuse of findings in this area means that the reporting of this research ought to be conducted with particular care.

We consider that researchers and those who report research have a duty to communicate findings in a responsible manner. We welcome the *Guidelines on Science and Health Communication* published by the Social Issues Research Centre, the Royal Society and the Royal Institution of Great Britain and recommend that further initiatives in this area should be encouraged (paragraph 11.14).[3] In the context of research in behavioural genetics, we recommend that the following points, concerning the various types of research, are borne in mind by those who report on, comment on and evaluate such research:

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[2] Rutter, M. & Silberg, J. (2002). Gene-environment interplay in relation to emotional and behavioural disturbance. *An. Rev. Psychol*. **53**, 463-490.

[3] Social Issues Research Centre, the Royal Society and the Royal Institution. Guidelines on Science and Health Communication. November 2001. http://www.sirc.org/publik/revised_guidelines.pdf (9 Aug 2002).

Quantitative genetics

- Quantitative genetics involves statistical methods that attempt to distinguish the effects of genetic and environmental factors on variation in certain behavioural traits, which can be quantitatively measured, between groups of individuals.
- The subjects of the research are usually twins, siblings, adopted children, and families.
- The statistics such as estimates of heritability generated by the research refer to groups of people, not to individuals. Nor do they refer to particular genes or regions of DNA or to specific environmental factors. This requires further research and additional measurement.
- Estimates of heritability and other statistical techniques are useful in understanding the relative contribution of different types of influence and their relation to each other. They are also useful for understanding why some types of behaviour often occur together. They do not, however, lead directly to predictive information regarding individuals, nor do they give reliable estimates of how strongly predictive a genetic test might be if it were developed (Box 4.1).

Molecular genetics

- Research in molecular genetics tries to identify variation in particular genes that influences behaviour, by examining the DNA of individuals.
- This is difficult because there are usually many genes involved, each of which may only have a small effect. Many associations between a genetic variant and a behavioural trait have been reported but have not been successfully repeated by other researchers.
- In most cases, the research does not explain how the gene influences the behaviour. However, some researchers predict that they will overcome these difficulties and that genes that influence behaviour will be reliably identified.
- When associations are reported by researchers, it is important to consider the following questions:
  - How convincing is the evidence, in terms of both statistical analysis and the supposed pathway of causation, that the claim is correct? Much more credibility can be attached to findings that have been independently replicated by a different research group, and first reports of gene–behaviour associations should be treated with caution until they are replicated.
  - Over what range of populations and environmental conditions has the effect been tested?
  - If claims are made about the practical application of the findings to influence human behaviour, what is the size of the effect of the genetic variant? Is it large enough to have any relevance for the testing of individuals?
  - What are the implications for the pathway of causation of the behaviour? (Box 5.1)

Research involving animals

- Animal models have greatly advanced our understanding of how genes have an effect in the organism and of how the brain develops.
- Animal models can be created by various techniques including selective breeding and the direct manipulation of specific genes.
- Although there are many similarities with regard to genetics between human and non-human animals, there are also considerable differences in the expression of their genes both within the organism and over time.

- It is difficult to equate directly the richness of complex human traits such as intelligence, personality and sexual orientation with the behaviour of animals. This may limit the potential value of the research.
- For these reasons, caution should be exerted when hypothesising that genes studied in research involving animals will have the same effect in humans (Box 6.2).

The evidence for genetic influences on human behaviour

In Chapters 7–10 we set out some recent findings in research in behavioural genetics into antisocial behaviour, intelligence, personality and sexual orientation. As these chapters demonstrate, research is at different stages in different areas. For some traits, areas of the genome have been identified that might contain genes which have an effect on behaviour. For most traits, the route from such genetic factors to a particular behaviour is unclear. The bulk of research in behavioural genetics to date has relied on quantitative methods to assess the relative contributions of different types of factor. However, the use of molecular genetics is increasing, a trend which is expected to continue. In Chapter 11, we draw some general conclusions about the research in all the areas described and highlighted some central themes that emerge. These inform our consideration of the ethical, legal, social and policy issues to which the research gives rise. The central themes that emerge are:

– the difficulty of defining and measuring behavioural traits;

– the dangers of the misinterpretation and misapplication of heritability estimates;

– the lack of replicated findings relating to specific genes that might influence behaviour.

