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Tor Lezmore  
Nuffield Council on Bioethics  
28 Bedford Square  
London WC1B 3JS

**Genetics and Human Behaviour: the ethical context. The response of the Genetic Interest Group to the Nuffield Council on Bioethics consultation.**

1. INTRODUCTION

As the UK alliance of support groups and charities for those affected by or at risk from genetic disorders the Genetic Interest Group welcomes the opportunity to respond to this consultation. This response was generated by a working party of GIG's staff, trustees and other interested individuals before being circulated to relevant member groups for their comment and endorsement. The final version was approved at a meeting of the trustees held on 19th July 2001. This response follows the format of the consultation document issued by the Nuffield Council and seeks to provide commentary on the issues raised.

A number of single gene disorders, including for example fragileX syndrome, tuberous sclerosis and neurofibromatosis, have distinct abnormal behavioural aspects. From the perspective of the groups representing patients with these conditions, any research that increases understanding of such behaviours is welcome, and it seems clear that specific research on the behavioural aspects of these disorders and more general behavioural genetic research can be mutually reinforcing. That is why GIG takes the view that research under the broad heading of behavioural genetics should be supported and funded, subject to the normal rules of quality assessment.

2. BACKGROUND

We recognise that for some people there is a link between aspects of modern genetics and the attitudes that informed historical eugenics. In GIG's view the ideology of eugenics and the practices it helped to inspire were social and political in origin, and are widely held, in western Europe and north America at least to have no place in modern genetic medicine. Behavioural genetics could, perhaps more easily than modern medical genetics, be associated with eugenic notions of the inherent superiority of certain groups and individuals, and indeed some of its practitioners have made such arguments. However, most leading researchers in the field understand the limited contribution of many different genes. Their study is primarily individual variation, not

purported race or social group differences, and very few working in the field link genetics to ideas of racial or national success and failure. Finally, these fields of research do not impinge on antenatal or pre-implantation services, and are unlikely to do so for the foreseeable future.

Conflating present possibilities and past abuses seems likely to hinder rational discussion, particularly given the widely held consensus that such an approach would be morally repugnant and politically unacceptable.

### 3. WHAT IS BEHAVIOURAL GENETICS?

GIG endorses the statement in the consultation document:

*“Human behaviour is vastly complex and it is wrong to speak of a ‘gene for’ a specific trait. There is no evidence of a simple correlation between one gene and one trait. Rather, a number of genes may be involved in an individual’s susceptibility to possessing a particular trait. But there will also be environmental influences on both behaviour and genes and genetic influences on both the environments we seek out and the activity of other genes. So even if some genes are associated with certain types of behaviour, the contribution they make may be individually very small and the precise effect they have on any particular person may be very difficult to predict. A further complication is that one gene or group of genes, is likely to affect more than one trait”.*

The starting point for behavioural genetic studies is understanding the contribution of genetic and non-genetic factors to *population variation* in human behavioural and psychological traits. To date this approach has comprised the main focus of work in the field. However, such population studies are now beginning to generate possible targets for molecular genetic investigations with the aim of locating specific genes involved in such variation. This may, in time, lead to the ability to test individuals for the presence of relevant alleles.

In addition to the study of normal variation in behavioural traits, where this is under the influence of many genetic and non-genetic influences, a key issue is the relationship between variation within the normal range and that at the extremes. These two aspects are distinguished in the consultation document, but at times it is unclear whether the examples and questions relate to behavioural genetic studies of variation within the normal range, or to issues such as cognitive disabilities and psychopathology. The latter are of particular interest to behavioural geneticists, and raise specific issues, such as the appropriateness of genetic testing and the danger of stigmatisation. Greater clarity on this would have been useful. A further distinction is between abnormal behaviour due to complex causes, and behaviours associated with an underlying medical condition, perhaps caused by a single gene mutation of large effect.

Such distinctions also suggest fruitful avenues for comparison. One particular synergy between the methods employed by behavioural geneticists and the study of disorders associated with single gene mutations may be the elucidation of the genetic and non-

genetic factors that affect the phenotypic variation seen in the behavioural aspects of some of these single-gene disorders. At the same time, the observation—that even in the case of single gene disorders the relationship between a clearly specified mutation and behavioural aspects is often far from clear—should serve as a warning against deterministic interpretations of what are likely to be more complex multiple effects in the field of behavioural genetics as a whole.

