# Chapter 13

## Selecting and changing behavioural traits

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## Introduction

13.1 In the next three chapters, we consider some of the questions that may arise if ways of identifying genetic influences on the traits or characteristics of an individual could be developed. In this chapter, we consider whether there are reasons for choosing certain types of intervention to select or change the traits and characteristics of individuals, both before and after birth. In Chapter 14 we assess whether research in behavioural genetics ought to change our conception of legal responsibility and the way in which we treat those who break the criminal law. In Chapter 15, we discuss the use of genetic testing for behavioural traits in the contexts of employment, education and insurance.

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

13.2 Before we begin, however, we need to confront a sceptical challenge, to the effect that these reflections serve no useful purpose. The basis of this challenge is that, 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, the challenge runs, if the workings of the many genes involved in behaviour are so complex that it is impossible to make any robust predictions based on genetic tests, or to design any effective interventions as a result of them, there is no point in discussing the ethics of their application.

13.3 One response to this challenge is that it does not exempt us from considering anxieties aroused by popular beliefs in this area, even if these beliefs turn out to be misconceptions. 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: the US National Sickle Cell Anemia Control Act of 1972 led to the unjustified discrimination and stigmatisation of African Americans in education, employment, insurance and the granting of licences to adopt and marry.[1]

13.4 A second response is to consider the available evidence in the field of research in behavioural genetics and to try to make realistic predictions about whether it will lead to practical applications. As we noted in Chapter 11, it is clear that, currently, very few individual genes that influence human behavioural traits in the normal range have been identified. Despite this, we need to keep in mind 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.

13.5 Hence, 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. As Barbara Katz Rothman has argued, there is reason to consider these possibilities now:

> 'The scientists quickly speak up: that isn't possible, they reassure us, you don't understand the genetics involved. Five years later, of course, that *is* possible, and then it is too late to decide whether or not to do it: we wake up to find it done.'[2]

[1] Serjeant, G.R. (1985). *Sickle Cell Disease*. Oxford: Oxford University Press.

[2] Katz Rothman, B. (1998). *Genetic Maps and Human Imaginations*. New York: WW Norton. p. 37.

13.6 As information about genetic influences on behaviour in the normal range is acquired, ways of changing the traits in question may also be developed. Such interventions could take one of three different forms: genetic manipulation; the use of medicines; or changes to the individual's environment. In this chapter, we will refer to these three categories as 'genetic interventions', 'medical interventions' and 'environmental interventions'. In discussing these, we also distinguish interventions which take place before birth from those which occur later in life. We consider the issues raised by prenatal selection in paragraphs 13.57 – 13.78 below.

## *Genetic interventions*

13.7 Genetic interventions can be of two types, depending on the cells in the body to which they are applied. Somatic gene therapy is the process of changing the genotype of an individual by modifying the DNA in the cells of their body. This type of therapy is currently being studied as a potential cure for genetic disorders such as haemophilia and cystic fibrosis. The aim is to replace, in the relevant parts of the body, the mutated DNA that causes the disease. For example, a person with cystic fibrosis might receive gene therapy that was targeted at the lungs. An individual who has received this type of gene therapy would, however, be unlikely to pass on the genetic changes to his or her children, because the therapy would not affect the cells that are important in reproduction, namely the egg and sperm cells.

13.8 The second type of gene therapy is called germline gene therapy (it is also referred to as germline genetic engineering). This involves modifying the germline cells, those cells that are transmitted to children by their parents. Thus, germline gene therapy would change not only the characteristics of the individual who received the therapy, but also the characteristics of their children and future generations. There is a general consensus that, at present, the consequences are not well enough understood for this procedure to be attempted safely, and thus that germline gene therapy should not currently be attempted.[3] Indeed, the Council of Europe (1997) *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine* states in Article 13 that 'an intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants'.[4]

13.9 Genetic interventions are still at a preliminary stage even in the comparatively less complex case of single-gene disorders. The possibility of their use in altering complex traits is still far off, but as the *Report of the Committee on the Ethics of Gene Therapy*, presented to Parliament in 1992, observed: 'We are alert to the profound ethical issues that would arise were the aim of genetic modification ever to be directed to the enhancement of normal human traits'.[5] (We consider the possibility of somatic and germline gene therapy for traits in the normal range in paragraphs 13.31 – 13.32).

[3] See 'Changing the World' in Harris, J. (1992). *Wonderwoman and Superman*. Oxford: OUP for an interesting analysis of the ethical arguments against germline gene therapy.

[4] Council of Europe (1997) *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. ETS No: 164.

[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. p. 7, paragraph 2.16.

### *Medical interventions*

13.10 It seems more likely that if new interventions aimed at changing behavioural traits in the normal range are developed as a result of research in behavioural genetics, they will take the form of drugs, or of environmental interventions such as changes in diet or in social policies. Medical interventions such as anti-depressant drugs and drugs that claim to alleviate shyness are already in use, and it may be that additional drugs will be developed that can alter normal behaviour. Predictions that there will be drugs to enhance our memories, improve our cognitive function, or change our personalities are often made when scientists, journalists and other commentators speculate on future advances. Research in behavioural genetics might lead in this direction by suggesting which genes might be the best targets for new drugs.

### *Environmental interventions*

13.11 The third type of intervention involves environmental strategies for changing behaviour. We already have some clear examples of such interventions. For example, it seems likely that improving the diet and standard of living of children also improves their IQ.[6] There is also good evidence that exposure to chemicals such as lead can adversely affect behavioural traits.[7] Other social policies such as the provision of free education and schemes such as Sure Start[8] are specifically premised on the capacity to change or enhance various traits in the population.

13.12 In paragraphs 13.26 – 13.48, we consider whether there are good reasons to prefer a particular type of intervention to change behavioural traits, both at an individual level and with regard to the wider community. Before that, we discuss two general concerns about the consequences of applying findings from research in behavioural genetics – medicalisation and stigma – that apply more generally to the research itself and the use of tests, as well as to potential interventions to change traits.