Ethical issues arising from research in behavioural genetics

Free will and human dignity

We conclude there is no inherent conflict between a greater understanding of genetic contributions to behaviour and due regard for human dignity. A non-reductive, rationalist, understanding of human freedom can coexist with recognition of the genetic influences on our human abilities, capacities and motivations, even though a reductive, functionalist, account fits more readily alongside the scientific perspective employed by behaviour geneticists. It is not necessary here to take a stand on this debate. But any sensible understanding of human freedom and dignity must allow for some starting-point in the development of the abilities which are central to this freedom and dignity. Behavioural genetics promises to elucidate this starting-point, and thereby contribute to the understanding of humanity. But it no more offers a complete theory of human behaviour than does any other single scientific discipline. Thus, 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 (paragraph 12.38).

Will there be any practical applications of research in behavioural genetics?

While everyone accepts that genes have an impact on behaviour, genetic tests will have a low predictive capacity because of the myriad other factors that influence our behaviour and the vastly complex interactions between genetic factors themselves. Hence, it has been argued that it will be impossible to make any robust predictions based on genetic tests, or to design any effective interventions as a result of them, and therefore, that there is no point in discussing the ethics of their application. We take the view that these considerations do not exempt us from

considering anxieties aroused by popular beliefs in this area, even if these beliefs turn out to be misconceptions. For in the past, social policies, for example eugenic policies, have been built on minimal or erroneous scientific foundations. More recently misunderstandings about genetics have led to unwarranted discrimination. Moreover, we consider that, in the future it may become possible to make predictions, albeit limited ones, about behaviour based on genetic information and to design useful applications of this knowledge. Therefore, while it is certainly too early to discuss detailed applications of behavioural genetics, we need to confront anxieties based on current beliefs about this subject (paragraphs 13.2-13.6).

Medicalisation and other concerns

Traits such as sexuality, aggression and intelligence have in the past been thought of as outcomes of inheritance, family background, socio-economic environment, individual choice and even divine intervention. If research in behavioural genetics identifies the influence of genes on such traits, these traits may mistakenly come to be thought of as being fundamentally determined by genetic factors and even as aspects of life which belong to one's 'fate'.

As the reviews of the evidence in chapters 7-11 indicate, fatalism about genetics is a misconception. Even when behavioural traits are influenced by genes, there are always other influences, and the existence of genetic influences does not show that we are powerless to change or modify our character. Nonetheless, this misconception is pervasive and gives rise to the anxiety that behavioural genetics will lead to the 'medicalisation' of those who are found to be genetically predisposed to certain behavioural traits. At the root of such concerns is the idea that behavioural traits that have previously been regarded as 'normal' will come to be viewed as 'abnormal' or pathological.

Medicalisation is an issue that affects many areas of life, not just behavioural genetics. In the case of behavioural traits, since research into genetic influences is at an early stage, it is not possible to say whether medicalisation will be likely, or whether it will have, on balance, positive or negative implications. However, examples of the deleterious effects of medicalisation in other areas suggest the need for awareness of potential problems. **We conclude that research in behavioural genetics has the potential to contribute to the existing phenomenon of medicalisation. Deleterious effects that should be borne in mind include shifting the boundary between normal variation and disorder further away from the extremes of variation; reducing social tolerance of previously 'normal' behavioural traits; and the routine selection of genetic or medical interventions without adequate consideration being given to environmental interventions and other options** (paragraph 13.23).

Any discovery of biological mechanisms that influence behaviour, including genes, may aid in the development of drugs which modify behaviour. We consider that there is potential for the unhelpful widening of diagnostic categories, to encourage the use of medication by people who would not necessarily be thought of as exhibiting behavioural traits outside the normal range. In addition to the potentially harmful effects already listed, this could lead to unnecessary increased expenditure by the health service. **We recommend that health service providers, and in particular the Department of Health, specifically charge a named agency with monitoring and, if necessary, controlling, this means of the deliberate medicalising of normal populations** (paragraph 13.24).

