
BIOETHICS OUTLOOK

Plunkett Centre for Ethics

Volume 18 Number 1

March 2007

Our Genetic Future

Bernadette Tobin

It is sometimes said that, since the human species is gaining the capacity directly to manipulate its own genome, we shall soon acquire the ability to bring about fundamental changes in the nature of humanity.¹ Is this so? And if it is, what constraints should be put on the development of these technologies?²

In this paper, I shall attempt to do three things. First, I shall outline the possibilities said to be opened up by the new genetic technologies. Secondly, I shall consider whether we have the resources truly to evaluate them in advance. And, thirdly, I shall consider what, if any, constraints we ought to impose on them, and how that might best be done.

I

What possibilities are opened up by the new genetic technologies? Are they such as to lead to some fundamental changes in the nature of humanity? Here it is useful to distinguish between two kinds of possibilities: (a) those which will use knowledge of the human genome in the pursuit of medicine's traditional goals (for example, preventing illness and disability from occurring, curing illness and reversing disability, relieving the symptoms of ill-health, maintaining someone in an 'all things considered' satisfactory organic condition³; (b) those which use technologies developed largely for purposes associated with medicine's traditional goals for purposes unrelated to those goals: for example, to satisfy our desires for better children, superior performance, ageless bodies and happy souls. These four ways in which we might use genetic technologies to bring about fundamental changes in humanity were recently distinguished and examined in a publication of the US President's Council on Bioethics called '*Beyond Therapy: Biotechnology and the Pursuit of Happiness*'⁴. Let us call the first kind of possibility 'therapeutic' and the second kind 'beyond therapy'. In this paper, I shall be mainly concerned with the second kind.

We now have techniques to test human embryos for the presence or absence of many genes. Should we use these techniques not only to prevent disease but also to enable us to have better children? We are acquiring genetic technologies to boost muscle strength and performance. Should we use these technologies not only to treat muscular dystrophy and the weak muscles of the elderly but also to enable athletes to attain superior performance? We are gradually learning how to control the biological processes of aging. Should we use this control not only to diminish the physical and mental infirmities of old age but also to engineer large increases

in the maximum human lifespan? We are gaining new techniques for altering mental life, including memory and mood. Should we use these techniques not only to prevent and treat mental illness but also to blunt painful memories of shameful behaviour, to transform melancholic temperament, to ease the sorrows of mourning, etc? In ease case, enhanced therapeutic possibilities raise questions about new 'beyond therapy' possibilities.

With respect to the former, medicine's traditional goals and internal ethics provides us with appropriate standards of evaluation. With respect to the latter, we shall need some other standard of evaluation, a standard such as: would the possible change amount to an improvement in the lot of the human kind? Notice that there is nothing in principle wrong with these 'beyond therapy' purposes, at least in the case 'better children', 'superior performance' and 'happy souls'. And even the goal of immortality is a very ancient and persistent one! So the question to be asked is not whether there would be something morally wrong with pursuing any of those 'beyond therapy' goals, but rather whether there would be something unwise about so doing, a question which encompasses both the goals themselves as well as the means chosen in the pursuit of them.

Of course, there are at least two reasons for maintaining a health skepticism about what is going to be possible in the 'bright new future'. First, we need to be aware of the distorting effects of scientific hype which tends to ebb and flow in response to the prospect of a relaxation in the law or in other forms of regulation of biotechnologies. Secondly, the genetic revolution has spawned a new version of the old nature *v* nurture debate, a debate about what makes us differ from each other, about why some people are smarter and others duller, some nicer and others nastier, some bolder others more shy. 'Behavioural geneticists' say the answer lies in our genes, 'blank-staters' say that it does not. That is to say, they disagree about whether all behavioural traits are heritable. They disagree about the significance of the effects of shared environment on children, and indeed on whether the family or the peer group is the critical element in the shared

environment. But both groups agree, or at least they could agree, that some part of the explanatory story lies in neither genes nor shared environment: that it lies in chance events in the assembly and development of the brain of the biologically-unique organism which each of us is, that the explanation is to be found in the 'neuro-developmental roulette' to which each of us is subject. So, whether or not we should try to bring about fundamental changes in the nature of humanity, it may turn out not to be possible for us to do so in the first place!

2

Can we evaluate the 'beyond therapy' possibilities in advance? Those who have a 'subjectivist' view of evaluation would think that it is not possible: on this view, evaluation is purely a matter of personal preference: different strokes for different folks. I shall assume that, though there is a part of the truth about human affairs that is captured by individual subjectivism (that is, that moral or ethical evaluation is *first-personal*), this view ignores too much of what is objective in human reasoning (for example, the simple fact that we know we can get things wrong). The same goes for those whose thinking is wedded to some form of cultural relativism about evaluation. Once again, though it captures a part of the truth (that, for example, cultures have their own ways of expressing our shared human values), cultural relativism ignores too much of what is objective in human reasoning (for example, the fact that we know that whole cultures can get things wrong). As for the 'postmodernists' who think that all ethical appraisal is fatally undermined by bias and greed. Well, it is true that people do often use what Nussbaum calls the 'mantle of truth seeking' to pursue their own interests and to assert the received wisdom of habit.⁵ But that just means that we need to be aware of the temptation, in ourselves as well as in others, to characterise things in ways that suit ourselves and our circumstances. As Plato pointed out, the powerful often define justice as obedience to rulers: but as both Socrates and he knew, the pursuit of truth is an ineliminable motivation of human beings. Nor, finally, should we be put off ethical appraisal by the nay-sayers of the 'science has outstripped ethics' school of thought. They