## 'Medicalising' human behaviour

13.13 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, they 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' (see paragraphs 12.10 – 12.15). Indeed, being diagnosed as at risk of disease may have a tendency to make healthy people feel ill, or feel fatalistic about their chances of survival, despite the existence of diets, life-styles or treatments to avoid the development of disease. It is possible that information about genetic factors that indicate susceptibility to a disease may make people think that the unwanted outcome is

[6] See for example Center on Hunger, Poverty and Nutrition Policy. (1995). *Statement on the Link between Nutrition and Cognitive Development in Children*. Medford, MA: Tufts University School of Nutrition and Meyers; A. F. *et al*. (1989). School Breakfast Program and school performance, *Am. J. Dis. Child*. **143**, 1234–9. Also, Ivanovic, D. M. I (2000). Long-term effects of severe undernutrition during the first year of life on brain development and learning in Chilean high-school graduates. *Nutrition* **16**, 1056–63.

[7] See for example Stein, J. *et al*. (2002). In harm's way: toxic threats to child development. *J. Dev. Behav. Pediatr.* **23**, S13–22 and Dietrich, K. N. I. (1993). The developmental consequences of low to moderate prenatal and postnatal lead exposure: intellectual attainment in the Cincinnati Lead Study Cohort following school entry. *Neurotoxicol. Teratol*. **15**, 37–44.

[8] Sure Start is a programme run by the UK Government that aims to improve the physical, social and intellectual development of babies and young children so that they can flourish at home and at school. It focuses on encouraging good health in families with young children in deprived areas and on making available other facilities such as early learning.

inevitable.[9] It has been suggested, that the word 'genetic' is interpreted as synonymous with something fixed or unchanging in Western culture, when it is used in relation to disease.[10] With regard to behavioural traits, therefore, information about genetic susceptibility might engender similarly fatalist beliefs.

13.14 As the reviews of the evidence 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: 'scientists may well identify an allele that causes a genetic predisposition to shyness, but such a discovery does not mean that shyness cannot be overcome.'[11] 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.

13.15 At the root of concerns about medicalisation is the idea that behavioural traits that have previously been regarded as 'normal' will come to be viewed as 'abnormal' or pathological. In addition, behavioural traits within the normal range may turn out to be amenable to influence by pharmacological interventions as a result of knowledge about the biological factors that affect them. Concerns about medicalisation have been expressed for many decades, for example in relation to the increasing number of psychiatric conditions that are recognised, and in the increasing use of medicines. In the era of genetic research, the fear is that the identification of the influences of genes will exacerbate this trend, encouraging the re-classification of behavioural traits as within the realm of medicine.

13.16 In some cases genetic research may indicate that a behavioural trait is one for which medical interventions are appropriate and welcome. 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. In such cases, it should be acknowledged that this 'medicalising' tendency is beneficial: the research helps to confirm the view that the individuals concerned should be perceived as ill, rather than bad, and in need of medical help, rather than discipline and punishment.[12]

13.17 However, in other cases, medicalisation may have adverse effects. One such problem is that of diagnostic spread, or the tendency for disorders to be broadly defined so that more and more individuals are caught in the diagnostic net. This tendency may arise as a result of an erroneous assumption that once a biological influence on a trait has been identified, the trait becomes the proper subject of medical intervention. Or, it may be that if medicines are developed that have an effect on a trait, that trait will come to be seen as a disorder, or something to be treated and altered.

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[9] Senior, V., Marteau, T. M. & Weinman, J. (1999). Impact of genetic testing on causal models of heart disease and arthritis: an analogue study, *Psychol. Health* **14**, 1077–88.

[10] Marteau, T. M. & Senior, V. (1997). Illness representations after the human genome project: the perceived role of genes in causing illness. In Petrie, K. J. & Weinman, J. A., editors. *Perceptions of Health and Illness: Current Research and Applications*. Reading, UK: Harwood Academic Publishers. pp. 241–66.

[11] Rothstein, M. A. (2000). Genetics and the work force of the next hundred years. *Columbia Bus. Law Rev.* **2000** (3), 371–401 at p. 383.

[12] See for example Conrad, P. & Schneider, J. W. (1992). *Deviance and Medicalisation: From Badness to Sickness*. Philadelphia: Temple University Press.

13.18 An example of this latter phenomenon is the prescription of methylphenidate (Ritalin) to children with Attention Deficit Hyperactivity Disorder (ADHD). This example is controversial because there are undoubtedly some children who have serious behavioural problems and who benefit greatly from the drug. It would be wrong to suggest that ADHD has been invented; indeed, the condition has been recognised for many decades. However, the advent of medicines that are effective in improving concentration and reducing hyperactivity is a fairly recent development. In 1999, the US National Association of State Boards of Education estimated the number of children taking Ritalin on a daily basis at between 1.3 and 2 million. The National Institutes of Health in the US has recently undertaken a study to examine prescribing practices.

13.19 Similarly, the producers of new 'anti-shyness' drugs, such as Paxil and Luvox, have been accused of applying to normal behaviour, interventions developed for pathological traits.[13] Paxil is licensed in the US for the treatment of depression, Social Anxiety Disorder (SAD), Generalised Anxiety Disorder (GAD),[14] Obsessive Compulsive Disorder, Panic Disorder and Post-traumatic Stress Disorder. The Paxil website notes that approximately 10 million adults are diagnosed with GAD each year in the US.[15] The website encourages individuals to take an online 'self-test' for GAD, which involves answering three questions:

1. Do you worry excessively or are you anxious a lot of the time?

2. Are you often bothered by the following:

- Feeling restless, keyed-up, or on edge?
- Feeling tense?
- Feeling tired, weak, or easily exhausted?
- Having difficulty concentrating?
- Feeling irritable?
- Having difficulty sleeping?

3. Would you say your anxiety or worry interferes with your work, family or social life?

Answering 'yes' to more than 1 of the complaints listed in question 2, even if the answers to questions 1 and 3 are negative, is sufficient to generate a response that says the results are inconclusive and suggests discussing them further with a health professional.

13.20 A similar self-test can also be undertaken for SAD, the key symptoms of which are a persistent fear of and an associated avoidance of social situations involving strangers. In an article in the *New York Times Magazine* about SAD, one commentator observed:

> 'until recently, it was thought to be a rare disorder ... Then in 1999, buoyed by the success of the new psychotropic drugs, the pharmaceutical company SmithKline Beecham began marketing its antidepressant Paxil as a treatment for social phobia ...

[13] See for example Koerner, B. I. (2002). First, you market the disease…then you push the pills to treat it. *The Guardian*, (30 July). taken from Koerner, B. I. Disorders made to order. *Mother Jones* magazine. July/August (2002).