Despite concerns about medicalisation and stigma, we consider that there is, *prima facie*, no reason for preferring one type of intervention over another as a matter of principle. For any given trait and any given individual, the factors influencing the development and expression of

that trait are likely to be many and varied. In different cases, there may be reasons for thinking that different forms of intervention are appropriate. We identify five features of any intervention that may provide moral reasons for accepting or rejecting their use, namely the effectiveness, safety and reversibility of the intervention, the extent to which one can make choices about its use, and its implications for individuality (paragraph 13.26).

Gene therapy

The United Nations Educational, Scientific and Cultural Organization (UNESCO) Universal Declaration on the Human Genome and Human Rights states in Article 5 that '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 national law'.[4] The Clothier Report on the ethics of gene therapy identified a number of ways in which gene therapy might pose a risk to safety.[5] These included mistakes in inserting the correcting gene, the possibility that the gene would be expressed in the wrong place or at the wrong time, the possibility that insertion of the gene might cause a new mutation or genetic disease, and the possibility that the correcting gene might move from its target location in the body and affect other cells. As a result, all applications to carry out trials of gene therapy in humans in the UK are monitored by the Gene Therapy Advisory Committee (GTAC). **We consider that in view of the risks inherent in gene therapy, considerable caution should be exercised before contemplating its application to traits that do not have serious implications for health. We note that if somatic gene therapy for traits in the normal range were to become a possibility, any research would fall under the remit of the Gene Therapy Advisory Committee (GTAC).[6] We recommend, therefore, that the GTAC and other relevant bodies should develop guidelines for research into gene therapy for normal behavioural traits before such research takes place** (paragraph 13.31).

Germline gene therapy raises particular issues concerning safety because the effects of the therapy reach far into the future and cannot be easily predicted. The Clothier Report concluded that 'there is insufficient knowledge to evaluate the risks [of germline gene therapy] to future generations' and that therefore 'gene modification of the germ line should not yet be attempted'. In the context of behavioural variation within the normal range, which by definition is not life-threatening, we cannot envisage any circumstances in which the modification of the human germline would be justifiable (paragraph 13.32).

Access to interventions

Therapy versus enhancement

The way to distinguish between those interventions which count as 'therapies' and those which count as 'enhancements' is by reference to the condition that is to be altered: therapies aim to treat, cure or prevent diseases and to alleviate pathological conditions which place someone outside the normal range, whereas enhancements aim to improve already healthy systems and to advance capacities which already fall within the normal range. This distinction is often used to justify a distinction between interventions which merit public support and those which do not.

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[4] United Nations Educational, Scientific and Cultural Organisation. (November 1997). *Universal Declaration on the Human Genome and Human Rights.*

[5] Committee on the Ethics of Gene Therapy (Chairman: Clothier, C.). (1992). *Report of the Committee on the Ethics of Gene Therapy*. London: HMSO; Cm 1788.

[6] GTAC's remit is 'the deliberate introduction of genetic material into human somatic cells for therapeutic, prophylactic or diagnostic purposes'. An analogous role is performed in the US by the Food and Drug Administration (FDA). In July 2002, it was reported that the FDA is to create a new department to oversee gene therapy, within the Center for Biologics Evaluation and Research (New FDA Office for Gene Therapy. (2002). *Nat. Med.* **8**, 646).

The suggestion is that there is a duty to ensure that our fellow citizens receive therapies, but no duty to ensure that they receive enhancements. The distinction between therapy and enhancement is not straightforward and requires qualification, but the principle which associates it with that between public and private provision is a useful starting-point in this area.

Although therapy is usually thought of as the treatment of diseases with an identifiable biochemical basis, there can be cases in which someone suffers from a pathological condition which places them outside the normal range in some respect, without there being any such identified basis for it. In such cases, interventions to overcome the resulting impairment are also to be regarded as therapies; hence, such interventions merit public support to make them available to all. The important issue is the severity of the handicap, not its cause. We take the view that this conclusion should be applied to interventions which become available in the field of behavioural genetics. Any decision to provide public support through the National Health Service (NHS) for interventions to enable individuals to overcome disabilities which obstruct their capacity for behaviour in the normal range should not be dependent on the underlying cause of the disability (paragraphs 13.41-13.43).