misconceive ethics. As Buckle says, though it is certainly true that answers to questions such as whether reproductive cloning is contrary to human dignity are not written down anywhere for us merely to look them up, nonetheless the claim that 'science has outstripped ethics' should be treated with suspicion because it relies on a false picture of ethics: it treats ethics as a body of very specific rules which tell us what to do in each situation.⁶ I shall assume, then, that we can indeed ethically evaluate the new genetic possibilities.

What kind of reasoning is ethical reasoning? One popular answer is to be found in utilitarianism: evaluate actions, policies, proposals, possibilities according to their 'utility', that is, according to their likeliness to bring about the greatest happiness for the greatest number. This form of reasoning is popular both within and without moral philosophy, but it fails to accommodate the intuitive knowledge we have that some things are wrong *in and of themselves*, that we can evaluate some proposals *in advance* of knowing their utility. If the American humiliation of Iraqi suspects in the Abu Graib gaol had had the consequences of quelling the insurgency, stabilising the social order, etc, surely we would still think it wrong: that is to say, though we recognise the importance of anticipating the likely consequences of our actions, we also think that some ways of acting are wrong *in and of themselves*. All forms of consequentialism (including utilitarianism) are, I submit, a distortion of morality. Consequences matter, but they are not all that matter. Indeed, sober attention to them is just one of the ingredients of morality. Common morality also encompasses prohibitions (the idea that there are some things we shouldn't do whatever the consequences), exhortations (the idea that there are standards of thought and feeling and resolution towards which we ought strive, virtues (that is, qualities of character - and of mind - which enable us to appreciate these standards in the messy circumstances of our lives and which draw us to them, strengthening our resolve to rise to them when other things intervene).

Aristotle recognised that some proposals are just out of the question for a decent person (my

earlier example was intentionally humiliating another: he thought this was true of adultery, theft and murder⁷). But he was much more interested in spelling out morality's positive injunctions/exhortations. Be courageous, generous, sociable, truthful. Act with good temper, proper pride and ambition. Be just. Strive for good judgment and practical wisdom. Indeed, without these qualities, you will miss the mark. Kant thought that we could sort out what is to be absolutely avoided and what is worth striving for by considering our proposals in the light of the thought: what would it be like if everyone were to do that?⁸ So, do not make lying promises, do not ignore the needs of others, etc.

All this is very familiar. But notice how these contributions to common morality supply us with a set of evaluative instruments of the kind we need to structure our thinking about both the 'therapeutic' and the 'beyond therapy' possibilities of the new genetics. Recall, first, the therapeutic uses of genetic knowledge (preventing illness and relieving disability, curing illness, relieving symptoms, etc.). If someone proposes to achieve one of those undeniably worthy goals, via (say) breaching the confidentiality of a doctor-patient relationship or by invading the privacy of a person with a genetic disorder, then that is a reason for not pursuing the goal in that way. The means to the end is one that morality requires us to avoid.

My point is not that what will be a proper and an improper use of genetic data will always be obvious. It is rather that our common morality has some powerful resources for enabling us to evaluate the new genetics: for instance, it requires us to evaluate both means and ends.

Morality also invites us to deepen our understanding of the significance of various proposals (here, the use of genetic data). Genetic testing and screening for inherited disorders is happening at a pace which far outstrips the availability of gene therapy and other treatments. Some of our present practices may be doing nothing more than burdening some individuals with knowledge that blights their lives. Morality draws our attention to the likely side-effects of the pursuit of worthy proposals, for example the likelihood that we will add to the burden of

genetic disadvantage the burden of social discrimination (the inability to get or keep a job because of one's genes, or the unlikelihood of being accepted as a migrant because of one's genes). And - to give just one more example of the resources of morality we can bring to the evaluative task - it requires us to distribute the benefits of the new technologies justly. With respect to the just distribution of the social good of health care: my hunch is that the commercialisation of genetic information with exacerbate the greatly rising levels of inequality that already characterise this global age, that the use of genetic information in the pursuit of therapeutic goals is likely to be limited to those who can afford extremely expensive private health insurance in a few Western countries.

So to sum up: Common morality includes not only the idea that there are things we ought not do (such as breach the confidentiality of the doctor-patient relationship) and the idea that there are standards of conduct towards which we ought to aspire (such as to make genetic therapies available on the basis of therapeutic need and not on the basis of capacity to pay). It also includes the idea that some people are better at appreciating the point of the prohibitions and better at responding to the standards set in the exhortations than are others: that is, that acting well requires certain qualities of character and of mind (the moral and the intellectual virtues).