[14] GAD is psychiatric disorder which features in the two main classification systems for mental illness, the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* (DSM-IV) and the ICD-10 *Classification of Mental and Behaviour Disorders*.

[15] http://www.paxil.com (17 July 2002).

> Experts cited alarming new statistics – around 13% of us were socially phobic, for example – and magazines dished up the requisite alarmist trend stories. A set of traits and behaviours, at least some of which were once regarded as neutral, or even desirable, re-emerged as a pathology – a function of brain chemistry, amenable to and indeed demanding pharmacological manipulation.'[16]

13.21 These examples can be viewed as illustrations of diagnostic spread, the re-classification of behavioural traits, and the possibility of commercial and social pressure to make use of medical interventions. While these examples are not the result of findings in genetic research, they demonstrate the existence of a tendency towards medicalisation, and corresponding problems, to which findings in genetics may contribute.

13.22 A further potential problem related to medicalisation is the tendency to focus excessively on the biological factors that influence particular traits, rather than the social or economic factors. In paragraph 3.17, we observed that those factors that are described as the 'cause' of a particular trait are often those by which one hopes to control or alter that trait. Thus, there is a risk that the role of genetic factors will be over-estimated, so that genetic and medical interventions can be provided, rather than focusing on the social and economic environments which are also likely to play a vital role. This may be so even though there is no scientific reason for assuming that if genetic influences on a trait are identified that trait will be easier to alter using medical or genetic interventions rather than other forms. Examples of this phenomenon include the risk that medicines may be prescribed for children who are disruptive but do not have a clinical diagnosis of hyperactivity, rather than investigating other approaches such as reducing class sizes, and that medication may be used rather than diet and exercise as strategies for dealing with hypertension or obesity.

13.23 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.**

13.24 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**

[16] Talbot, M. (2001). The shyness syndrome: bashfulness is the latest trait to become a pathology. *New York Times Magazine* 24 June.

**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.**

## Stigma

13.25 A rather different anxiety arises from the perception that the use of genetic tests might increase social stigma and tendencies towards the labelling of people who display the traits being tested. For example, claims that a genetic predisposition to homosexuality has been identified may give credence to the view that homosexuality is pathological, thereby increasing the stigmatisation of homosexuals, and leading to pressure for gay people to be 'cured', and for prenatal selection against 'gay' fetuses. This is illustrated in Box 13.1 below, which illustrates the public response to genetic research into sexual orientation that was summarised in Chapter 10. As Box 13.1 indicates, knowledge of a genetic predisposition may also help to reduce the stigma associated with a trait by leading to acceptance of it as 'natural'.

### Box 13.1: Public responses to genetic research into sexual orientation

Responses to research into genetic influences on sexual orientation, in particular the widely-publicised findings of Hamer and Le Vay, varied greatly even within the lesbian and gay community.* Many gay and lesbian groups seemed keen to capitalise on the trend, demonstrated in numerous opinion polls, towards increased acceptance of homosexuality if it is conceptualised as a biologically determined trait, regardless of whether or not this was shown to be accurate. However, others were more sceptical:

> 'Does your response to someone you know is gay depend on knowing why he or she is gay? Should the right to live free of discrimination depend on a biological explanation of difference? Most importantly, would finding a biological explanation make any difference in the way we perceive ourselves and each other?'†

Outside the gay community, most publicity was obtained by those who viewed the research as leading to the possibility of curing or eliminating homosexuality. The Chief Rabbi at the time spoke in favour of using the research in this way, saying that we may practise medical ingenuity to relieve suffering or a human disability.‡ (Other Jewish groups, including the Union of Jewish Students in Britain, vehemently rejected the use of genetic engineering or termination of pregnancy to eliminate homosexuality.) In 1997, James Watson published an article in a national newspaper in which he proposed that women should be allowed to abort fetuses predisposed towards homosexuality which drew similar opposition from gay and lesbian groups, journalists and other commentators.∫

* See Chapter 10 for a discussion of these findings.

† PFLAG (Parents, Families and Friends of Lesbians and Gays). (1995). *Why ask Why? Addressing the Research on Homosexuality and Biology*. (pamphlet).

‡ Chief Rabbi Lord Jakobovits, quoted in Rose, H. Gay brains, gay genes and feminist science theory. In Weeks, J. & Holland, J., editors. (1996). *Sexual Cultures*. Houndmills, Basingstoke: MacMillan.

∫ Langton, J. (1997). The genie of the gene. *Sunday Telegraph.* 16 February.

## Evaluating different ways of changing ourselves

13.26 Despite these 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. In the next section, we consider 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.

### *(i) Effectiveness*

13.27 The effectiveness of genetic interventions, which would be most likely to take the form of gene therapy, is difficult to predict. As we noted in Chapter 3, and as the reviews of the evidence reflect, genes that influence behavioural traits in the normal range are likely to exert small individual effects, which are likely to depend on the presence of other genes, as well as environmental factors. This means that, even if one could alter the expression of one or a few genes successfully, it would by no means be certain that the desired change in the phenotype would occur.

13.28 This is also likely to be true of medical and environmental interventions. Research in behavioural genetics does not suggest that pharmacological interventions are likely to be universally successful any more than environmental interventions, such as changes in parental care, diet, methods of education, social pressures, economic conditions and so on. The fact is that predicting the likely effectiveness of different types of intervention is a difficult task. For example, many commentators have argued that if we wish to enhance children's IQ scores, it is their environment rather than their genotypes that we should be seeking to affect. But our ignorance of the ways in which genes affect IQ is matched only by our ignorance of how the environment affects IQ. It is clear that environmental changes must have contributed to the 20–30 point rise in scores on standard IQ tests that occurred in the twentieth century (see Chapter 7, footnote 3). But we do not know which environmental changes. It seems probable that there were a large number, each with a small effect (changes in nutrition and general health, different styles of education, more emphasis on problem solving and more exposure to sophisticated visual messages, have all been suggested). Furthermore, the belief that it will be a simple matter to alter the environment in such a way as to increase children's IQ scores is just as fallacious as the converse belief that genetic effects are immutable. One intervention that has been shown to produce a substantial increase in the IQ scores of children living in poverty and neglect is to have them adopted.[17] But this can hardly be translated into social policy.

### *(ii) Safety*

13.29 At first glance, it might be thought that environmental interventions are the safest form of intervention, in the sense that they seem least likely to have unpredicted or undesirable consequences. However, it should be noted that changes in an individual's psychosocial environment can have adverse results that persist throughout his or her life.

