CHAPTER 1

A recovery of virtue for the ethics of genetics

Why is there so much interest in ethical issues in genetics compared with other areas of science? What form does this ethical discussion take, and what might be the contribution of theological ethics to this discussion? This chapter attempts to set out the scope of ethical discussion in genetics, and to offer a commentary on its development in the light of the particular position being argued for in this book, namely the relevance of a theologically informed virtue ethics. Genetics, especially human genetics, intuitively seems to equate with our distinctive nature as individual humans, but it also reaches out beyond this to wider social and political questions. Therefore it is not just relevant for individual ethics, or ethics in a family setting through the new reproductive technologies; it also reaches out to significant issues of public and political concern. In facing such diverse issues, the temptation for medical science is to resort to a case-by-case approach and to rely simply on ethical principles such as patient autonomy and informed choice. Yet it is clear that the practice of medicine is itself being reshaped by the new genetic technologies, changing the ethos of medicine, with social and political repercussions, far beyond the limits of medical science. I will argue in this chapter for a recovery of prudence, or practical wisdom, alongside the other cardinal virtues of justice, fortitude and temperance. I will also suggest that the classical understanding of these terms offers fruitful avenues for exploration in the light of particular issues raised by contested issues in genetics. While I argue that these virtues have relevance for decision making by individuals and communities, in the specific instance of the Christian community they need to be understood as fully integrated with the theological virtues of faith, hope and charity.

WHAT IS GENETHICS?

Biomedical ethics is a field that has grown up and transformed itself from a discipline that was once loosely based in Christian morality to one that is

more akin to a specialist science. Biomedical ethics has more often than not looked to the principles of respect for beneficence, autonomy, justice and non-maleficence, bringing in a discussion of the virtues almost as a way to supplement these pre-supposed principles.[1] Genethics overlaps with bioethics in that it raises similar issues connected with the start of life, but it is also even broader than bioethics in that it includes research in genetic science and its practice even prior to clinical applications. The scope of ethical discussion, among theologians at least, has tended to limit the ethical analysis of genetics to those areas connected with reproductive biology, rather than considering in more depth those wider medical practices that rely on genetics that have social and political implications, such as genetic screening, gene patenting and feminist concerns. There is also a tendency to focus on emotionally charged debates about the status of the embryo and avoid considering broader ethical questions. Those who adopt the most conservative stance, equating the beginning of personhood with the moment of conception, view more liberal gradualists as trivialising the dignity of embryos or, worse, as murderers. On the other hand, gradualists who perceive personhood as emerging later in embryonic development view conservatives as judgmental or, worse, as self-righteous and legalistic. Neither caricature need apply, but such undercurrents lead to suspicion and stalemate in ethical discourse. Conversation is no longer possible within such entrenched positions.

The boundary between an ethics of genetics and bioethics is hard to define, and it is certainly not appropriate to draw too rigid a line in delineating the scope of ethical analysis. Broadly speaking, where there is the possibility of a treatment that uses the results of fundamental knowledge in genetics, or where a change is brought about because of a change in genetics, then this could be thought of as relevant for consideration. There are grey areas, such as the ethics of human cloning and of stem-cell research. In these cases, both the replacement of the egg nucleus by a nucleus that has a different complement of genes, as in cloning, and the analysis of environmental influences that lead to a change in gene expression, as in stem-cell research, can be considered as arising out of genetic knowledge. There may be other situations where genetic knowledge might be indirect, but they would not be perceived as falling within the scope of genetics and ethics. There are more obvious cases of ethical issues in genetics, such as deliberately changing the genetic makeup of a living person, or gametes or

[1] See Beauchamp and Childress, *Principles of Biomedical Ethics*. I will return to a discussion of principles in chapter 2.

embryos prior to implantation. Julie Clague has suggested that we should use the phrase 'genomorality' in order to draw attention to the wider political issues that are under discussion in the general rubric of genetics.[2] Rather less common is the discussion about the influence of genetics on medical practice itself, so that it becomes a new way of doing medicine. Are such shifts desirable from an ethical point of view? In addition, genethics moves beyond the boundary of medicine in that it covers genetic issues in veterinary practice as well as in agriculture. It is also situated in the context of other discussions about the ethics of biotechnology, and biotechnological progress.