Providing tests and interventions

Who should be able to make use of genetic tests and interventions if they are developed? And who should bear the cost of the tests and interventions? 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. Because these techniques would enhance capabilities, this could lead to even greater inequalities and increase social and economic polarisation. Public provision of new tests and interventions, especially when accompanied by further efforts to prevent the formation of an underclass, would, of course, require considerable resources. From an egalitarian perspective, if these resources are not available, then the tests and interventions should not be introduced at all. However, libertarians argue that there is no moral basis for a distinction between interventions based on genetic variants and the familiar use of extra resources in the fields of education and sport. In particular, if a trait is desirable and there is an intervention that will increase the likelihood of it occurring, the correct response is to ensure that it is available as widely as possible. While this may entail that, for at least a limited period of time, there will be some who do not have access, the overall goal should be to raise everyone to the highest level.

It is difficult to adjudicate in the abstract between these egalitarian and libertarian positions. It is only once some effective intervention is under consideration that the costs and benefits of full public availability versus limited private availability for a privileged few can be assessed seriously. **We believe that equality of opportunity is a fundamental social value which is especially damaged where a society is divided into groups that are likely to perpetuate inequalities across generations. We recommend, therefore, that any genetic interventions to enhance traits in the normal range should be evaluated with this consideration in mind** (paragraph 13.48).

Monitoring the provision of genetic tests and interventions

If genetic tests and corresponding genetic, medical or environmental interventions relevant to traits

in the normal range are developed, it is important to consider how such tests and interventions may be made available. Genetic tests for variants that influence behaviour in the normal range might be thought of as comparable to personality or IQ tests, rather than genetic tests that are used to diagnose or predict the onset of a serious disease such as cancer. Similarly, interventions might be seen as comparable to vitamin supplements or cosmetic surgery. In both cases, therefore, if the comparisons are a guide, it may turn out that individuals are left to make decisions about whether to make use of tests or interventions without the involvement of health professionals.

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. This is particularly likely in novel areas of science, where most people will not be well placed to make informed judgements. In the case of genetic tests, there is currently no specific legislation in place that would provide a regulatory mechanism for assessing the efficacy or reliability of a test. This applies even to genetic tests for diseases, as well as to the hypothetical tests for genetic influences on behavioural traits that are the focus of this Report.

We consider that the issues raised by tests for behavioural traits and other traits that exhibit normal variation, rather than tests for diseases, require specific attention. The questions addressed by these tests include very sensitive areas of personal and family vulnerability, and there is considerable potential for exploitation of the anxieties and aspirations of members of the public in an area where the science is not well understood. This danger is particularly important since both tests and interventions might be applied to children without their consent. Thus, we take the view that it is not adequate in this area to rely on the same mechanisms that apply to non-genetic or non-medical enhancements, such as recourse to the Advertising Standard Authority or the Office of Fair Trading, to prevent misleading claims being made and ineffective tests from being sold.

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*.[7] The ACGT was subsumed in 2001 by the Human Genetics Commission (HGC), which currently has responsibility for administering the Code of Practice. The HGC issued a public consultation document on the supply of genetic tests direct to the public in July 2002.[8] This summarises the current situation and poses a number of specific questions covering issues such as consent to testing, storage and use of samples, and confidentiality of data. It notes that tests in the field of behavioural genetics are likely to be particularly controversial.

On the presumption that tests for genetic influences on behavioural traits in the normal range, of varying quality and predictive power, will become available, we welcome the consideration by the Human Genetics Commission (HGC) of genetic tests supplied directly to the public. We encourage the HGC to give thorough consideration to the issues raised by genetic tests for behavioural and personality traits. We recommend that both the public and private provision of such tests, if they are developed, should be stringently monitored and regulated as necessary (paragraph 13.53).

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[7] Advisory Committee on Genetic Testing. (September 1997). *Code of Practice and Guidance on Human Genetic Testing Services Supplied Direct to the Public.* London: Health Departments of the United Kingdom.

[8] Human Genetics Commission. (July 2002). Consultation on Genetic Testing Services supplied Direct to the Public. http://www.hgc.gov.uk/testingconsultation/index.htm (16 Jul 2002).

In addition to genetic tests, interventions may be developed, whether medical, genetic or environmental, on the basis of information about genetic variants. The HGC consultation document recognises that some genetic tests may be accompanied by a corresponding intervention that is recommended, depending on the test results. How should such interventions be regulated?

