

Disabilities, Justice and the New Eugenics of Gene Therapy

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Abstract

Eugenics is a difficult matter for discussion because, even as a term, it has fallen into disrepute. Yet a eugenic mindset pervades the discourses of reproduction and genetics in the West. I utilise the futures scenario of gene therapy to explore conceptually how the intersecting trajectories of science and religion make a new eugenics possible. The problematic of an inherent elitism within these sources, combined with a quest for power, leads me to renew the call for an adequate moral space within which to explore the requirements of social justice.

Working in advocacy for people with disability, and writing for the Queensland Advocacy Incorporated newsletter,¹ I've been reflecting on recent developments in science and medicine, to try to understand some of their implications for the future. A particular area of interest is the science of genetics applied as gene therapy. The first question I ask is about how the therapeutic application of genetics might be understood as eugenic—and not just eugenic in a way that was understood in the past—but in a new way. The second question is about how we assess this situation. For disability advocates, such assessment embraces the point of view of a human being who is, at the very least, adversely affected by a society in which disability is largely regarded in negative ways and addressed through exclusionary policies.² It is also from the point of view of those who are concerned about the emergence of a worldview from which the idea of social justice³ is eliminated.⁴

Eugenics

Francis Galton coined the term 'eugenics' about 1880. Following the work of his cousin, Charles Darwin,

and the announcement of the theory of evolution, Galton proposed that 'improvement' of human 'stock' was a prime human aspiration.⁵ To be 'well born' was not merely to be the result of an 'accident' of class or race, but was to be the product of science. The association of eugenics—the science of human breeding—with evolutionary theory gave eugenics a connotation of being a form of social Darwinism. Indeed one continuing form of eugenics, laissez-faire eugenics, might easily be interpreted as such.

The basic idea here is that society must leave it up to individual parents to decide whether or how to improve the overall 'competitiveness' of their offspring. Why leave it up to individuals? Well, they don't need any more motivation than what they already have. A competitive society creates a demand on individual parents to have successful children, and this provides a sufficient motive to find a technique for creating fit offspring that are superior to, say, random selection. Many humans already mate with a degree of selectivity that is greater than random. Some matings are more successful than others. This indicates that some techniques of selection

are better than others. The fittest individuals, taken overall, will be those who originate from the most successful technique. Genetic science potentially offers the most successful technique. Fitter (presumably more intelligent) individuals will select their offspring via the means of genetic science. Hence, as science develops better opportunities for selection, social evolution will reasonably be expected to proceed according to science. That, crudely put, is the *laissez faire* version of the theory of eugenics. What this theory is based on are naturalistic norms for humanity—for example competition and selection—that are supposedly discoverable by observation of successful adaptations to the environment.

For people whose faith in science extends to embracing social versions of Darwinism, this version of eugenics no doubt has some persuasive value. A somewhat more attractive version for others is what is known as 'utopian eugenics'. This has conceptual roots going much further back in history than Galton or Darwin. Plato discussed such a version in Book Five of *The Republic*. He devised a plan to selectively breed guardians for the ideal state.⁶ Utopian eugenics begins not with individual competition, but with ideals about society or a vision for the good life. Philip Kitcher contrasts *laissez-faire* and utopian eugenics this way. He says:

Laissez-faire eugenics allows people to make up their own minds about which traits to promote, which to avoid. Yet matters have proved not quite so simple. Utopian eugenics proposes that there should be some encouragement to draw the distinction in a particular way. Which way?... There is an obvious answer. Abortion is appropriate when the fetus suffers from a genetic disease. Preventing disease has nothing to do with imposing social values, for whether or not something is a disease is a matter of objective fact.

Ultimately this answer will prove inadequate, but understanding its difficulties will point us towards something better. Once we have left

the garden of genetic innocence, some form of eugenics is inescapable...⁷

Despite difficulties involving distinctions such as 'fact/value', 'objective/subjective', and 'encouragement/imposition', many people find utopian eugenics attractive because it seems to fit snugly with ideals of beneficence. A healthy, well endowed, gifted, productive society seems to mean happy individuals and a good life. This version of eugenics cohabitates well with utilitarian versions of the good, that is, the idea that the good life or the good society is one in which the greatest number of people are enabled to be happy.