Alasdair MacIntyre once gave a marvelous illustration of the significance of this last aspect of morality, one which bears directly on our subject-matter.⁹ Asked to consider whether we should, if we could, design our descendants, he pointed out that the project of designing our descendents could be thought of in two different ways: as a question about how to raise our children and as a question about what would be desirable traits to engender and construct in the whole society. To address the second question, he said, we would have to answer two further questions: Should we do this? And in the interests of what ideals or goals? The project would be in part political and in part a problem of identifying the virtues for ourselves. So he sketched a set of seven new virtues, one of which was the ability to engage

in non-manipulative relations with others. He then invited his audience to reflect on what it would be for a society to have men and women who possessed that character-trait: and of course he hardly needed to make the significance of his point explicit. For if we succeeded, we would have contrived to have made descendents who, in virtue of this very quality we had designed into them, would be unwilling in turn to design their descendents. If so, the whole project of 'bringing about a fundamental change in humanity' would come to an end. If we can anticipate this, he argued, it would be better not to embark on the project in the first place. Otherwise we would risk producing descendents who would be deeply ungrateful and aghast at the people, ourselves, who had brought them into existence.

3

If then, we do have the resources for evaluating the possibilities that the genetic revolution opens up to us, we shall need to consider whether we ought to impose constraints on those possibilities.

Some years ago the United Nations adopted a *Declaration on the Human Genome and Human rights*. Provision 1.1 says: 'Practices which are contrary to human dignity, such as reproductive cloning of human beings, shall not be permitted. States and competent international organisations are invited to co-operate in identifying such practices and in taking, at national or international level, the measures necessary to ensure that the principles set out in this Declaration are respected.' That is to say, we should discourage, prohibit, in some way constrain the uses of genetic technologies which are contrary to human dignity, practices which in other words 'wound' or 'infract upon' human dignity.

Not everyone agrees with this constraint. Some think that the notion of human dignity is incoherent.¹⁰ Others think that it is essentially a religious concept, representing a way of surreptitiously slipping religion into what ought to be a secular debate.¹¹ Still others think that, in being relative to time and place, the concept of human dignity is insufficiently objective.¹² On the other hand, what is it that we objected to in the

humiliation of Iraqi prisoners by American soldiers if it were not that such practices were contrary to the human dignity of the Iraqis, that the Iraqi prisoners deserved a certain respect just because of their humanity? Though the concept of human dignity is sometimes put to work in unconvincing ways, it seems hard to deny that it does and should inform our public reasoning.

The second formulation of Kant's great categorical imperative says: "So act that you use humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means."¹³ At the centre of Kant's moral thought is a conception of the individual as a unique limit to our will.¹⁴ This Kantian conception of human dignity provides us with what we need to orient our thinking about the possibilities opened up the new genetic technologies. For reference to it implies that what we should be thinking about is whether a proposal will wrong a human person. Not whether it is the wrong thing to do, not whether it will fail to bring about the greatest happiness for the greatest number, but whether it will wrong *someone*.

If, then, we accept the idea that 'practices which are contrary to human dignity ... should not be permitted', will that provide us with a robust way of evaluating the new technologies? I will show why I think it will be by considering just two possibilities, one which is not strictly a matter of genetics (sex selection) and one which may be a matter of genetics: performance enhancement.

Sex selection marries modern technology with an ancient primordial desire.¹⁵ Admittedly, the debate about sex selection is often distorted by other controversies: controversies about the proper character of genetic counseling, controversies about gender stereotypes (that is, about how to think about the relationship between the mere biology of sexual difference and socially constructed gender roles), controversies about the means used (until recently, sex selection necessarily involved abortion: nowadays it can be done by pre-implantation genetic diagnosis combined with IVF, and soon it may be possible to do by 'sperm-sorting'), and

controversies about whether sex selection is likely to upset socially-desirable ratios of men to women.

All these controversies are interesting and important. But if we accept the proposal that we should avoid any practice which is contrary to human dignity, the question to be asked is whether, in satisfying our own priorities or desires about the sex of a future child, we wrong the 'to be born child'. In dictating so essential a part of that child's identity, are we not at least running the risk of failing to treat the 'to be born child' as a unique limit to our will? Are we not moving subtly from procreation to production, from begetting to making, from 'issue of our love' to 'product of our will'?

As for the debate about performance enhancement, it is not new: EPO and other performance enhancers have been around for some time. But now the new genetic technologies make possible powerful ways of bringing about superior performance in (say)sport. Some of the concerns are the familiar ones: injustice to competitors, coercion of athletes themselves (East Germany's treatment of its athletes comes to mind), adverse side effects on their health (being an athlete should not mean accepting a sentence premature disease or disability), etc. But considering performance enhancement in the light of the requirement that we avoid any practice which is contrary to human dignity, we are invited to think further and deeper. For the possibility of enhancing performance by genetic means calls into questions the meaning of the performance itself: the performance may be less real, less the competitor's own, less worth of admiration.