In the case of genetic interventions the use of gene therapy will be regulated by the Gene Therapy Advisory Committee (GTAC). Medical interventions such as pharmacological substances will not necessarily be classified as medicines. While some would be subject to the existing regulation in place for medicines, others might be classified as foodstuffs or herbal remedies. Those which are not classified as medicines are unlikely to be harmful, but there is a risk that they will be promoted on the basis of unreliable, or even non-existent scientific evidence, and that consumers will be misled. Similarly, environmental interventions, such as changes in lifestyle or surroundings, may be promoted on the basis of genetic information about an individual. As noted above, we do not consider that there are currently any public bodies constituted in such a way as to monitor the provision of such interventions effectively and ensure that they are appropriate and of sufficiently high quality. **We recommend, therefore, that those charged with the monitoring and regulation of genetic tests for behavioural traits in the normal range should also be responsible for ensuring appropriate monitoring of the provision of interventions based on such genetic information, which fall outside the scope of other regulatory bodies** (paragraph 13.55).

We note the difficulties for monitoring and regulation raised by the sale of existing tests and interventions on the internet, and encourage the efforts of the Office of Fair Trading and consumer protection agencies such as the National Consumer Council and the Consumers' Association in developing codes of practice and strategies, such as kite-marks, for assisting consumers.

Prenatal selection

There are various ways in which we can affect the characteristics of our children. Most fundamentally, our children are influenced by our choice of mate. However, in recent decades, other techniques have been developed which extend our capacity in this area. The first is prenatal diagnosis (PND) which is in widespread use in the UK to detect pregnancies affected by diseases such as Down's syndrome and spina bifida. Many couples opt for termination of pregnancy if abnormalities are detected. Secondly, in the past 15–20 years, the technique of preimplantation genetic diagnosis (PGD) has been developed, which enables embryos created by *in vitro* fertilisation (IVF) programmes to be tested for genetic disorders before they are implanted. A third, largely theoretical, approach is to move selection further back in time, by allowing choice between different gametes. Experimental techniques now allow sperm to be sorted, enabling parents to choose the sex of their embryo. This technique remains somewhat unreliable: there are reports of an 8% error rate for females and 28% in males. It is not clear that this type of technique will ever be applicable to traits other than sex, and it is particularly difficult to envisage its applications to the complex traits considered in this Report.

The use of these techniques, particularly PGD and gamete selection, has often been referred to in the press and in popular debate as a question of 'designer babies'. 'Designer baby' is one of those terms, like 'Frankenstein foods' and 'slippery slope', which is central to public discourse on genetics, but which can be misleading. The selection of gametes before fertilisation, of embryos before implantation, or selective termination of pregnancy are all examples of the selection or choice of alternative options rather than the manipulation or design of babies. The possibility of

truly designing a child, by choosing characteristics from a menu of possibilities to create a child, for example using gene therapy, is still in the realms of science fiction (Box 13.2).

The forms of selection outlined above are currently only practised on clinical grounds in the UK. However, a trend towards selection on other grounds can be identified. The recent decision by the Human Fertilisation and Embryology Authority (HFEA) to allow the selection of embryos that are free from genetic diseases and that can act as donors to existing siblings is an important move in this direction. Moreover, recently, the Government has requested that the HFEA examines the advances in techniques of gamete selection on the basis of sex, something which is already possible and unregulated in the private sector. The HFEA intends to launch a public consultation on sex selection in late 2002.

Law and clinical practice support the use of genetic information to provide informed choice for prospective parents. But professional and public opposition has been voiced, for a variety of reasons, to the use of non-clinical attributes such as the traits considered in this Report in testing and selection. There seems to be a consensus in clinical genetics and in public opinion against use of PGD or PND in order to select babies on the basis of non-clinical characteristics. **In the case of prenatal diagnosis (PND), we share this view. 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 fetus merely on the basis of information about behavioural traits in the normal range is morally unacceptable** (paragraph 13.65).