Given the scope of genethics, why has it become an area of such acute concern? One of the reasons is likely to be related to the view that in changing genetics we are changing something fundamental about human nature. Consider the following suggestion by John Harris and Justin Burley at the start of their *Companion to Genethics*:

> No branch of science has created more acute or more subtle and interesting ethical dilemmas than genetics. There have been and still are branches of science that create problems of greater moral importance ... But it is genetics that makes us recall, not simply our responsibilities to the world and to one another, but our responsibilities for how people will be in the future. For the first time we can begin to determine not simply who will live and who will die, but what all those in the future will be like.[3]

Have Burley and Harris fallen into the myth that genetics will completely take over the future evolution of the human species? Certainly, this was a myth that informed the early genetic scientists prior to the adoption of a more modest approach that was informed by population genetics, which categorically stated that genetic modification would not have population impacts.[4] In addition, even if 'enhancement' techniques were to be used (which would have wider implications, as they would be more attractive to a greater number of people), the expense of such transformations would inevitably mean that there would be differential access to the technology. Further, to claim that genetics will decide 'what all those in the future will be like' seems to affirm the very fallacy that Harris has previously resisted in arguing in favour of reproductive cloning, namely, genetic determinism.

[2] J. Clague, 'Beyond Beneficence: The Emergence of Genomorality and the Common Good', in Deane-Drummond (ed.), *Brave New World*, pp. 189–224.
[3] Burley and Harris, *A Companion to Genethics*, p. 1.
[4] Note that this applies particularly to genes that are heterozygous in a population. While it might be possible, in theory, to screen out homozygous dominant alleles, this is unlikely in practice. For further discussion, see chapter 4.

In other words, in making such a strong case for the significance of the impact of genetics for human evolution, does bioethics, as much as eugenics, share an objectionable genetic determinism?[5] Certainly, where there are overstatements about the importance of genetics on influencing human evolution, and, by association, genethics, there is a failure to raise a critical voice in the discussion that is vitally needed in the midst of heated public discourse. However, there are strong advocates among ethicists against genetic determinism, usually from those who believe that developments in genetics can be useful for human societies.[6] It is also reasonable to suggest that while, on the one hand, genetic science is continuing to make more and more discoveries about the importance of genes for bodily function and disease, it is also qualified by the realisation that environmental influences play a highly significant role in almost all cases under discussion. Genetic counselling aims to help those faced with the prospect of developing a genetically based disease make informed choices about reproduction. Yet it talks in terms of probabilities, rather than of fixed inevitabilities, except in particular instances where the genes are almost certain to be expressed, having a high degree of 'penetrance'. The level of expression in any individual may also vary enormously. Of course, this uncertainty then impacts on the ethics of screening programmes at the prenatal or pre-implantation stage, for in many cases there is no way of knowing in advance, other than in terms of statistical probabilities, which of the individuals who are born are going to be the most severely affected.

Another highly significant issue to consider here is the way medicine itself is shifting in its practice, so that genetics is beginning to inform the way medicine is done. For example, arguably, genetic deterministic attitudes have crept into the way medical practitioners and politicians have thought about health and disease. Such an attitude would be represented by the claim that, once all genetic elements are known, then future health would be predictable, and genetics plays a central role in health and disease incidence. For example, why does a woman who knows she has genes which predispose her to breast cancer, BRCA1 or BRCA2, choose to have prophylactic surgery, even though the probability of disease expression is also influenced by many environmental factors? Although the philosophy that permits such direct action is one of informed choice, is such choice partly guided by a subtle form of genetic determinism? Of course, genetic

[5] This point is made by Lewens in 'What is Genethics?', p. 327.
[6] For a theological discussion see, for example, Peters, *Playing God*. For other examples of discussions of genetic determinism, see Almond and Parker (eds.), *Ethical Issues in the New Genetics*.