Even competitive sports are not *only* competitions: they are also opportunities for a humanly-cultivated gift to be revealed. Their meaning is determined not just by the result but by who achieves it and how. And it matters that the achievement is genuinely an *achievement* of that person, of his or her conscious awareness, of his or her deliberate choice as well as skill. It matters that it is achieved not by muscle-enhancing agents,

pharmacological or genetic, but by that peculiar blending of mind and body which is sportsmanship at its best. Sporting achievement is not that of a fleet animal or clever machine: it is excellence pursued *as a human being*.

How should we constrain practice which we determine to be 'contrary to human dignity'? I agree with Leon Kass that 'legislation and prohibitions are suitable only for a few rare violations...'¹⁶ There is, of course, a place for professional self-regulation. But everything will depend on the public discussion which precedes such regulation. And here all I want to comment on is the need for getting the starting point of that public discussion right.

The starting point is often thought to be the following one: If a new technology is desired by some individuals, they have a right to it unless hard evidence (not merely speculative possibilities) can be advanced showing that it will be harmful. In addition, since no such evidence can be advanced with technologies not yet deployed and in use, the technologies may be deployed. I find this libertarian view unsatisfactory as a starting point for thinking about how to structure the constraints. For one thing, liberalism is generally only considered in relation to a relatively privileged class of consumers and a fairly narrow range of exotic or highly-technological interventions. And its handmaiden, the free market, is more likely than any argument to constrain individual liberty. In addition, liberty is not the only or even the fundamental social value. Rawls argues that equality is no less important, Kant argues the same of respect for human dignity, and the whole Aristotelian natural law tradition says the same about the value of maintaining and promoting the common good. As Bernard Williams once said of utilitarianism: liberalism is too simpleminded an approach: it has too few thoughts and feelings to match the world as it really is.

So the starting point for a consideration of the desirable limits on the uses of new genetic technologies had better be one which, at the very least, holds the value of individual liberty in tension with recognition that individual choices have social and political implications. Here I can do no better than restate Daniel Callahan's suggestions: What will the technology mean for all of us? Will this or that use be sufficiently compatible with the common good to permit its use? If its use is not wholly compatible, should it nonetheless be permitted on the grounds that a good society on occasion permits potential harms to itself in the name of accommodating the special needs of some of its citizens?¹⁷

Conclusion

Do the possibilities being opened up by the new genetic technologies amount to our acquiring the capacity to bring about fundamental changes in humanity? I am skeptical about whether they will. But I think that careful consideration of each of them, whether they be for better children, for superior performance, ageless bodies, for happy souls, or for some other 'fundamental change in humanity', can nonetheless enrich and deepen our public bioethics, an achievement worthy of pursuit in its own right.

Bernadette Tobin is the Director of the Plunkett Centre for Ethics

Defiant Birth: Women who resist medical eugenics.

A Review by Helen McCabe

Socrates held that a person's happiness depends not on what he or she possesses in the way of health, wealth or other human goods but, rather, on the extent to which he or she is virtuous. So, no matter the gains we make from following one course of action or another (making money, bearing children and so forth), the extent to which we will be happy depends, unequivocally, upon whether the course of action taken is, of itself, virtuous or vicious. If it is vicious, then we ought not to do it if, that is, we want to be happy. Indeed, we ought not to do it even even if the avoidance of such a course of action involves sacrificing our very lives (as Socrates, himself, ultimately did). For happiness consists in virtue only; other human goods (health, wealth and even life itself) will only bring us happiness if we use them well. And in order to use them well, thought Socrates, we must, firstly, be in possession of sufficient virtue. Plato elaborates by claiming that human goods are merely materials upon which virtue works, 'controlling and shaping' them to produce a 'well-organised life'.¹ In this way, Socrates, Plato and their philosophical descendants provide us with an account of (among other things) moral perfectionism.

To a large extent, the modern world has given up the sense of perfectionism that Socrates and Plato cherished and replaced it with a less sturdy, less inspiring understanding of *material* 'perfectionism' which now focuses our ambitions and defines our moral landscape. So, it is now generally held that our happiness depends not so much on our virtue but, rather, on the extent to which we realise a narrow conception of material perfection (wealth, health, youth, and physical beauty). How we go about

achieving these things is, to a large extent, of strategic interest only.