But the issues raised by the use of PGD are different. Whereas selective termination following PND is applied to a fetus that has already implanted and is developing in the womb, PGD is used to select which embryos to implant. Thus, PGD does not precede the termination of a potential human life, but precedes instead the choice as to which embryo, among those created by IVF, is to be given a chance of developing into a human being. And in this context, it is not so clear that it is morally unacceptable to make this choice on the basis of genetic information about the traits that are the focus of this Report. Whereas PND would be used to end a life, PGD is, in effect, used to choose which life to start. Hence, the moral prohibitions which apply in the case of PND, do not apply in the same way in the use of PGD. Nonetheless, the potential use of PGD to select embryos that are more or less likely to exhibit particular behavioural traits is widely thought unacceptable.

One line of argument in favour of the use of PGD is described in terms of a 'right to procreative autonomy' which would include a right to employ safe and reliable methods for the selection of children with a genetic predisposition for enhanced abilities within the normal range.[9] However, we identify a number of arguments against the use of PGD for traits in the normal range. In particular, we address the question of 'natural humility'.

At present, parents accept their children as they find them in an attitude of 'natural humility' to the unchosen results of procreation. This attitude is an important feature of parental love, the love that parents owe to their children as individuals in their own right; for this is a love that does not have to be earned and is not dependent on a child having characteristics that the parents hoped for. Parental love which includes this element of natural humility is, therefore, incompatible with the will to control. It is not compatible with attempts to interfere in the life of a child except where the interference is in the child's own interest. Equally, it is not compatible

[9] Dworkin, R. (1993). *Life's Dominion*. London: Harper Collins.

with the practice of prenatal selection which seeks to identify, as a basis for choice, genetic predispositions for enhanced abilities or special character traits. For this is an attempt to determine the kind of child one will have – which is precisely not the unconditional, loving acceptance of whatever child one turns out to have.

Given that we are dealing here with only speculative possibilities, and since the likely small effects of individual genes may make accurate predictions of future behaviour very difficult, it is hard to evaluate the disagreement between the contrasting positions. In particular, it may be that the contrast between the affirmation of a right to procreative autonomy and the defence of natural humility is too simple. It might turn out that there are possibilities for modest applications of PGD in relation to the traits considered in this Report which would not seriously undermine the present relationship between parents and their children. **While not entirely persuaded by this conservative line of argument, we do accept that, at present, the case for permitting prenatal selection based on the identification of genetic predispositions for enhanced abilities remains to be made. We recommend, therefore, that the technique of preimplantation genetic diagnosis, which is currently restricted to serious diseases and disorders, should not be extended to include behavioural traits in the normal range such as intelligence, sexual orientation and personality traits** (paragraph 13.78).

Legal issues: criminal responsibility

Attributing responsibility

We conclude that research in behavioural genetics does not pose a fundamental challenge to our notions of responsibility as they are applied in the legal context. We consider that genetic variants in the normal range are unlikely to be considered an excuse for legal purposes, at least for the foreseeable future. They fall outside the scope of the defences of insanity and diminished responsibility and cannot be said to absolve individuals from responsibility for their actions (paragraph 14.24). If progress in behavioural genetics were to be such that close and clearly identifiable associations between particular genetic variants and particular forms of antisocial acts were to be demonstrated, there would be a case for a re-examination of the legal implications. It might be that the concept of diminished responsibility, for example, could be expanded to embrace such conditions, perhaps by redefining views of illness. If this possibility were to be considered, thought would have to be given to the potential dangers of unwarranted over-reliance on genetic information and the consequences of reducing responsibility for our actions (paragraph 14.25).

Sentencing

We conclude that, with regard to the sentencing of convicted offenders, the criminal law should be receptive to whatever valid psychiatric and behavioural evidence is available. The taking into account of genetic factors would depend on the degree to which such evidence is convincing and relevant. Credible evidence of influence and a robust test for the genetic factor in question would be essential: the weight to be accorded to such information would be determined by the judge (paragraph 14.32). Currently, environmental, social and psychiatric assessments may be taken into account by judges in determining appropriate sentences. These must also be supported by valid, accurate and reliable evidence. It would be unwise to assume that genetics will not be able to assist in determining degrees of blame, even if the 'all-or-nothing' question of responsibility is not affected by genetic factors themselves. Such a role would not compromise basic assumptions as to responsibility.