[17] Duyme M. *et al.* (1999). How can we boost IQs of 'dull children'?: a late adoption study. *Proc. Natl. Acad. Sci. USA* **96**, 8790–4.

13.30 Medical interventions raise issues of safety because of the potential side-effects and adverse events that may be related to the use of a particular drug. The regulatory system for licensing medicines and the systems for warning individuals about potential risks will, of course, also apply to new drugs developed as a result of research in behavioural genetics. Nonetheless, it is important to note that adverse reactions to drugs are one of the leading causes of death in the developed world. One serious concern is that, once medical interventions are provided 'over the counter', without prescription, and perhaps fall outside the statutory regulations of medicinal products, in the way that some complementary therapies currently do, there may be risks of mis-selling and misleading marketing. We discuss this further in paragraphs 13.49 – 13.56 below.

13.31 Genetic interventions currently bring with them serious concerns about safety. 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'.[18] The Clothier Report on the ethics of gene therapy identified a number of ways in which gene therapy might pose a risk to safety.[19] 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 GTAC.[20] 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**.

13.32 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**.

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

[19] 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.

[20] 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).

### *(iii) Reversibility*

13.33 An important question concerning any intervention is whether or not it is reversible, since there may be unwanted side effects or other undesirable consequences, and because individuals affected by an intervention may themselves change their minds about the desirability of its effects as social trends and practical circumstances change. Genetic interventions may be difficult to reverse, even when they are not targeted at stem cells, and as such, their use in the context of traits that are not regarded as diseases, and which might be influenced by other forms of intervention, ought to be viewed with caution. The effects of medical interventions are often more easily reversible because the effect of a drug will usually wear off once it is no longer being ingested. The reversibility of environmental interventions is difficult to assess. It seems plausible that some interventions that take place early in a person's development may not be reversible in later life. The degree of reversibility of the effects of an intervention will be particularly important in considering whether an intervention is appropriate for a child, or someone unable to give consent.

### *(iv) Choice*

13.34 There are three ways in which the idea of individual choice is relevant here. The first, as we have just noted, is that individuals should be able to exert their autonomy with regard to the use of an intervention. This has implications for the use of interventions in infancy and childhood, and for interventions that may be applied to society at large, rather than to an individual. On the one hand, environmental interventions often benefit all the individuals in a particular population, whereas medical interventions would only benefit those identified as requiring the intervention, and such targeted interventions risk stigmatising the individuals receiving them. But, on the other hand, it may be harder for individuals to avoid an environmental intervention if they do not wish to make use of it. Examples of this problem can be seen in the debates about fluoridation of the water system or the systematic addition of folic acid to bread.

13.35 The second way in which the notion of choice is engaged is the possibility that there will be reduced tolerance for differences and increased pressure towards the cultivation or acquisition of traits that are perceived to be desirable within society. Familiar examples of this tendency (not based on the results of genetic research) include social pressures on individuals to make use of cosmetic surgery, cosmetic orthopaedics (the use of orthopaedic surgery to lengthen the bones in the legs), skin lightening and other processes to make individuals more beautiful, taller or Caucasian-looking. One can readily envisage similar pressure to use genetic tests, were they to become available, to help design medical interventions to eliminate 'unattractive' personality traits. In this way, individuals may feel obliged to make use of particular interventions. This seems a potential hazard in the case of any type of intervention.

13.36 The third aspect of choice that is important relates to the effect of genetic tests on an individual's self-perception. Genetic tests for intelligence or sporting ability might increase pressure on a person to develop an aspect of their personality for which the test is positive, or close off the possibility of enjoying an activity for which they are led to believe they are 'biologically unsuited'. In such cases, the tests could in fact only suggest malleable predispositions; but given the likelihood of their misinterpretation by parents as indications of their children's talents, any use of such tests would need to be very carefully introduced, controlled and monitored. Indeed, even now, in the case of disease or disorder, medical geneticists are usually reluctant to test children for genetic conditions for which they may

be pre-symptomatic and for which no early interventions exist.[21] If this is the case with non-behavioural or personality-relevant conditions, then there are even stronger reasons for caution when it comes to intelligence and personality where a diagnosis of predispositions might be misunderstood by parents or children themselves.

### *(v) Intervention and individuality*

13.37 It has always been acknowledged that achievement is related partly to factors outside an individual's control, such as accident of genetic endowment, privilege of birth and opportunity. But these factors alone are not sufficient to guarantee success in most fields. In order to be a first-class athlete, or to win a first-class degree, the individual has to work hard, to train the body or brain, and to master complex techniques and memorise information, among other skills. One anxiety concerning the future is that genetic and medical interventions might substantially replace the effort of an individual in achieving such goals. At present, of course, the possibility of such interventions is the stuff of science fiction and it is therefore difficult to assess and evaluate these hypothetical products. But what one can say is that if almost anyone might be helped by these techniques to achieve what are now regarded as remarkable results, the techniques would undermine the significance of these results as individual achievements.[22] As Parens has observed, 'in many valued human activities, the means of acquiring the capacities required for the activity are a part of the very definition of the activity, and transforming them transforms, and can devalue, the activity itself.'[23] This is one of the concerns that underlies disapproval of the use of drugs in sport.[24] It is of course also possible that even greater achievements might become possible through a combination of these interventions and individual effort and skill. But commercial pressures to exploit these possibilities would need to be resisted so that the value of these achievements could be judged carefully in each case.

13.38 Similarly, in the case of psychiatric disorders, it is sometimes argued that the use of medicines rather than other forms of therapy reinforces the tendency to think of ourselves in mechanistic terms, undermining our conception of ourselves as responsible agents. But this case is much less convincing than that envisaged above. Drugs do form an important and effective part of the treatment of psychiatric disorders, and if genetic tests indicate a predisposition to such disorders which might be prevented from having an effect by taking suitable drugs, it is hard to see what is wrong with such a course of action. There is little merit in the argument that a human life must involve suffering or lack of fulfilment where this could be averted by some intervention, only because this intervention is quicker or easier than some alternative.