At the same time, we have become enamoured with the achievements of science and technology, storing the kind of faith in these measures that Plato and his descendants would think of as idolatry. Indeed, the faith we attribute to the pronouncements of technology can, at times, take on the character of fundamentalism. For instance prenatal screening is valued for its propensity to 'screen out' those whose physical or mental condition is thought to be less than perfect. Abortion (including up to 34 weeks) has, for this reason, become 'standard medical practice' in cases where it is suspected that the foetus bears such conditions as dwarfism, Down syndrome or spina bifida.³

In a recent report from Britain's Human Genetics Commission,⁶ a so-called 'principle of reproductive autonomy' is employed as justification for both the provision of prenatal screening programmes and 'selective abortion' in cases where a foetus is found to have 'a serious condition'. Objections to prenatal screening have been raised, however, on the grounds that few women are adequately informed of its implications,⁵ as proponents of prenatal screening assume. Mindful of this objection, the authors of the above report call for greater attention to the way in which midwives and ultrasonographers inform women about prenatal screening; to this end, the report recommends that women be reminded that participation in such screening is 'voluntary'. In the same report, it is noted that the benefits of prenatal screening and 'selective abortion'

include that of cost savings: the fewer people with genetic disorders 'and impairments more widely', the less expense to be borne in caring for them. Once again, mindful of objections to this utilitarian view, the writers propose that any 'offence' caused by such claims can be avoided if such 'health economic studies' are conducted with 'sufficient sophistication' and with regard to public debate.

Defiant Birth: the book

In her book *Defiant Birth: Women who resist medical eugenics*,⁶ Melinda Tankard Reist provides a response to the kind of views implicit in the above report. More specifically, she provides an account of the subtle and pervasive emergence of this most recent expression of medical eugenics, raising her voice against what has become 'standard medical practice' to point out some of the more disturbing aspects of contemporary obstetric and radiological practice. In doing so, she becomes something of a maverick in the realm of feminist thought and writing. For at least this reason, *Defiant Birth* is a most interesting book. But, it is much more than that: indeed, Tankard Reist's book is an excellent contribution to the debate on the moral tenor of contemporary medical practice and on beginning-of-life issues.

Defiant Birth is structured around two themes: a) that the practice of medical eugenics is pervasive in our society such that resistance to eugenics requires, on the part of women, requires exceptional courage, and b) that underlying this development is the ideology of material perfectionism or (what the author calls) 'the ideology of quality control and the paradigm of perfection'. In exploring these themes, the author also challenges the system that supports the eugenic programme, noting the largely unquestioning acceptance of the use of medical technology for eugenic purposes, as well the forcefulness with which it is employed. Similarly, Tankard Reist reveals the cynical way in which the much touted principle of respect for a woman's autonomy applies only to the extent that a woman 'chooses' in conformity with the

generally accepted view of material perfectionism. Indeed, resistance to any alternative choice is shown to be effectively discouraged.

The book comprises three discrete parts. Part one presents an account of medical eugenics as it is currently practiced. The focus is on the medical profession and on the way in which prenatal screening is deployed for the purpose of validating the cultural bias against the 'imperfect'. In the 'Introduction', Tankard Reist makes explicit what is normally concealed beneath the cloak of technological and scientific progress: a deliberate programme of eugenics. As well, she demonstrates, through a number of examples, the way in which the autonomous choices of women are constrained by the dominant ideology of material perfectionism, particularly when articulated by members of the medical profession. In doing so, the author addresses such topics as the norms of obstetric practice, genetic screening, coercion, trust in the medical profession, the 'tyranny of expertise', the reckless use of medical technology and the fallibility of its findings, medical ignorance with regard to the conditions screened out, the dehumanisation of disabled people and, finally, a particular cost-saving agenda and its association with eugenic measures.

Part two comprises the personal narratives of nineteen women who have swum against the eugenic tide to proceed with pregnancies deemed 'abnormal'. Each narrative forms a short chapter in which a woman recounts her own struggle to overcome those obstacles to motherhood constructed by both contemporary obstetric practice and social norms. As such, each narrative is testimony to the courage of those who resisted the forces of material perfectionism.

In Part three, the 'Afterword', Tankard Reist provides a collection of reflections on related issues. For instance, mention is made of contemporary society's ambition to pursue a kind of anodyne world and the proclivity in Western societies to both fear suffering and avoid the imperfect. Mention is also made of the lack of adequate services for the disabled

in consequence of the dominant trend towards eugenic 'solutions' to the problem of disability. Accordingly, the courage of those who elect to keep their disabled babies is emphasised.

The accessibility of the book is greatly enhanced by the inclusion of a comprehensive and clear glossary of terms. And the compilation of a comprehensive list of references should also assist readers to pursue further study of the matter.

Defiant Birth: the argument

Tankard Reist's approach coheres with the terms of standard feminist approaches inasmuch as she views prenatal screening and the medical management of pregnancy through the lens of both women's experiences and the broader social and historical contexts out of which these experiences arise. Further, she confines the study of medical eugenics to the implications it has for the lives and well-being of women and the way in which women's bodies are manipulated in the quest for realising eugenic goals. As well, in relevant respects, she views the activities of the medical profession as, oftentimes, contrary to the interests of women. And she refrains from challenging, in any overt sense, the theoretical weight that is placed on the principle of respect for a woman's choice. However, Tankard Reist clearly and unapologetically champions the cause of those who choose life over abortion; she attempts to dignify an alternative choice to what is normally implied by the right of a woman to choose with regard to pregnancy and childbirth. In this respect, Tankard Reist sets herself apart from mainstream feminist thinkers.