counselling aims always to present genetic information accurately, but statistical results may be loaded by using language such as 'high risk', which then seem threatening to the patients. According to traditional understanding of medicine, the health of an individual is related to the physiological, functional and phenomenological appearance of disease; that is, persons are sick when they show the symptoms of disease. It is worth asking if there is a new trend to identify the sick with those who have genetic traits, regardless of expression of the disease. Tom Butler argues that gene therapy or screening programmes, where this is considered at the stage prior to the appearance of symptoms, reflects the idea of having the disease even before symptoms arise.[7] Yet, is Butler correct in suggesting that this is an entirely new way of approaching medicine? Certainly, the tradition of *preventative medicine* is one that is well established, even prior to modern genetic technologies.[8] The latter could be seen as a way of reinforcing disease prevention by more 'scientific' means, other than general advice about healthy lifestyles. It seems to me unlikely that a medical clinician would consider individuals 'diseased' if they carry genetic traits predisposing them to contract a given disease. Nonetheless, it is worth asking how far such results are taken up and used in social and political contexts. The use of such information by insurance companies or employers, who have a stake in knowing how far persons are likely to contract diseases, is a significant aspect of this trend towards the use of genetics in preventative medicine. In addition, knowledge of the presence of the gene will be a form of preventative medicine only where adjustments can be made in lifestyle or other drug treatments in order to reduce the likely onset of the disease. If environmental factors cannot be changed, it is worth asking what is the point of such genetic knowledge, which could lead to considerable anxiety, with its concurrent health impacts.

GENETICS AND HUMAN NATURE

Where genetic knowledge is used as a means to prevent the birth of certain types of individuals, usually because there is no 'cure' for a disease, this leads to a form of medical practice that prevents those who are likely to have a disease ever existing. Ethical issues in this case bear on the status of

[7] For discussion see T. Butler, 'Genetic Reductionism and the Concepts of Health and Disease', in Almond and Parker (eds.), *Ethical Issues in the New Genetics*, pp. 83–90.

[8] It would be inappropriate to name embryo-screening as a form of preventative medicine, since the embryos in this case are discarded. The term here refers to gene therapy and screening of existing babies, infants, children and adults.

the human embryo or foetus. Yet, we might ask ourselves, what if it were possible to change the genetics of such an embryo so that the disease were no longer present? Would this in effect be changing the person's human identity? Some philosophers have argued that if a faulty gene is no longer present, then the experience of life of that individual is so different from that of the one who would have lived had the faulty gene been allowed to express itself that such changes amount to changes in human identity.[9] In addition, the treatment of a young baby (for instance, a baby of eight or eleven weeks with SCID, severe combined immune deficiency syndrome) with somatic gene therapy would change the way that individual came to perceive himself or herself. Walter Glannon argues that, while there have been wrongful life suits in those cases where children have blamed the parents for bringing them into the world, this would be impossible for inherited genetic modification, for in this case the person's experience of life would have been completely different if the genetic change had not taken place.[10] He therefore proposes that inherited genetic modification (IGM) or somatic gene therapy of very young babies cannot be classed as a type of 'therapy', as the person who exists would have been very different and would have had a different identity had the treatment not taken place. Pilar Ossario makes a similar point in her suggestion that 'the problem is not that we do not know who will be harmed or benefited, it is that we change who will be born'.[11] Of course, this might sound like a form of genetic reductionism, linking identity with genetics, so that changing genetics changes identity. This is not being argued for here. Rather, just as twins share the same genes but have different identities, so each of those with certain profound diseases will have a particular identity associated with that experience. Those diseases that are the most severe, such as Tay-Sachs disease, will lead to a life of suffering that is cut short in infancy. A child born without such a disease would have a different experience of life than the one with the disease, and arguably a different identity. On the other hand, those who have late-onset diseases could be considered to be the same person if the faulty gene was removed prior to birth. Where the identity problem exists, decisions are not easy to make on the basis of benefit for the future child, since arguably this child's identity has changed.

[9] W. Glannon, 'Genetic Intervention and Personal Identity', in Almond and Parker (eds.), *Ethical Issues in the New Genetics*, pp. 69–80. Pilar Ossario makes similar arguments in her 'Inheritable Genetic Modifications: Do We Owe Them to Our Children?', in Chapman and Frankel (eds.), *Designing Our Descendants*, pp. 252–71.

[10] Glannon, 'Genetic Intervention and Personal Identity', p. 74.

[11] Ossario, 'Inheritable Genetic Modifications', p. 255.

Yet this form of philosophical reasoning seems counter-intuitive. The alternative approach is to use some form of utilitarian calculus in arriving at decisions, based on the projected future suffering of persons.[12] This form of reasoning also seems problematic, as it is not always clear what harms might arise. In addition, it is equally clear that the notion of harm is dependent on who is making the criteria about what counts as being harmful.