13.39 How does this argument translate in the case of behavioural traits in the normal range? One might argue that it would not only be wrong to inhibit people making use of such interventions, but that there are reasons to encourage their use. It is not immediately obvious why it would be a bad thing if people were generally less likely to exhibit antisocial

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[21] Clarke, A. The genetic testing of children. In Marteau, T. M. & Richards, M., editors. (1996). *The Troubled Helix*. Cambridge: Cambridge University Press. The Nuffield Council on Bioethics has recommended in earlier publications that predictive genetic testing of children in such circumstances should not be permitted. (Nuffield Council on Bioethics (1993) *Genetic screening: ethical issues* and (1998) *Genetics and mental disorders: the ethical context*).

[22] In addition, if everyone has the capacity to achieve certain goals, the advantage of attaining those goals may be lost. If everyone becomes more intelligent, then one individual's increased IQ score will not advantage him with respect to others.

[23] Parens, E. (1998). *Enhancing Human Traits: Ethical and Social Implications*. Washington, DC: Georgetown University Press. p. 52.

[24] See, for example, Radick, G. Discovering and patenting human genes. In Bainham, A., Day Sclater, S. & Richards, M., editors. (2002). *Body Lore and Laws*. Oxford: Hart. pp. 289–307.

behaviour, or more likely to be of high intelligence. As they get older, most people would welcome a way of maintaining their ordinary capacity for memory.[25] Assuming such traits could be enhanced in existing people without undesirable side effects or implications for genetic diversity, would it be wrong to aim at such goals? It could be argued that a general increase in intelligence would not, in fact, increase happiness or provide social benefits. But this gloomy prediction does not accord with our current social practices that aim to provide more education for individuals, to develop their cognitive abilities and so forth.

13.40 One way to think about the difference between interventions targeted at disorders, such as depression, and those interventions speculatively envisaged in this section, is that the former are primarily intended to help people overcome handicaps which prevent them from making the most of themselves, whereas the speculative interventions are supposed to make it easy for people to achieve results that are now only available to a few especially talented individuals. This difference is a case of a general distinction between therapy and enhancement; and, just as in the case of the interventions discussed here, there is a widespread view that whereas therapeutic interventions are generally valuable, the possibility of enhancement is more problematic, giving rise to, for example, questions of fairness where it is of limited availability. So we turn now to discuss this distinction and its significance.

*Therapy versus enhancement*

13.41 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. The distinction between health and disease is of course evaluative. Nonetheless, we largely agree on what counts as a disease and on the idea of an illness resulting from a failure to function properly. So, most medical care is therapy, concerned with the prevention, treatment or cure of disease. By contrast, for example, cosmetic surgery which simply aims to alleviate some of the manifest effects of ageing is enhancement.[26]

13.42 The distinction between therapy and enhancement is often used to justify a distinction between interventions which merit public support and those which do not. 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. In some respects, this principle needs qualification. Where resources are scarce, it may well be impossible to provide effective public support for therapies; equally, as later discussion will show (paragraphs 13.44 – 13.48), there may be enhancements which are such that, if they are permissible at all, they should be available to all. Nonetheless, the principle which associates the distinction between therapy and enhancement with that between public and private provision is a useful starting-point in this area.

[25] There is some evidence that the anti-Alzheimer drug Aricept can be used to enhance memory, though it has disagreeable side-effects. Yesavage, J. A. *et al*. (2002). Donepezil and flight simulator performance: effects on retention of complex skills. *Neurology* **59**, 123–5 (and see BBC News. 8 July 2002. *'Smart drugs' boost pilot memory*. http://news.bbc.co.uk/hi/english/health/newsid_2116000/2116476.stm. (9 August 2002)).

[26] There is an extensive literature on the definitions of and differences between health, disease, disorder and illness. An interesting analysis in the area of psychiatric disorders is provided in Fulford, K. W. M. (1989). *Moral Theory and Medical Practice*. Cambridge: Cambridge University Press.

13.43 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 the basic principle affirmed in the previous paragraph implies that 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.

## Access to interventions

13.44 Genetic tests and interventions which lack any therapeutic application and are designed to enable individuals to enhance their capacities within the normal range provide the context for the issue raised in paragraph 13.42: who should be able to make use of tests and interventions? 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, these interventions should not normally be provided as part of a public healthcare system. Nonetheless, it may also be argued, within a free society and a free market, these techniques should be available for purchase.

13.45 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. In particular, where not everyone has access to these interventions, equality of opportunity is threatened. One theory about the likely effects of such polarisation was postulated by Lee Silver in his book *Remaking Eden*.[27] In Silver's futuristic scenario, advances in diagnosis and reproductive technology enable those who can afford such services to produce children who have greater skills and talents. He postulates that over time, society will segregate into the 'GenRich' who control the economy, the media, and the knowledge industry, and the 'Naturals,' who work as low paid service providers or as labourers. (It may be observed that this scenario is not dependent on genetic enhancement; arguably, it has always happened, as a result of inequitable distribution of other inherited resources such as wealth, except in so far as the modern state has intervened to promote equality of opportunity).[28]

13.46 The implication of these considerations is that a society which values equality of opportunity will ensure that genetic tests and interventions to enhance important behavioural traits, such as intelligence, should either be made freely available to all or limited to special cases not dependent on private wealth. In both cases, as a history of the NHS in the UK shows, it may well be that financial barriers to access are not the only ones; there may be geographical, institutional and cultural barriers that need to be given active consideration. For without some active engagement to break down these barriers, it could

[27] Silver, L. (1998) *Remaking Eden*. London: Weidenfeld.

[28] Martin Richards has identified other problems with Silver's theory. See Richards, M. Future bodies: some history and future prospects for human genetic selection. In Bainham, A., Day Sclater, S. & Richards, M., editors. (2002). *Body Lore and Laws*. Oxford: Hart. pp. 289–307.

be that a society divides, not into Silver's 'GenRich' elite and a 'Natural' majority, but into a talented majority and a 'Natural' (or 'GenPoor') minority underclass.

13.47 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. For the egalitarian, if these resources are not available, then the tests and interventions should not be introduced at all. But there is a powerful libertarian counter-argument which draws on the existing patterns of investment in the future of children by those who pay for private schooling, tennis coaching or French lessons. 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, in the context of what might be termed 'desirable' traits such as increased intelligence, it is simply wrong to 'equalise downwards' by banning a particular intervention. 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. As Ronald Dworkin argues:

> 'We should not … seek to improve equality by levelling down, and, as in the case of more orthodox medicine, techniques available for a time only to the very rich often produce discoveries of more general value for everyone. The remedy for injustice is redistribution, not denial of benefits to some with no corresponding benefits to others.'[29]

13.48 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.**

## Monitoring the provision of genetic tests and interventions

13.49 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.