The principle of respect for individual autonomy serves an important function in other (non-feminist) liberal theories; in all these approaches, however, objections can be raised to (among other things) the 'thinness' or weakness of this principle in determining what ought to be done, morally-speaking. Tankard Reist does not attempt to refute these objections, nor does she advance any philosophical objection to the primacy of this principle; she does not provide a rigorous

philosophical argument. So, those seeking this kind of approach will be disappointed. Nonetheless, in a novel way she addresses these objections, by bringing to the fore the moral content of what is actually chosen: this is found in the second part of the book where she records the experiences of women who have resisted the powerful urgings to terminate their pregnancies.

Tankard Reist begins her project by taking to task the medical profession, concentrating on the way in which it has embraced a project of eugenics; under the title 'the medical gaze', she provides an account of medical surveillance intent upon eliminating the less than perfect human being. The initial chapter describes the ways in which women are subtly coerced to undergo screening (prenatal diagnosis is now 'standard practice' and many women consent to screening without fully understanding its implications).⁶ In providing on empirical support for her case, the author focuses on two matters in relation to this practice: firstly, its propensity to induce unnecessary fear in expectant mothers and, secondly, the way in which women are deemed 'irresponsible' and, even, 'selfish' should they either refuse to undergo screening or, more to the point, should they refuse to terminate a pregnancy on the basis of any abnormal findings.

In her discussion, Tankard Reist turns the gaze back to the medical profession, criticising its members for imposing on women a programme of eugenics. At the same time, she keeps the broader social context in focus such that it is possible to see that the profession does not act independently of what is popularly considered to be socially desirable. That is, although this is not the author's point, the influence of utilitarianism on medical practice is revealed in this book, along with its influence more broadly.

Of course, not all members of the medical profession deploy eugenic practices, as becomes apparent in the women's narratives where it emerges that each woman *eventually* finds a medical practitioner supportive of her choice to give birth to an actual or supposedly disabled baby. That there are exceptions to the charge is significant in ways that the

author does not fully appreciate. Like many feminist critiques of the medical profession, her tendency to generalise too broadly diminishes her argument. Nonetheless, the author's claims are not, thereby, to be dismissed; indeed, a sizeable proportion of the profession is either involved in, or supportive of, the kind of activities of which Tankard Reist is rightly critical. Moreover, that any member of the medical and other health care professions is implicated in eugenic activities is cause for moral concern. However, recognition of exceptions to the charge is called for, if not so much to mark *their* courage, at least for the sake of accuracy.

The thinness of those arguments supportive of the project of which Tankard Reist speaks is revealed in the women's narratives where a very different moral orientation to the living of a human life is expressed; indeed, these narratives portray an acceptance of sick and disabled babies based on morally deeper, richer reasons than the mere right to exercise one's choices. For instance, Teresa insists that she loves her children not because they are healthy but because they are her children!¹⁰ On learning that her unborn baby had Down syndrome, Julia did not contemplate an abortion because, as she explains, he was *already* her son, owed the love and protection that her other children enjoyed.¹¹ Michelle tells of her three-year-old daughter who is 'popular', 'independent', 'witty' and who 'whistles all day long'; she idolises her big brother, loves to draw and has Down syndrome. Michelle 'would not trade her for the world'; she knows, however, that 95% of her daughter's peers are 'eliminated' in the drive for human perfection.

Tankard Reist describes how, in this modern quest for perfection, it is also thought desirable to encourage only those who qualify as sufficiently fit and healthy to enlist as mothers. Attempts are made to dissuade those who bear a higher probability of producing a less than perfect baby, such as those women who carry 'imperfect' genes, who are disabled themselves in one way or another, or those who are thought 'too old' (those over the age of thirty-five). Diana speaks of this difficulty when she had a (healthy) baby at the age of forty-six,

mentioning the disapproving attitudes of medical practitioners and the 'withering looks' of friends and family.

Tankard Reist argues that fear of physical 'imperfection' is such that the decision to end the lives of the unborn often rests on less than sure evidence; several chapters in Tankard Reist's collection tell of the births of healthy, able-bodied babies which were deemed, by the (erroneous) findings of medical technology, to be harbouring illnesses and disabilities. That women, such as (among others) Stephanie, Alison and Lisa resisted medical advice to terminate the lives of (what medical technology had indicated to be) their 'disabled' babies, proves its fallibility; they each gave birth to a healthy child with no hint of the grave conditions of which they had been warned.

At the same time that Elizabeth was informed that her unborn baby had Down syndrome, it was also (at least) implied that she be 'responsible' and 'choose' abortion, a recommendation which prompted Elizabeth to comment that a child is now reduced to a 'choice', and not a unique human being. She states: '[t]he medical professionals I was dealing with through all those tests were not trying to find information to help me protect the health of my baby'. Instead, the results of those tests were thought, by those medical professionals, to indicate the need for an abortion.⁸

The author refers to those who argue that the termination of an 'unviable' or less than perfect foetus is done in the interests of women; they think that women are spared the suffering associated with giving birth to a baby with Down syndrome or any other such anomaly. However, Amy declares that aborting the life of her anencephalic baby would have 'been a shortcut through our grief'. After her baby died, Julia believes she learned more about 'how to live', about how to order priorities and to 'value what is really important in life'. Sandi's baby proved a prenatal diagnosis wrong; however, after the birth of her baby, Sandi felt that even had her

daughter been born seriously ill, the 'hours or even minutes holding her' would have been worthwhile. Other expressions of gratitude and relief at having resisted consenting to 'the standard care' are expressed through this collection irrespective of whether babies were born disabled, ill, dying or perfectly healthy.