Overall, there is a growing consensus among scientists in the field that the models employed are valid and reliable, and that some of the estimates of genetic influences on variation indicate a large effect. However, questions remain concerning interpretation and significance. Many would accept that the science has yet to progress to the point of postulating plausible causal models of variation. A specific criticism is that in studying human behaviour as the outcome of genetic and environmental influences, issues of human subjectivity, choice and motivation are poorly theorised.

#### 4. WHY STUDY BEHAVIOURAL GENETICS?

GIG believes there is no logical reason **not** to study behavioural genetics. If genetic factors account for a significant proportion of variation for a particular trait these will continue to operate in the absence of research. Whilst the research is legitimate, this does not imply that any or all uses of the resulting knowledge will be legitimate. Judgements will have to be made on a case-by-case basis as to what uses may or may not be permitted when research is completed.

##### **4.1 *What do you think are the likely advantages and disadvantages of research in behavioural genetics?***

As has already been stated, there may be advantages for some groups where behaviour is associated with a particular single-gene disorder and the pathology is part of the condition. Under such circumstances research may help with our understanding of the condition and this knowledge may help parents, carers and those affected in day-to-day management. This knowledge is also helpful for those in non-medical contexts (e.g. education and social services) who need to design and provide appropriate services and support that reflect the totality of the diagnosis.

More generally the advantage of work in the field is that it can contribute to a better understanding of the phenomena under investigation. It is often said, and we have alluded to our agreement with this, that many of the behaviours investigated by behavioural geneticists are complex and often difficult to define accurately. One obvious example is human intelligence. But conversely, if, at a particular moment in time, heritability estimates for such phenomena, or components of them—for example the aspect of intelligence measured by cognitive ability tests—indicate a large genetic contribution to variability, it seems unlikely that we will be able to develop a rounded understanding without the findings of behavioural geneticists.

Disadvantages that may result from this research include the geneticisation of behaviours that may or may not be abnormal with a consequent risk of the

medicalisation of characteristics that should be seen as part of normal human variation. This is really an issue about the interpretation and use of the research. Similarly, educational efforts are needed to avoid confusion arising from the conflation of heritability estimates and individual risk estimates. In general the study of behaviour has the potential for legitimising value judgements and freezing interpretation of socially acceptable norms, which would otherwise be shifting over time. For example, some aspects of the behaviour of nobles at the court of Louis XIV were seen as entirely normal then. Today they would be seen as seriously deviant.

**4.2 *Do you think that behavioural genetics has special features?***

It has some unique features, but not such that decisions on whether to fund the work should be subject to different rules than other areas of science.

**4.3 *Should there be limits to scientific inquiry in this field?***

We do not believe there should be any artificial limits to scientific research. The issue is the use that is made of the knowledge and the impact that it has on our perceptions of those around us.

**4.4 *In your view, will research in behavioural genetics have a negative or positive impact on research into social and environmental issues?***

In our view the impact of research in this field will be determined by the interpretations given to the approach and findings of behavioural genetics as well as the political and legislative framework that controls the applications of new knowledge that may arise. In principle, behavioural genetics is committed to the view that heritability estimates are environment specific, which suggests that genetic studies cannot advance without social and environmental research, and vice-versa. The attempt by William Dickens and James Flynn (<http://www.apa.org/journals/rev/rev1082346.html>) to square the data on large generation-by-generation rises in IQ test scores with data showing a more limited role for environmental effects at a moment in time suggests that novel historical and theoretical approaches will also be needed to contextualise and define the behaviours and traits under investigation.

**5. HOW WILL FINDINGS IN RESEARCH IN BEHAVIOURAL GENETICS BE TRANSLATED INTO PRACTICE?**

**5.1 *Should genetic tests for behavioural traits and personality characteristics be developed? Why or why not? Does this apply to all types of behavioural trait?***

As the consultation document indicates, genetic testing as a part of a research programme to gain **knowledge** is likely to figure highly in the next phase of behavioural genetic research. Broadly, we think that this is a legitimate activity. In this context the difficulties are of course substantial. It is often difficult to define qualities in isolation from the context in which the behaviour occurs. For example, aggression in pursuit of a just cause may differ in quality from that exhibited in other circumstances.