So far I have used the term 'eugenics' as if eugenics is only a kind of ethical or political theory. That is problematic. It can also be used to describe a certain kind of social trend. There are overtly material powers at work to create social trends, such as economics, involving changing patterns of community and family. It may be about affordability, about stress, and about coping with stigma and lack of support. Thus, on the one hand, 'eugenics' may be used to describe a kind of ideology, with people looking forward to scientifically-assisted human evolution or to a utopian future. But it may also be used to describe trends of selection that come about through constraining political circumstances. As Diane Paul argues, eugenics is not just one thing.⁸ I will assume that eugenics is the sum total of all the social, political and biological factors that reinforce a deliberate and articulated policy of support for programs of selective human reproduction. I do not assume at the outset that eugenics is, in itself, either right or wrong. Some forms of eugenics are clearly ethically problematic—for example, forced sterilisation and involuntary euthanasia—and other forms of eugenics, like operations to prevent or correct defects in-utero are widely accepted. Eugenics is an ongoing part of medical and reproductive practice.⁹ Ethical questions however do continue, in relation to the 'prevention' of disability and the 'betterment' of humanity.¹⁰

Most people probably will not think much about eugenics if they eventually participate in the new eugenics of gene therapy. As I argue below, already established, but almost forgotten

Taken as having the right to be a kind of moral law giver, second space advocates often create an adversarial stance with respect to first space, whenever these substantive goods are threatened. Yet the problem within second space is that these claims often fail to make the impact intended. Voluntarism is simply not cancelled out by non-voluntarism. Choice and substantive goods are not inherently contradictory. It is not even contradictory to hold the view that

something is both good because of a choice and good independently of the choice. That view is merely that there may be at least two sources of the good, volitional and non-volitional. There is no necessary reason why these should not be combined. Indeed, the fullest realisation of the good may sometimes occur when both sources are realised. The willingness to understand and assess the combination of these sources of the good is what gives rise to third space.

Fig. 10

Third moral space

- there may be at least two sources of the good, volitional and non-volitional
- the fullest realisation of the good may sometimes occur when both sources are realised together
- willingness to understand and assess the combination of these sources

So in conclusion, today is an opportunity to try to understand how we might enter into moral third space. Thank you

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5 Australasian Bioethics Information, Friday Oct 4, 2002. "PERSONHOOD / Bush extends health care benefits to fetuses" www.australasianbioethics.org

6 See Diane B Paul, *The Politics of Heredity*, State University of New York Press, 1998, Chapter 10

Endnotes

- 1 Silver, L.M. *Remaking Eden: Cloning, Genetic Engineering and the Future of Humankind?* Phoenix, 1999: 273, 274
- 2 See also: Tumbull D. *Disabilities, Justice & the New Eugenics of Gene Therapy*, in this issue.
- 3 Andrew Cameron "Consuming Our Unborn Is Indefensible" *Sydney Morning Herald*, August 7, 2002
- 4 Australasian Bioethics Information, Friday Oct 4, 2002. "GENETIC SCREENING / Pick-a-baby programs booming" www.australasian-bioethics.org

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hopes may make the new eugenics of gene therapy possible. What will be new, if it indeed occurs, is not just the technology shaped by a new way of thinking, but a particular technology that appeals to old hopes—utopian hopes—not laissez faire ideologies. Yet, even if what gets people interested in the technology is utopian, the actual trend may turn out to be quite laissez faire.

Finding the links between gene therapy, disability and the new eugenics

Gene therapy can broadly be defined as a range of therapies involving modification to aspects of the human genome in order to improve human prospects. These modifications are divided into two classes: somatic cell, and germ-line cell, gene therapy. Somatic cell therapy aims to only make changes in the cells of an individual and therefore, theoretically at least, no changes are heritable. Up until this point of time in Australia (2002) National Health and Medical Research Council (NHMRC) guidelines prohibit germ-line cell gene therapy on the grounds that altering the germ-line may produce harmful heritable changes in future generations.¹¹ But there are calls to overturn such a prohibition given that social measures can be used to manage future harms involve gene therapy. For example Skene and Coady say:

...harmful effects on the choices of future people can often be mitigated in various ways. Consider gene therapy. If an attempted change in the human genome proved deleterious, for example, causing an unwanted side effect, then that could be "bred out" by the affected people not bearing biologically related children. We are not talking of compulsory sterilisation since this would very probably occur by choice.¹²

Given these reassurances, the response from some people could be: So why should anyone carry on about eugenics? ¹³ Well, anything new needs to be understood and its relations to past and future traced out.¹⁴ But is there something inherently problematic about the new eugenics? I claim that at least there are some important concerns that relate in no small measure to the kind

of suggestion made by Skene and Coady. I don't believe that concerns about gene therapy can be simply dismissed by appealing, as they do, to the efficacy of science and to choice.¹⁵ Appreciating these concerns more fully requires two things. First, to understand how gene therapy as an assertion of the authority of science, reinvigorates an ancient debate concerning a question of justice. Second, to understand how the production of the new eugenics via the interplay between science and a religious worldview, strengthens a tendency to eliminate considerations of social justice.