In this second part of the book what is actually at stake in the adoption of eugenic approaches to pregnancy and childbirth is made explicit: the intrinsic dignity of human beings as it is revealed under the gaze of a mother's love. That is, the women's narratives reveal that what matters is the life of a baby, and not, merely, the opportunity to exercise an autonomous choice. For the women's narratives make explicit the importance of the content of choice; they lend meaning to the nature of the problem of eugenics beyond merely that of its proclivity for undermining the autonomy of women. For this reason, the stories suggest the deeper moral problems arising out of eugenic practices. They also reveal expressions of the kind of virtue that Socrates and Plato so much admired.

Of course, it could still be objected, as proponents of modern liberalism would do, that as long as women who choose to keep their disabled babies are able to do just that, there is no reason to complain. For on this view, the only objection that can be made to the current standard obstetric practice is that women may be *coerced* into undergoing such procedures. So, in order to do what is morally required, they would think it necessary to ensure that consent to prenatal screening be fully voluntary which amounts, on this view, to a simple matter of improved communication. And as the women whose narratives occupy this book *did* choose to keep their babies, *and* their choice was realised, there is no reason to think, that there is anything morally amiss.

Tankard Reist does not tackle this understanding of the issues in her book; *Defiant Birth* is not written for readers seeking a philosophical argument. And while the women's narratives lend moral content to the story beyond the concern over individual autonomy, they are not presented in a

philosophical or argumentative style. Nor is their meaning necessarily transparent in the contemporary, liberal world. For this reason, the underlying 'pro-life' position emanating from the book may continue to be rejected by those committed to upholding only the more slender strands of liberal worldviews.

Nonetheless, *Defiant Birth* is insightful, informative and written in a style that is engaging, accessible, and reflective of the author's background in journalism. Tankard Reist makes explicit what is usually concealed beneath the veneer of technological and scientific progress. In likening this situation to the eugenics movements of bygone eras, Tankard Reist expresses the moral offence that has always accompanied eugenic practice no matter where or when it has occurred and for no matter what reason. Ultimately, she leaves contemporary eugenic practice in need of defence, along with the societies in which such activities are condoned.

Whether or not one agrees with the opinions expressed in this book, the issues discussed are of the utmost importance. For this reason, a perusal of *Defiant Birth* would profit a wide audience. In particular, it is a book that should find its way on to the reading lists of students studying medicine, midwifery, social work and nursing. The issues raised are also relevant to politicians, as well as those engaged in health and other social services for women and children. Given the clarity with which Tankard Reist has written, together with the inclusion of an excellent glossary, this book is readily accessible to a broad readership; this is fortuitous as it is the kind of book which could also be read by expectant parents, as well as more generally. Indeed, its broad accessibility is one of its strengths. Any questions left unanswered do not detract from the clarity with which the case is put. *Defiant Birth* is a remarkable achievement.

Dr. Helen McCabe is a Research Associate at the Plunkett Centre for Ethics.

Footnotes to "Our Genetic Future"