The debates over whether or not it is permissible to screen in favour of deaf foetuses prior to implantation are relevant in this context.[13] John Harris has claimed that deliberately deafening a child is morally the same as selecting a deaf embryo prior to implantation; both choices lead to the same overall result, namely the existence of a deaf child. Yet this argument is faulty both morally and conceptually.[14] The case also illustrates the problems associated with an ethical analysis based on impersonal principles that rely on utilitarian arguments about the sum total of suffering. However, Harris fails to consider the identity problem, namely that if the deaf child *had not* been selected, he or she would not have existed, while if the hearing child had not been deafened, he or she would still have existed. In the case of choosing the embryo for selection, the argument about what is in a child's best interests cannot be used, as the child would not have existed had the choice not been made. Accordingly, Häyry believes that the 'real policy choice must be made between reproductive autonomy and socio-economic considerations' in providing for the special needs of the child.[15] He does not consider the other possible hearing children who would have been born had the decision been made *not* to select a deaf embryo. The parents arguing for parental autonomy in this case also do so on the basis of the welfare of the child, namely that a deaf child so born would then be integrated into the deaf community.

This is an unusual example in that genetic screening has been advocated more often for screening *out* those who are likely to suffer various disabilities, rather than for selecting in their favour. On one level one might argue that if hearing parents were to be given the opportunity to choose, through pre-implantation genetic diagnosis (PGD), a hearing rather than a deaf child, why should this choice not also be given to deaf parents, who desperately want a child who can be integrated into their social and communal life?[16] The suggestion that we should not burden society with

[12] Parfit, *Reasons and Persons*. [13] For further discussion see Dennis, 'Deaf by Design'.
[14] Harris's position is discussed in Häyry, 'There is a Difference', pp. 510–12.
[15] Häyry, 'There is a Difference', p. 511. [16] Dennis, 'Deaf by Design'.

another deaf child elevates socio-economic considerations above the freedom of choice for the parents. Of course, if the selection works the other way round for hearing parents – that is, deliberately selecting an embryo that is *not* likely to develop into a deaf individual – this might imply that deaf existence was a life not worth living. The 'welfare of the child' argument in favour of screening for a deaf child does not make sense, since if the child had not been selected, it would not have lived. On the other hand, if the capacity were present to genetically alter what might have been a deaf child, this too would change the identity of that child. It seems to me that in this case the mantra of autonomy has overreached itself. In other words, to use PGD either to screen in favour of a deaf child, or to select against a deaf child, is an inappropriate reification of freedom and parental 'rights' for children of their own choosing and an inappropriate use of PGD. In other words, the condition is not sufficiently serious to screen out, and to screen in favour implies parental control over their children, rather than parental acceptance of children as gifts, with all their associated weaknesses and strengths. It is, arguably, a version of liberalism that puts value entirely on freedom of choice, rather than rooting such choices in the virtues with an orientation towards the common good. Hence, it is not so much on the basis of socio-economic gains that such an action needs to be resisted, but rather on the basis that there are some uses of the technology that overreach its intentions as medicine, namely to seek to heal those who are sick. Deaf parents who have hearing children face the same sorts of difficulties as hearing parents with deaf children, but few would dare suggest that deaf children should be screened out prior to birth.

In addition, this example raises issues about the kind of society we are becoming and the human practices that are being condoned through the use of genetic technologies. Rather than being concerned that human nature, or even the identity of a child, might be different if that child were to be given genetic 'therapy', we should be more concerned with broader cultural trends that elevate liberalism to such an extent that children become rights that can be purchased according to parental desires and wishes. The limits of a personalist approach that faces the identity problem, and of more impersonal approaches that lack the ability to identify with those facing the problems at hand, come more clearly into view. The question then becomes: are there ways of viewing ourselves as persons that might help us navigate such difficult territory?