Exchanges between genetics and the criminal law are at present not very productive given the uncertain nature of the evidence. This is likely to change. **We recommend that the criminal**

justice system should be open to new insights from disciplines that it has not necessarily considered in the past. The regular exchange of ideas in this area between researchers in behavioural genetics, criminologists and lawyers could be an effective means of ensuring that legal concepts of responsibility are assessed against current evidence from the behavioural and medical sciences (paragraph 14.33).

Predictive use of genetic information

We take the view that while the reduction of antisocial behaviour and crime are important goals, any attempt to predict the behaviour of an individual who has not exhibited antisocial behaviour, and to intervene accordingly, poses a significant threat to civil liberties and should be treated with great caution. The use of predictive genetic tests to anticipate antisocial behaviour for the purposes of preventive action in the case of individuals who have not already exhibited such behaviour raises ethical questions about balancing the interests of individuals against those of society. **We consider that the predictive use of genetic information about behaviour in the normal range, used in isolation in the case of individuals who have not exhibited antisocial behaviour, is unlikely to be warranted because of the predictive power of such information is likely to be weak and there is a risk of false predictions. However, we take the view that the use of such 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. We recommend that the prediction of behaviour with a view to detaining an individual who has not committed a crime is not justified, whether such predictions are based on information about genetic or non-genetic influences on behaviour** (paragraph 14.44).

Policy issues: employment, education and insurance

Employment

Various bodies have made recommendations concerning the occupational health and safety of employees and jobseekers in the context of genetics. These have tended to apply a model of the autonomy of the individual patient in the medical sphere to the employment relationship. In the case of behavioural traits within the normal range, which are the subject of this Report, we are not concerned with patients. Moreover, the employment relationship is less receptive to the application of the medical model. 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. The public interest or paternalistic justifications for overriding the individual's wishes where there is a serious danger to the health or safety of the employee or third parties do not exist in the case of non-clinical behavioural traits (paragraph 15.20). This leads us to make the following conclusions and recommendations in the context of the use by employers of genetic testing for behavioural traits:

- **The primary duty of employers is to provide a safe environment for their employees and others. The aim should be to remove hazards from the workplace, not to remove employees on the basis of inherited characteristics or susceptibility to particular forms of behaviour within the normal range.**
- **Employees should be selected and promoted on the basis of their ability to meet the requirements of the job, and they should be monitored to ensure that their performance meets those requirements.**

- **Employers should not demand that an individual take a genetic test for a behavioural trait as a condition of employment. The proper approach would be to monitor employees for early warning signs of behaviour (such as violence) that would make them incapable of performing the job satisfactorily.**
- **Any inquiry into the potential use of genetic testing of behavioural traits in the workplace should include an investigation of the use of other purportedly predictive scientific methods, such as psychometric tests, for similar purposes** (paragraph 15.21).

Education

We note, with some concern, that the implications for education of research in behavioural genetics have not yet received significant critical attention. **In the light of the issues that may arise if genetic information about behavioural traits is applied in the context of education, we recommend that further investigation of the ways in which such research might be applied, and the resulting ethical and social issues, be undertaken. We recommend that dialogue between those involved in education and researchers in behavioural genetics be promoted. We recommend, further, that until such dialogue and research is undertaken, genetic information about behavioural traits in the normal range should not be used in the context of the provision of education** (paragraph 15.26).

Insurance

We recommend that the use of genetic information about behavioural traits in the normal range should be interpreted as falling 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. Future discussion of possible legislation should include specific consideration of genetic information regarding behavioural traits. If the use of such information were considered, a thorough examination of the accuracy and reliability of any genetic tests and their likely predictive power would be essential (paragraph 15.37).

Funding research in behavioural genetics

It has proved difficult to gauge the precise extent of UK funding in this area. Our public consultation showed that many people consider that, compared to research on disease, research into genetic influences on behavioural traits in the normal range ought to receive low priority for funding. This was partly due to doubts about the likely success of the research, and partly due to concerns about the potential applications. **We take the view that research in behavioural genetics has the potential to advance our understanding of human behaviour and that the research can therefore be justified. However, we note that it is important 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. In addition, we recommend that research sponsors who intend to focus strategic funding in this area should pay careful attention to public concerns about the research and its applications** (paragraph 11.17).