- 1 Footnotes are found on p.12
- 2 This article was first published in *Issues for Church and Society in Australia*, St Paul's Publications, Sydney, (2006) 33-46
- 3 It is likely that knowledge of the human genome will help medical science treat the more than 4000 genetic diseases which presently afflict humanity and to understand and maybe to treat the many multi-factorial diseases in which genetic predisposition plays an important role.
- 4 President's Council on Bioethics, 2003b. *Beyond Therapy: Biotechnology and the Pursuit of Happiness*, Washington, DC: U.S. Government Printing Office
- 5 Martha C. Nussbaum, *Cultivating Humanity, A Classical Defense of Reform in Liberal Education*, Harvard University Press, 1997, 39
- 6 Stephen Buckle: Can ethics keep pace with scientific change? Unpublished paper
- 7 Aristotle, *Nicomachean Ethics*, 1107a11
- 8 Kant: *Groundwork of the Metaphysics of Morals*, 4.422; 4.423
- 9 Alasdair MacIntyre: 'Seven Traits for the Future: Designing our Descendants', *Hastings Center Report*, February, 1979
- 10 John Harris, Stem Cells, Sex and Procreation, *Cambridge Quarterly of Healthcare Ethics*, Vol 12, No 4, 2003, p 369
- 11 Lee M. Silvers, Biotechnology and Conceptualisations of the Soul, *Cambridge Quarterly of Health Ethics*, Vol 12, No 4, 2003, p 338 Criticising those who are opposed to destructive human embryo research, he says that they are people who "... who hold a spiritual view of human life ... they know that the overt imposition of religious concepts on political decisions is anathema to many mainstream Americans who nonetheless, believe in the sanctity of some form of human spirit. Therefore it becomes politically expedient to drape a secular veil over spiritual convictions, replacing the notion of the 'sanctity of the soul' with the 'dignity of human life'.
- 12 '[N]otions of human dignity and of what is acceptable or not change in time. In part, the changes come about with increasing public familiarity with the scientific and technological developments, a perception of the benefits which they can bring in identified cases, and a realisation that the dangers to human dignity and freedom may be less than first feared.' Justice Michael Kirby, International Workshop on Freedom and Risk Situations: 25.1.99 www.lawfoundation.net.au/resources/Kirby/papers/19990125_val.html (accessed on 4th June 2004)
- 13 Kant, *Groundwork of the Metaphysics of Morals*, 3.329
- 14 Alan Donagan says that this formulation of the Categorical Imperative, that one should never treat persons simply as means to our ends, but always as ends in themselves, is an attempt to render perspicuous to reason the basis of the biblical injunction to love one's neighbours. Ralmond Gaita thinks it goes the other way around: that it is the biblical injunction, stories and parables, that enable us to make sense of the idea of a person as an end in himself. Setting aside that meta-ethical debate, Gaita is surely right to say that we are indebted to Kant for his placing at the centre of moral thought a conception of the individual as a unique limit to the will of others. Alan Donagan: *The Theory of Morality*, Chicago, The University of Chicago Press, 1970. Ralmond Gaita: *Good and Evil: An Absolute Conception*, London, Macmillan, 1991
- 15 By sex selection, I do not mean selecting the sex of a future child in order to avoid transmitting a sex-linked genetic disease (such as haemophilia): that form of disease prevention uses sex selection as a means (which of course raises its own ethical questions): but the goal is not to predetermine the sex of a 'to be born child' *per se*.
- 16 Leon Kass: Reflections on Public Bioethics: A View from the Trenches, *Kennedy Institute of Ethics Journal*, Vol 15, No 3, September 2005, 241
- 17 Daniel Callahan: 'Individual Good and Common Good: a communitarian approach to bioethics', *Perspectives in Biology and Medicine*, Vol 46, No 4, 2003, 496-507

Footnotes to "Defiant Birth"

- 1 J. Annas, Plato: *A Very Short Introduction*, 2003, Oxford University Press, Oxford, pp. 55-8.
- 2 L.J. de Crespigny & J. Savulescu, 'Abortion: time to clarify Australia's confusing laws', *Medical Journal of Australia*, Vol. 181, No.4, 2004, p.202.
3. See for instance, R. Favre, N. Duchane, C. Vayssiere, M. Kohler, N. Bouffard, J-C, Hunsinger, A. Kohler, C. Mager, M. Neumann, C. Vayssiere, B. Viville, C. Herve & G. Moutel, 'How important is consent in maternal serum screening for Down Syndrome in France? Information and consent evaluation in maternal serum screening for Down syndrome: a French study', *Prenatal Diagnosis*, Vol. 27, No.3, 2007, pp 197-205.
4. Human Genetics Commission, 'Making Babies: reproductive decisions and genetic technologies', as published in *Bulletin of Medical Ethics*, Vol. 213, 2006, pp.6-10.
- 5 M. Tankard Reist, *Defiant Birth: women who resist medical eugenics*, 2006, Spinifex Press, North Melbourne.
- 6 A study of maternal serum screening procedures and processes found that screening was imposed as mandatory by 41.5% of providers and performed in the absence of patient consent in 16% of cases. Further, 67.5% of research participants believed there was no possibility of a false-negative result. J. Gekas, J. Gondry, S. Maxur, P. Cesgron & F. Theopot, 'Informed Consent to Serum screening for Down syndrome: are women given adequate information?', *Prenatal Diagnosis*, Vol. 19, No. 1, 1999, pp. 1-7; & M. Parker, 'Prenatal Diagnosis: discrimination, decriminalization and eugenics', *Monash Bioethics Review*, Vol. 25, No.3, 2006, pp.41-53.
- 7 I have recorded the first names only of the women whose narratives are published in 'Defiant Birth'.
- 8 Elizabeth likened this response to the treatment of the disabled in Hitler's Germany where disability of one sort or another indicated the need for admission to a killing institution.

Bioethics Outlook is a quarterly publication of the Plunkett Centre for Ethics, a university Centre of Australian Catholic University and St. Vincents & Mater Health, Sydney

Telephone: (02) 8382 2869
Facsimile: (02) 9361 0975
e-mail plunkett@plunkett.acu.edu.au
Editor: Bernadette Tobin
Layout: Linda Purves
Subscription is \$90 (Institutions) \$50 (Individuals) and \$25 (Students/Pensioners) + 10% GST and \$10 overseas airmail

Plunkett Centre for Ethics,
St. Vincent's Hospital, Darlinghurst
NSW 2010

ISSN 1037-6410
www.acu.edu.au/plunkett/centre/