Even assuming the behaviour can be adequately described there remains the difficulty of establishing significant causal links and controlling for other variables.

It is hard to be definitive about testing for the purposes of **intervention or treatment**. For single gene disorders, involving highly penetrant genetic mutations of large effect, genetic testing is an appropriate part of diagnosis and management. Testing samples from an individual who has an abnormal behaviour for the presence of gene(s) that may have contributed to their chance of developing the condition could also be of use, for some purposes more than others. On this issue we agree with the Nuffield Council's report *Mental disorders and genetics: the ethical context*: 'The Working Party concludes that genetic tests will not be particularly useful in the near future in diagnosing mental disorders with more complex causes... It is more probable that identifying genes involved in susceptibility to common mental disorders will lead to the development of more effective drug treatments.' (p. xiii). Pre-symptomatic testing is likely to be a more difficult and controversial issue. If research leads to an understanding of the many different genetic factors that raise an individual's risk for a mental disorder, for example, and new technologies allow for the rapid detection of such genes, then large populations could be tested to isolate individuals with most or all of the 'wrong' alleles. GIG's view is that we should await the findings of research before deciding such issues on a case-by-case basis. The cumulative risk for such individuals will be an important factor, as will the efficacy of preventative measures.

## **5.2 *Would the pre-natal selection of behavioural and personality traits within the normal range be morally acceptable?***

Under current UK legislation abortion on genetic grounds because of variation in normal characteristics is illegal and there is no pressure to amend the law to allow this to occur. It would also be an impractical way of achieving the desired result—a woman would have to be prepared to go through many abortions in order to secure the right combination of the many genes involved. Pre-natal interventions would have to be through pre-implantation diagnosis or through gene therapy. Given the scientific and technical constraints that would govern any such intervention it seems unlikely that this will become feasible in the foreseeable future.

However, such choices cannot be ruled out as possibilities at some point in the future. For example, while intelligence is much more multi-faceted than the skill that is measured in modern IQ tests, nevertheless scores on the latter correlate well with academic achievement, which society takes to be an important measure of abilities. Furthermore, evidence suggests a substantial genetic contribution to what is, at any moment in time, a large variation in test scores. Isolating the purported 100 or more genes involved may prove impossible, but the more important ones might be found. Without wanting to write the script for GATTACA 2, such findings allied with the ability to choose from a larger number of eggs than are currently fertilised during IVF procedures and improved methods of genetic testing could lead us into something resembling the possibilities discussed by Lee Silver under the heading 'reprogenetics'. This is the world of 'designer babies', where genetic selection, even modification, to achieve enhanced abilities is possible.

Such speculation frustrates many of the more down to earth geneticists with experience of service delivery. ‘Now even the *British Medical Journal* is at it!’ complained Marcus Pembrey recently, commenting on an article by US Bioethicist Arthur Caplan in the *BMJ* which asked: ‘The next generation: will they be designer babies?’ For Pembrey, such talk is ‘designer nonsense’, not simply because the picture painted has nothing in common with present realities, but also because the laws of genetics make such forms of selection impossible. In his view, ‘they might as well be arguing that people should be free to select babies that can walk on water.’

His point about the ridiculous character of such speculation when presented as a serious discussion of contemporary ethical issues is well made. But there is also a hint of avoiding the issue in claiming that the forms of enhancement he discusses could never happen; they could, as Silver shows. Whether they will is another matter of course—though if some people today are willing to pay for the sperm of Nobel Laureates, some interest in these, probably slightly less unreliable methods, seems inevitable.

According to Pembrey, the law of diminishing returns rules out the kinds of selection using PGD that Caplan and others agonise over. Here’s his argument on selecting against susceptibility to common diseases and for preferred extremes of normal traits:

‘There will usually be many specific gene variants (alleles) influencing each susceptibility or quantitative trait. Even the most modest shopping list will need thousands of embryos from independent eggs and sperm in order to stand a chance of getting two embryos with the preferred complex combination of alleles.

Even if the challenge of the numbers were solved, selection has an inherent problem. You can only select from what there is in the first place! The would-be parents of a designer baby would naturally want their child to have ‘fast reaction time’ alleles. To their shock and disbelief, despite his prowess at squash and her typing speeds, they don’t actually have any of these alleles. Now it is not really their baby any longer as they start on the law of diminishing returns of selecting from a selection of sperm and egg donors.’