There is a recognisable trend in bioethics, including a discussion of genetics, to become 'thinned out' in such a way that overlapping consensus

is arrived at through formal modes of reasoning.[17] Such a development could be viewed as a mixed blessing, for formal reasoning seeks to calculate the most effective way of reaching an end that is assumed to be a good. In the case of deaf selection, the good assumed is that shaped by liberalism, namely that parental choice trumps other considerations. The shift to 'thinner' versions of discourse has been particularly evident in the United States, where genetic advisory commissions were set up apparently in order to avoid the possibility of more stringent regulatory bodies that might interfere with scientific research.[18] The ends that were assumed were respect for persons (that is, autonomy), beneficence, and justice; and bioethics was perceived as simply being about how to arrive at such ends. This may be one reason why healthcare provision has apparently lacked any real reference to virtue ethics,[19] for it has relied on policy-making that has taken up this 'thinner' bioethical discourse.

Given these presumptions, it is not surprising that some of the most critical voices about genetic practice come from outside the discipline of bioethics. Francis Fukuyama has voiced particular concerns about the dangers of genetic engineering in terms of changing our identity as human beings.[20] This is not so much the narrow issue of whether someone who has been genetically changed is the same person or not (as discussed above), but more widely about whether human power over nature has changed the meaning of what it is to be human.[21] Even stronger is the suggestion made by C. S. Lewis in his book *The Abolition of Man*, that humanity's attempt to subjugate nature actually leads to its own subjugation. In other words, when humans are treated as artefacts, those acting cease to be human.[22] Or do they? Certainly, there are those who believe, correctly in my view, that treating humans as 'objects' is wrong, but the border between the artificial and the natural is becoming much more blurred in our present century. Is this invasion of the natural by the artefact necessarily to be resisted? While we need to guard against treating human persons as experimental objects rather than as subjects, some theologians have warmed to the idea that we live in a technological age. In this sense technology becomes the means to express creativity, to become made in the image of God, to find meaning through that technology, rather than in pitting oneself against it.[23] Philip Hefner makes the following proposals:[24]

[17] Meilaender, 'The Thinning of Bioethical Discourse'. [18] Evans, *Playing God*.
[19] Messer, 'Health Care Resource Allocation'. [20] Fukuyama, *Our Posthuman Future*.
[21] I will come back to this discussion in chapter 6. [22] Lewis, *The Abolition of Man*.
[23] This is the position advocated by Philip Hefner, see his provocative *Technology and Human Becoming*.
[24] Ibid., p. 88.

(a) Technology is a sacred space.
(b) Technology is a medium of divine action as it involves the freedom of imagination that constitutes self-transcendence.
(c) Technology is 'one of the major places today where religion happens. Technology is the shape of religion, the shape of the cyborg's engagement with God.'
(d) Technology is the place where we wrestle with the God who engages with human cyborgs.

Hence, rather than fear technology, Hefner suggests that we should welcome it as an aspect of our human identity and meaning, a place where God can act. Yet I am uncomfortable with this seemingly blanket endorsement of all things technological. In the first place, it seems to lack ethical analysis, bringing religious language into technology in such a way as to reinforce such goals without asking whether such goals are desirable or not. If bioethics works without proper analysis of goals, then theology's contribution needs to challenge such presumptions and seek a critique of both means and ends. Hefner seems to avoid such critique, other than speaking in vague terms about a 'wrestling' with God. Of course, the advantage of his approach is that it counters some of the unnecessarily hostile accounts that make the opposite presumption that technology, especially genetic technology, is a force for evil. Gerald McKenny, for example, is particularly critical of those religious ethicists who resist genetic engineering out of fear that this might impinge negatively on our self-understanding as *imago Dei*.[25] He argues, correctly in my view, that it is incoherent to locate image-bearing in DNA, as if it were untouchable, for this seems to locate what is normative in what is passed from one generation to the next. Yet, there are other considerations indicating that inherited genetic modification (IGM) may be ill advised – to do with responsibilities for future generations – which he fails to consider.[26] He also believes that to focus exclusively on IGM misses the wider issues raised by other practices, such as selective abortion, which could equally serve to devalue human beings. While this is true, it is also important to be aware of the major part that genetic evaluations are now playing in social and political terms. He argues that an important question to ask is: what is the role that genetic knowledge plays in forming us as subjects, and how does this compare with formation according to a religious tradition? In other words, in what ways is humanity

[25] G. P. McKenny, 'Religion and Gene Therapy: The End of One Debate, the Beginning of Another', in Burley and Harris, *A Companion to Genethics*, pp. 287–301.
[26] I will come back to this discussion in chapter 6.