The authority of science and a question of justice

Early phases of eugenics depended on mechanical methods that were politically crude and scientifically ineffective. These have largely been abandoned. In gene therapy the emphasis is not, as in Plato, on manipulating people to get the desired results, but on delving deeply into 'the meaning' of what it is to be human. Genetic science is proclaimed as the science of human meanings, having moved on from the science of mechanisms. The gene, quite literally, is language. It is a storage and transmission unit of information. Some philosophers of biology, such as Evelyn Fox-Keller,¹⁶ understand the phrase 'the genetic code' as a metaphor. As plausible as this view might be, it is not the view held by genetic scientists. When they say 'the genetic code', they mean quite literally, genetic information in coded form that can be utilised in recoding human life.

The idea of finding the code for, and then recoding human life, inevitably geneticises human attributes, that is, it makes them appear as if they are primarily the product, even if not the 'total' product, of genes.¹⁷ Negative attributes such as those involving disability apply potentially to all people. The critical question that arises at this juncture is: If all people are potentially disabled, how is disability to be managed in society? In particular, on whom is the primary responsibility for managing disability? This question falls within the general one of how social institutions and individual people should respond to what can be spoken of more broadly as 'the human condition'. Prior to the 18th century, it was commonly understood that religion stood at the centre of social institu-

tions and personal life, through the agency of theology and the church. But this agency came into disrepute as science asserted itself as the authoritative foundation for knowledge and for society. How has this come about?

A common idea is that central biblical doctrines have been disproved by science. It has been assumed that the change has been based on facts, not values. But, the claimed authority of science over religion was not a result of scientific discovery, as such. Long before science provided alternatives to the creation account, for example, many biblical doctrines had been rejected by the philosophically literate intellectual elites for reasons both political and moral. The biblical idea of God, as interpreted by those elites, seemed to fit with the notion of a tyrant, whose favours were only partial, and whose condemnation of those outside that partiality was total and terrible. Many people rejected the biblical doctrine of God and of creation and therefore the biblical account of the genesis of human life, not because of scientific flaws, but because it seemed inadequate or improper or offensive that God should display favouritism and be so hostile to outsiders. This, in part, is why there has been, since the 18th century, an 'enlightened' exodus from this version of religion.

The subsequent widespread acceptance of scientific accounts of natural phenomena gave rise to a belief that there has been a replacement of religion as "God's domain", by science, as "man's domain" (sic). In the end, claims Lee M. Silver, "God's domain vanishes into... nothingness."¹⁸ It is commonplace that influential writers such as Silver assume that science has displaced religion by a combination of good empirical research and rational argument. According to these writers, the major ethical objections to genetic engineering and gene therapy belong within the now discredited domain of religion or spirituality. Under the heading, *Treading In God's Domain*, Silver says:

Genetic engineering has been attacked on many of the same grounds used to attack embryo selection. We hear that it's a dangerous idea with "eugenic potential" and that its use will be an assault on the free-

dom and dignity of human beings. ... We are told that it will discriminate against the disabled and be unfair to those who can't afford it ... As is so often the case with new reproductive technologies, the real objection lies in the realm of spirituality, not science.¹⁹

Silver dismisses the general claim that human freedom, dignity, and fairness are under threat in reproductive technologies. His argument depends on identifying these claims as religious claims that are extinguished by science and reason. So how are science and reason supposed by him to produce this feat? Silver speaks of "the essence of human life" which "lies within the human mind, not within the inert molecules of DNA."²⁰ He then goes on say:

If human minds have the ability to contemplate and direct changes in the copies of their own genomes that give rise to future generations, the human mind is much more than the genes that brought it into existence. While selfish genes do, indeed, control all other forms of life, master and slave have switched positions in human beings, who now have the power not only to control but to create new genes for themselves.