[29] Dworkin, R. (2000). *Sovereign Virtue: The Theory and Practice of Equality*. Cambridge, MA: Harvard University Press. p. 440.

13.50 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. 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*.[30] 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. The ACGT noted that it would be necessary to review how successful the voluntary system proved to be, and to consider recommending 'a more rigorous statutory regime' if necessary.

13.51 The remit of this code of practice was restricted to tests for genetic disorders, and did not include tests for traits in the normal range. Some of the code's requirements are pertinent, including the need for verifiable external quality assurance and control of laboratories conducting the tests and the importance of protecting the confidentiality of the data obtained. However, we consider that the issues raised by tests for behavioural traits and other traits that exhibit normal variation 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.

13.52 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.[31] 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.

13.53 **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 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.**

[30] 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.

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

13.54 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? It is useful here to consider the types of intervention separately. In the case of genetic interventions, we have already noted (paragraph 13.31) that the use of gene therapy will be regulated by the GTAC.

13.55 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**.

13.56 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

### *Technologies for prenatal testing and selection*

13.57 The speculative interventions discussed so far are generally applied to those already born (although many environmental and medical interventions can affect fetuses, and it is possible that gene therapy could be carried out *in utero*). In the last section of this chapter we consider a different type of intervention that affects the traits of an individual, not by altering them but by selecting them in advance. One such intervention is prenatal testing, which has been practised on clinical grounds for thirty years in the UK. Techniques such as serum screening, ultrasound scanning and amniocentesis are in widespread use to detect pregnancies affected by Down's syndrome, spina bifida or other abnormalities, in order to offer couples early information on the pregnancy. Many couples opt for termination of pregnancy if abnormalities are detected. These techniques are known as prenatal diagnosis (PND).

13.58 A second intervention has been developed over the last 15–20 years, in which the process of *in vitro* fertilisation (IVF) has been coupled with embryo biopsy. Fertilisation of eggs by sperm takes place in the laboratory. Embryos are allowed to grow to the eight-cell stage, at which point one or two cells are removed for genetic testing. The remaining cells of the embryo still have the potential for normal development. Having tested each embryo, doctors can offer prospective parents the choice of which embryo is reintroduced. This technique is known as pre-implantation genetic diagnosis (PGD). In the UK, stringent

regulation of this technology by the Human Fertilisation and Embryology Authority (HFEA) means that it is only currently offered to families affected by inherited disorders such as Duchenne's muscular dystrophy and cystic fibrosis.[32] PGD means that parents can ensure that their child does not have these serious diseases, but avoid the termination of pregnancy, a process which is emotionally or morally unacceptable to many people.[33] The benefits of PGD over PND are that the outcome is a healthy pregnancy, rather than termination of an established pregnancy accompanied by the need to start again at conception. The disadvantage is that IVF is an intrusive procedure, which may have to be carried out on numerous occasions before a successful pregnancy is achieved. There are, however, difficulties in obtaining funds from health authorities for IVF, so in practice it is provided largely by the private sector in the UK.

13.59 Another, largely theoretical, approach would 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.[34] The use of PGD and sperm sorting are just two technologies that have generated concerns about so-called 'designer babies' (see Box 13.2).

### Box 13.2: '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 word 'design' can connote a *purpose*, a *plan* or the idea of *fashion design*. The use of the phrase 'designer babies' in the media and public debate confuses these three aspects of the term. Understood in the third sense listed, that of fashion, the phrase 'designer baby' could refer to a general process in which babies are valued for what might be thought trivial reasons, such as hair or eye colour. This would be a 'designer baby' in the sense that it exemplifies the values of a

[32] Recently, this was extended to allow the parents of a child with a serious blood disease to select an embryo that did not have the same condition and which had been tissue-typed to ensure that it could be a matched donor of bone marrow cells to its sibling. The HFEA announced on 13 December 2001 that PGD and embryo selection would be allowed in order to ensure the birth of a child without a genetic disorder who would be a matched donor for a sibling. The way in which this decision was reached was criticised by the House of Commons Select Committee on Science and Technology. (House of Commons Science and Technology Committee. (18 July 2002). *Developments in Human Genetics and Embryology*. Fourth Report of Session 2001–02. London: HMSO). The HFEA subsequently rejected an apparently similar request from a family whose child suffered from a rare condition called Diamond Blackfan anaemia. Their application was turned down on the grounds that the embryos were at no increased risk of having the condition: the use of PGD and tissue typing would be purely for the benefit of the existing child, and was not necessary to ensure the health of the implanted embryo. This ruling contradicted the advice of the HFEA's own Ethics Committee which took the view that there was no moral distinction between the two types of case (Ethics Committee of the HFEA. (November 2001). *Ethical Issues in the Creation and Selection of Preimplantation Embryos to Produce Tissue Donors*).

[33] PND, which can lead to the selective termination of pregnancy, can be distinguished from PGD, which involves the selective implantation of embryos. Because abortion is an invasive procedure often associated with distress, it might be suggested that PND on non-clinical grounds is less likely to become widespread than the less traumatic process of PGD.

[34] It is possible to take selection back yet another stage: there is a phenomenon important in research in genetics called 'assortative mating', which refers to the fact that people often choose partners who have similar traits (see paragraph 9.12). For example, there is a positive correlation as high as 0.47 between husbands and wives on IQ scores (eg. DeFries, J. C. *et al*. (1979). Familial resemblance for specific cognitive abilities. *Behav. Genet*. **9**, 23–43), though correlations for other personality traits are much lower. Whatever the precise correlations, the fact remains that people do choose who to have children with, and these decisions may in part be based on characteristics such as appearance, intelligence and personality. Thus, the philosopher John Harris has argued that all decisions to have a child involve selection: natural conception is not a random exercise.

consumer society and an unhealthy focus on unimportant, frivolous characteristics. An alternative use of the term 'designer baby' has been to refer to a child whose characteristics have been deliberately chosen, rather than left to chance, such as the recent cases of embryos being selected in such a way that their cord cells can be used to provide donor cells for a sibling.* This use of the term misleadingly implies that particular characteristics of a child are being manipulated or engineered. In reality, the only techniques currently available are the selection of gametes before fertilisation, of embryos before implantation or selective termination of pregnancy. These techniques are all examples of the selection or choice of alternative options rather than the actual manipulation or design of babies. There is a third potential use of the phrase 'designer baby', which refers to the possibility of truly designing a child, by choosing characteristics from a menu of possibilities to create a child, for example using gene therapy, but this notion is still in the realms of science fiction.