Lee Silver’s riposte is that such arguments ignore both genetic manipulation and cloning technologies. This is how it works according to Silver:

Route 1: harvest thousands of eggs and mature outside of the woman’s body. Fertilise them all then select the best one. Then, clone many copies so that repeated attempts at implanting the same embryo can be attempted.

This might of course run into Pembrey’s objection that you can only select from what there is in the first place! Silver might well respond that with enough eggs you would have a pretty good choice. But he has a second point:

Route 2: first, generate a mass of millions of embryonic stem cells, then add the

desired DNA fragment. Test the cells and select the ones in which the DNA fragment has combined correctly, then use the nuclei of those cells to generate many copies of an embryo with the desired genes using cloning technologies.

To the sceptics, Silver adds: ‘gene replacement has already been used successfully to produce mice having thousands of specific genetic alterations, and there is no technical reason why it couldn’t be applied to human cells as well.’ All we need to do is refine cloning technology to introduce the safety valve of ensuring that we generate many copies for repeated attempts at implantation using embryos we know have the correctly inserted genes.

Will this ever happen? Probably not, and certainly not for some time yet! We are all becoming aware of the technical difficulties and simple safety issues involved at every stage in the above scenario. But such obstacles may be overcome. The question then will be: Will people want to use it, and should they be allowed? In GIG’s view the day when such decisions need to be made is some way away. The areas of research that may make such choices possible are likely to continue regardless of whether such choices are forbidden, for they have other uses. We should judge the acceptability of the decisions when we know more about the reality of the possible choices

6. WHAT ARE THE ETHICAL, LEGAL, PRACTICAL AND SOCIAL IMPLICATIONS OF THESE APPLICATIONS OF RESEARCH IN BEHAVIOURAL GENETICS?

**6.1 *What, in your view, might be the effect of research in behavioural genetics on our understanding of health, illness, disability and abnormality?***

In our view research in this area may help to refine concepts and generate greater understanding of the inter-relationships between a wide range of causal and pre-dispositional factors.

**6.2 *Is there a moral difference between the correction of a trait thought to be the result of a genetic abnormality or defect and the enhancement of that same trait for a ‘normal’ individual? If so, why?***

This question seems to suggest that a single answer may be possible. In our view the issues are too complex for generalisation and conclusions should be reached on a case-by-case basis.

**6.3 *Is the genetic enhancement of behavioural or personality traits morally different to enhancement by non-genetic means such as education or medical intervention?***

Parents make decisions about their children that affect their potential all the time. They usually make these in the context of a framework of generally accepted legal and moral codes, interpreted in the light of their own personal set of beliefs and values. These decisions are generally regarded as morally valid. We see no reason to assume that people will be either more or less capable of making similarly morally valid judgements

simply because the route being chosen is a genetic one as compared with any other course of action.

**6.4 *Are there implications of research in behavioural genetics for our general responsibility for our own behavioural and personality traits?***

This whole area is highly speculative. As regards variation within the normal range it seems unlikely that the findings of behavioural genetics will fundamentally alter our notions of responsibility or provide answers to timeless questions about free will.

**6.5 *What are the implications for criminal justice and the legal process generally of research in behavioural genetics in the areas of aggression and antisocial behaviour?***

There are two sides to this. The consultation document mentions the cases where defendants have tried, unsuccessfully, to argue that they were not responsible for their behaviour. In our view the existing legal categories dealing with diminished responsibility are unlikely to need to be adjusted in the light of new genetic information. Rather, defence counsels will have to satisfy juries and magistrates that their clients' behaviour was sufficiently determined. This may prove difficult. The flip side of the determinism argument could be a genetic version of the usual suspects, wherein the police's choice of suspects was influenced by their genetic profile. In principle this should not happen; the UK legal code has consistently moved away from the practice of intervention based on suspicion. Proof of guilt is required before the law can convict. In our view any move away from this arising from interpretations of behavioural genetics would imply an ability to determine individual behaviour more precisely than could be sustained by a knowledge of the underlying biology. Any movement in this direction would be politically rather than scientifically driven and should be opposed.