Why not seize this power? Why not control what has been left to chance in the past?²¹

The feat then, is based on an assertion of power and control by those with the strength of mind and will to seize it. Consistent with approaches that assert control over nature via the human mind understood as a rational tool, rather than acknowledging dependencies upon nature including tradition and a wide range of relationships, Silver states his allegiances in an ancient debate concerning how human institutions should respond to 'the human condition'. One record of this debate has come to us from Plato as a conversation between Thrasymachus and Socrates concerning justice. But what is justice? Thrasymachus insisted that justice was only what is in the interests of the stronger, whereas Socrates questioned

whether justice could be what the powerful, by virtue of their power alone, might think is their interests.²² Silver, in identifying with the Thrasymachean position, decrees²³ a form of justice that operates according to the control of the weak by the strong, and the favouring of a powerful 'master plan' from which to conduct human affairs. Gene therapy offers ways to enact such a master plan. But how would it happen, and what would this master plan imply for an ethics of the future?

As earlier stated, gene therapy rests upon the idea that a 'code' exists for all the significant biological and psychological attributes of human life, and that the therapy is a matter of 'altering the code'. Geneticists can thus 'instruct' the developing human being how to develop in different or 'improved' ways. This is termed the geneticisation of human attributes.²⁴

Geneticisation done, at least partly, via identification of susceptibility genes²⁵ for disability. The idea of 'genetic susceptibility' though, is very woolly. We all have genetic susceptibility to becoming disabled in some way. Some susceptibilities are to inherited diseases; others are to acquired disabilities. For example, the fact that we don't have the genetic makeup to grow another arm if one is cut off demonstrates the genetic basis for at least one kind of acquired disability. Understanding which susceptibilities to target seems to be an issue. Accidental arm loss is hardly a serious genetic susceptibility. What then about serious and fatal diseases such as Tay Sachs? At a genetic level, the genes for such diseases as Tay Sachs are present in a much higher proportion of the population than those who actually have the disease. These genes make future generations susceptible to the disease, but that alone is not enough to warrant making gene therapy available to its carriers. It all comes down to a question of risk which can be calculated according to Mendelian genetics. The risk of Tay Sachs is not high. But as genetic knowledge increases, more and more susceptibility genes are identified. There are many genetic susceptibilities spread right across the entire population, most of which taken on their own, are low risk, but taken all together constitute a broad spectrum of human vulnerabilities in

which we all share. On top of Mendelian susceptibilities, there are those genetically predisposed conditions that only occur in the presence of particular environmental triggers. It is becoming better understood, for instance, how industrialised lifestyles produce these. We are all therefore involved in a complex, woolly story concerning susceptibility genes for disability, either in receiving them and passing them on in reproduction, or in environmental production of their triggers or both. But—and here's the catch—advocates for genetic science seem to be increasingly putting an onus of responsibility for identifying genetic susceptibilities on those who reproduce. There is thus an implicit reproductive bias in targeting susceptibility genes within genetic medicine. For many people, the idea of offering gene therapy before or during pregnancy in cases of susceptibility to disease is what makes genetic medicine so attractive. But it all seems so far off, realistically, and indeed highly unlikely as a widespread treatment regime. And for many people with actual disability, it is not better genes they want; it is better, more equitable environments, as a primary requirement of social justice.²⁶ Profound future difficulties therefore concern which version of justice is to be more widely recognised. So then, which?

Intervening with everyone's susceptibility genes is simply unworkable—scientifically, socially or economically. Any therapies on offer must, therefore, be limited to those who fit into the 'most likely to yield good results' category. One approach to gene therapies would demand a utilitarian framework—the greatest good for the greatest number. What is the greatest good? It is, according to science, having a genome with optimal functional genetic possibilities. What is the greatest number? It is that number of people with less than optimal functional genetic possibilities who can be 'serviced' within the cost-benefit calculations available to policy makers. Who will determine that number? In this neo-liberal age, it is reasonable to suggest a reference group of bioscientists, clinical geneticists, and biotechnology companies, acting as advisors to governments. A particularly pertinent observation is that the social consequences of such determination would not be within the purview of that

group of interests to manage. Yet, according to current managerialist ideas of ethics, managing future social consequences is not in itself a major ethical issue. The next bunch of managers can worry about that. If a technology is shown to be safe within reasonable determinations of acceptable risk, and if demonstrated to be beneficial, then not only is it permissible, but it may well be obligatory for scientists to develop it, doctors to use it, and reproductive partners to adopt it.²⁷ Other social consequences, for example, its effect on claims for social justice for people with disability, would not feature as important ethical matters.