* For example: *The Sun* (11 April 2002). A designer baby would end our heart ache; *Guardian* (23 February 2002). Designer baby gets the go ahead; *The Times* (25 February 2002). British couples queue up to have 'designer' babies; *Independent* (24 February 2002). Five more designer babies on way in UK.

13.60 Before discussing the ethical arguments surrounding use of prenatal selection by PND or PGD, it is important to emphasise points made earlier regarding the practical difficulty of selecting for behavioural traits using these technologies. Because of the multiplicity of genes involved, a very large number of embryos would need to be screened before the desired 'chance' combination of genes was obtained. Indeed, given that the available genes will depend on the genotype of the parents, it may not be possible to find the 'ideal' combination. Currently, IVF tends to produce, on average, only about four to five embryos for each couple undergoing treatment.

## *Selection on non-clinical grounds: ethical arguments*

13.61 The forms of selection outlined above are currently only practised on clinical grounds in the UK. However, the start of a trend towards selection on other grounds can be identified. The recent decision by the HFEA to allow the selection of embryos free from genetic conditions that can also act as donors to existing siblings is an important move in this direction.[35] Another relevant example is sex selection. In the UK, PND and PGD can be used for sex selection if it is necessary for clinical reasons, for example to avoid the birth of a child with an X-linked genetic disease. However, there is a policy of not offering sex selection on non-clinical grounds using PGD or PND. In the US, the Ethics Committee of the American Society of Reproductive Medicine concluded that PGD should not be initiated for purposes of sex selection, and that PGD for sex selection during IVF treatment should not be encouraged.[36] A complex set of concerns underlies such policies, involving the ethics of terminating healthy pregnancies, the need to accept offspring for themselves and not their particular characteristics, tendencies in some societies to favour male rather than female offspring, and the limited availability of genetic services.

[35] See footnote 32 above.

[36] Ethics Committee of the American Society of Reproductive Medicine. (1999). Sex selection and preimplantation genetic diagnosis. *Fertility and Sterility* **72**, 595–8.

13.62 Recently, some commentators in the US have called for this policy to be reassessed and for the possibility of sex selection of gametes to be reconsidered in certain circumstances.[37] In the UK, 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.

13.63 There are numerous companies in the US that offer infertile couples the opportunity to purchase donor sperm or eggs. Donors with a few common genetic or infectious diseases are excluded, although some genetic risk remains nevertheless. Some information about various characteristics of donors is made available to prospective parents, including eye, hair and skin colour, so that parents can aim to have children who bear some physical resemblance to them. In the UK, couples requiring donated sperm are able to make use of similar information to provide a means of matching the characteristics of the donor to that of the husband. However, it has been suggested that private fertility clinics in the UK may allow couples to 'select sperm donors who bear little resemblance to themselves', in particular, donors who have 'desirable' characteristics.[38] The *5th Code of Practice* of the HFEA does not explicitly state that parents may not select 'desirable' traits when choosing a gamete donor.[39] It only states, in section 3.18, that 'centres should take into account each prospective parent's preferences in relation to the general physical characteristics of the person providing gametes for donation.' Preventing the selection of gametes based on non-clinical features, whether physical characteristics or behavioural traits such as intelligence or personality would therefore require new guidance.

13.64 In the US, most companies also provide information about the educational qualifications of donors and even their grades on school and college examinations. Some individuals who regard themselves as 'high achievers' have subsequently sold or given away their sperm on the internet. The most famous sperm bank of this kind was the Repository for Germinal Choice, which operated from 1980 to 1999. It collected sperm from people of high intelligence, including a number of winners of the Nobel Prize and the Field medal, a prestigious award in mathematics. Men of high intelligence who had family histories of serious genetic disease or disorders such as schizophrenia were excluded. Women purchasing the sperm were excluded if they were unmarried, unhealthy, over the age of 40 or had criminal records. Another group that received considerable publicity is Ron's Angels, which offers donor eggs and sperm from attractive men and women. The company's website asks, 'If you could increase the chance of reproducing beautiful children and thus giving them an advantage in society, would you?'[40]

13.65 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-

[37] Robertson, J. A. (2001) Preconception gender selection, *Am. J. Bioethics* **1**, 2–9.

[38] Calvert, J. & O'Reilly, J. (2002). Babies-to-order raise 'eugenic' fears. *The Sunday Times*. 21 July.

[39] Human Fertilisation and Embryology Authority. (2001). *Code of Practice*. 5th Edition.

[40] Ron's Angels. Egg Auction. 2000. http://www.ronsangels.com/auction.html (16 Jul 2002). The website states that the company has generated an income of $3.2 million in sales since 1999.

**Box 13.3: Views about prenatal selection expressed by respondents to the public consultation**

'We have grave concerns regarding prenatal testing for any trait other than in untreatable genetic disorders that normally result in death.'

*Royal College of Psychiatrists*

'We need a wide variety of behaviours, personalities and temperaments if human society is to adapt to the changing circumstances we find ourselves in. Variety is the spice of life, and it is also essential for evolution.'

*Grant Vallance, PhD student, Open University*

'in an increasingly autonomy-oriented climate, it may be impossible to draw firm lines against such selection ... Use of law to prevent such selection is the worst possible alternative, because it opens the door to other restrictions on people's decisions about reproduction.'

*Professor Dorothy C Wertz, University of Massachusetts*

clinical characteristics (Box 13.3 contains examples of responses to the Working Party's public consultation that address this issue). **In the case of 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.**

13.66 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. In the final part of this chapter, we attempt to evaluate this position.