**6.6 *In your view, might research in behavioural genetics heighten or reduce discrimination, stereotyping and social discrimination between groups?***

Cavalli-Sforza has documented that 'regardless of the type of genetic markers used (selected from a very wide range), the variation between two random individuals within any one population is 85 percent as large as that between two individuals randomly selected from the world's population.' He also tells us that 'for most genes, the frequency differences between populations are nil to very slight and their contribution to the global genetic distance between populations is close to zero.' These points do not prove that in principle a number of important alleles influencing a given behaviour could not be found disproportionately in one particular group or that important gene(s) might express themselves differently in different environments. But they strongly suggest that attempts to explain existing group or population differences using genetics should be treated with extreme caution.

Following the discovery of a purported 'gay gene' some years ago, though the science was very dubious some activists celebrated their 'natural' difference and thought that it

would break down prejudice, while others feared the opposite, that it would strengthen prejudice and allow selection against them. The former championed the notion of ‘different but equal’; the latter feared that *belief in* natural difference would buttress prejudice and discrimination. In this example culture and politics played a bigger role than science. In other situations, as we have already discussed (5.1), it is possible that groups may be identified as possessing all the ‘wrong’ alleles and thus at significantly raised risk for a mental disorder say. In such circumstances, a link between the group and genetic factors might have more plausibility than in the situations discussed by Cavalli-Sforza or in the ‘gay gene’ story. However, it is equally possible that associations between group identity and genetic differences could be politically and culturally shaped, through an exaggeration of the importance of the genetic factors, either by members of the group or others.

**6.7 *What do you think will be the impact of genetic knowledge about behavioural traits on the individual, on families and on communities?***

Any answers to this question are likely to be highly speculative. Continuing the point developed above (6.6) it seems probable that the interpretations of the findings will be as, if not more important than the findings themselves.

**6.8 *How might health professionals, governments, employers, insurers, education authorities and others use genetic information concerning human behaviour?***

It is impossible to predict how information **might** be used. Because of this it is important to try and ensure that, if it **is** used the use is based on a sound grasp of the underlying science, in the context of an appropriate regulatory framework devised for the explicit protection and benefit of the individuals likely to be affected—especially where intervention or treatment is possible. In all such situations informed consent of the individual will be essential.

**6.9 *Are there any circumstances when such information should be available to third parties either with or without the consent of the individual?***

Informed consent to disclosure is an essential pre-requisite to the communication of genetic information. Genetic information relating to human behaviour is no different.

**6.10 *How can we ensure that consent to the disclosure of such information is properly informed and freely given?***

Clinical good practice would require the obtaining of informed consent and the regulatory mechanisms currently in place to ensure this should be extended and enforced to cover the field of behavioural genetics. It is possible that in some circumstances communication with third parties regarding people with learning difficulties or mental health problems may be deemed appropriate. In such cases it should not be assumed that people with these problems are incapable of making sophisticated decisions in their own right if the information is appropriately presented. Organisations such as “Change” and “People First” have examples of good practice in

drawing up materials for use with those who might easily be assumed on first glance to be incapable of sophisticated understanding or making complex decisions.

**6.11 *Given the complex and sensitive nature of research in behavioural genetics, how can members of the public best be informed about it?***

We feel there is a need for a balanced and rational debate informed by sound science and drawing on a realistic evaluation of what is technically and politically feasible in this area of research. Care needs to be taken to avoid feeding people's anxieties about outcomes that are scientifically improbable, remote in time and/or unlikely ever to come about. This is an areas where organisations like our own could contribute greatly by active engagement with the media and through national public educational programmes.

**6.12 *Do you think that research in behavioural genetics might require new codes of practice or new regulatory controls? What in your view should be the nature of such codes of practice or controls?***

Existing regulatory mechanisms, properly applied and policed provide a series of checks and balances that should stop research taking place which is either scientifically unsound or ethically unacceptable. We see no need for the development of new codes or controls specific to this field.

**6.13 *Do you think that genetic tests for behavioural traits might require new codes of practice or new regulatory controls? What in your view should be the nature of such codes of practice or controls?***

See 6.12

**6.14 *How much priority would you accord research in behavioural genetics in the competition for necessarily limited research funds?***

It is not possible to make a blanket judgement. Each proposal should be evaluated on the basis of its scientific merits, its ethical defensibility and in the light of the funds available and the competing priorities for those funds.

We would be happy to expand on any of these points if it would be helpful to the committee for us to do so.