## For selection

*(i) The right to proceative autonomy*

13.67 The main argument in favour of the permissibility of selection is that this is a legitimate exercise of individual liberty. There is, quite generally, a strong presumption in favour of the exercise of individual liberty wherever its exercise does not conflict, directly or indirectly, with the legitimate interests of others. This presumption is especially powerful when the activity in question lies within what is normally the sphere of private life, as the conception of children clearly does. For, on the one hand, within this sphere it is hard to see how others are harmed by what is done; and, on the other hand, intimate matters of

this kind matter greatly to those directly concerned, so that it is all the more important and difficult to justify any interference in them. Hence, the liberal position is sometimes described in terms of the existence 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.[41]

## Against selection

*(i) The 'expressivist' argument*

13.68 One 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. Many advocates of disability rights use this 'expressivist' objection to oppose selection on clinical grounds, arguing that termination of pregnancies affected by disability signals that disability is unacceptable or that disabled people are inferior.[42] In the case of behavioural genetics, if parents used selection to avoid the birth of babies carrying alleles associated with homosexuality, for example, this might reflect and reinforce prejudices such as homophobia. Selection for higher intelligence or sporting prowess might be thought to similarly devalue others who did not possess these traits, or whose parents could not afford to invest in selection techniques. However, this argument does not seem particularly strong in the case of non-disease traits. By definition, most of the traits in question are possessed in some degree by everyone and many of them, such as higher intelligence, are already valued widely in society and aimed at through educational programmes and other social policies. So it is hard to see why permitting selection on the basis of genetic predispositions in favour of enhanced abilities within the normal range, if it were possible, should be thought to 'express' a specially worrying evaluation of these abilities which is not already manifest in social practices.

*(ii) Equality*

13.69 We have noted previously (paragraphs 13.44 – 13.48) that the introduction of interventions based on genetic tests which aim to enhance abilities within the normal range poses a threat to the equality of opportunity. Does the same anxiety apply here? Since prenatal selection is the issue, it is not clear that it does: for a child who is conceived and born without any method of selection is not someone who has been deprived of an opportunity for enhancement that has been made available to a child whose conception has made use of methods of selection such as PGD. In this context, the method involved is one that selects for different people, rather than enhancing the abilities of a given person. Nonetheless, egalitarian anxieties do have a genuine basis: 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

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

[42] This concern can be seen as arising from the eugenic programmes we discussed in Chapter 2, in which people without desirable traits were devalued and abused.

there is no reason why the latter should welcome the creation of a larger and correspondingly more powerful elite.

13.70 The conclusion to be drawn, therefore, is that the introduction of PGD as a method of prenatal selection does provide grounds for egalitarian anxieties; but also that if one assumes a background social and political system in which anti-elitist egalitarian values are already well entrenched, it should be possible to accommodate prenatal selection without any great resulting unfairness. Hence, the judgement in any particular case as to whether there is a significant egalitarian objection to prenatal selection depends on whether egalitarian values are already well established in the social and political context in question.

*(iii) Natural humility*

13.71 The intuitive objection to prenatal selection is that it is 'interfering with nature'. By itself this is no argument, since all medical interventions involve some such interference. But the 'conservative' opponent of prenatal selection will argue that the kind of interference involved in prenatal selection undermines the proper relationship between parents and their children. For by inviting parents to exercise their preferences in making a selection it introduces an element of control over the result of conception which makes the experience of parenthood very different from the present situation in which, in the majority of cases, parents are happy just to take their children as they find them. One might compare the present situation to that of eating at the kind of family restaurant which used to be common, where there is no menu and one simply takes what is given; and then compare the envisaged use of prenatal selection to eating at a restaurant where there is a menu from which one can make a selection (and send back a dish if it was not what one ordered). Just to make this comparison, of course, is not to provide an argument; and 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' (see paragraph 13.67 above).

13.72 One attempt to do so has been made by Deena Davis, who deploys Joel Feinberg's argument that children have a right to an open future.[43] This concept was developed by Feinberg in relation to existing children, to explain that they had rights which they were not capable of exercising but which should be 'held in trust' for them until they were fully autonomous individuals. Until that point, anything that reduced the child's available options and eliminated opportunities for it to make its own choices could be said to infringe its right to an open future. If this argument is transferred to prenatal selection, it might suggest that choosing traits – from sex to enhanced abilities – narrows the options for that child. The obvious difficulty with this argument, however, is that it mischaracterises the parental choice: for it is a choice between different possible children and not one concerning different abilities which one and the same child might have possessed. So it is not true in a straightforward sense that prenatal selection 'narrows the options' for a child.

13.73 Nonetheless, it can be argued that what is wrong with prenatal selection is that it restricts a child's freedom by the pressure it places upon a child to fulfil the hopes and wishes of the parents which guided their decision to select that child for implantation rather than the other embryos that were available. People who want a male child so strongly that they resort to prenatal selection techniques may well seek to bring up their

[43] Davis, D. S. (2001). *Genetic Dilemmas*. New York: Routledge.

son to conform to a stereotyped gender role. It can be objected that one should distinguish the selection of an embryo from what parents do to the resulting child once he or she exists. There is no reason to assume that parents, having selected a child, would necessarily place pressure on the child or treat him or her in an undesirable way. However, if people care so strongly about a trait that they are willing to select for it, it is perhaps to be expected that they will rear the child in a stereotypical way or place pressure on the child and be upset if he or she does not fulfil the aspirations for which they have selected.

13.74 The conservative opponent of prenatal selection holds that this kind of parental pressure is a symptom of the changed relationship between parents and children which prenatal selection will motivate. At present, parents accept their children as they find them in an attitude of 'natural humility' to the unchosen, or chance 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. When we fall in love as adults we exercise some degree of choice in selecting our partner, the person we love. But parental love for children does not include a similar element of choice and it would be very destructive of it if it were to do so.

13.75 Natural humility is entirely compatible with the familiar parental aspiration, which is indeed another element of parental love, that one should do what one can to enable one's children to make the best of themselves by overcoming natural weaknesses and developing natural abilities by means of education, encouragement and so on. Involvements of this kind, however, are not attempts to ensure a specific future for a child. Not only are such attempts likely to fail, thereby leading to resentment or a sense of failure or both; more importantly, they manifest a failure by parents to understand that parental love requires the respect which gives children the opportunity to frame their lives for themselves in accordance with their own abilities and aspirations.

13.76 For the conservative, 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 with the practice of prenatal selection which seeks to identify, as a basis for choice, genetic predispositions for enhanced abilities or special 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.

13.77 For the conservative, therefore, the advocates of prenatal selection in the name of the right to procreative autonomy fail to take account of the value inherent in our present attitude of natural humility, which informs the loving relationship between parents and children. They urge that in this most intimate area of personal life we should seek to curb our will to control.

13.78 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 conservatives and the liberals. In particular, it may be that the contrast between the liberal's affirmation of a right to procreative autonomy and the conservative's 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**.