Many people may see this as something of a concern.²⁸ Yet this concern may be routinely dismissed, through the domination of the Thrasymachean conception of justice that accords well with what is developing in genetic science. We turn next to a consideration of how this conception of justice, as eugenics, may be reinforced by a cultural interplay between science and religion.

A eugenic worldview reinforced by an interplay between science and religion

In the past, eugenics has been opposed as discriminative. It is not fair, opponents said, that society should seek to eliminate some people on the basis of their characteristics. It is not fair that society only values people with particular human characteristics that fit a narrow range of social norms and devalues those with characteristics that don't fit that range. But advocates for gene therapy have undercut this avenue of resistance, by appealing to a different set of ideas that define the meaning of justice, not as fairness²⁹ to all, nor of making sincere attempts to accept all or most kinds of difference, but as the scientific attempt to produce functional uniformity, which implies asserting ownership over the meaning of being human. Advocates for gene therapy have prospects of success in this because of the cultural embedding of scientific goals in a religious worldview of a return to the Garden of Eden and the reappropriation of religious language by science to such ends.³⁰ Some have already recognised aspects of this trend, for example as the human genome project became science's Holy Grail to unlock the 'secrets of DNA'.³¹ Thus whilst religion

may have lost its appeal to many, its ideals have not. The importance of this code is that it is claimed to contain the secret of human life with all its potential for greatness—and its imperfections.

It is the promise of gene therapy to deal with human imperfections that connects it with those older cultural-religious traditions. But it is the reinterpretation of religious language within the science of genetics—giving an apparently unified theoretical superstructure—that makes the connection potentially so persuasive for many. How is this possible? At the heart of much Judeo-Christian tradition in western culture is the doctrine of inborn human imperfection. In the first biblical family, Cain killed Abel. Every subsequent generation was riddled with murders, lies, thefts and other forms of social disruption. No matter what any individual did to overcome the tendency, the following generation was beset by the same. Little wonder that people began to think of imperfection as a 'sinfulness' passed down from generation to generation. In Neo-Darwinian and Mendelian terms, imperfection is in the genotype that creates the inter-generational characteristics, not in the phenotype. Mere moral reform is always phenotypical. The problem seems to be in the latent inherited characteristics at birth. The idea of inherited imperfection paves the way for a religious foundation for eugenics—the idea of needing to be 'good at birth'.

In the biblical story, Jesus pronounced an era of 'new birth'. He spoke a cryptic language. 'Not ... of the will of the flesh, but of the will of God.' 'That which is flesh is flesh. That which is Spirit is Spirit ... You must be born again'.³² What does this all mean? For centuries, the mainstream Church interpreted the new birth as a spiritual rebirth or a moral awakening of an individual. But science isn't mainstream Church. Another meaning has been around for centuries anyway: Gnosis (knowledge). How does the idea of gnosis change our account? The 'spiritual re-birth' is a metaphor for knowledge, for truth. Science is truth. It will set you free. People, in order to be good at birth, must be the product of scientific knowledge. Science will remove the 'bad' genes, the bad information of inborn imperfection. Through science, humanity will be reborn. The only remaining conceptual problem is then to translate the Judeo-Christian

language of morality and spirituality into the language of science and of medicine, so that issues can be dealt with through those agencies. That project is well in hand. Children are not disobedient to their parents. It's not that they refuse to listen. They can't listen because they have ADHD. The next move is to find the genes and replace them in the next generation.

The importance of the link between science and the biblical tradition does not stop at an interesting conceptual similarity. We have inherited science embedded within a Judeo-Christian culture. In a post-modern era, many connections have been broken, but not all of them completely, and in the case of the new eugenics, the connection between science and religious culture is re-asserted. It is a connection in which science still maintains authority. Yet the authority of science is remarkably overstated and is philosophically and ethically very contentious.

Is the authority of science in the new eugenic worldview ethically supportable?

What writers like Lee M. Silver fail to recognise is that their espoused view of justice is in the same mould as a theocentric view that has its roots in history dated over thousands of years. A deep embedding of this view within the scientific account not only makes science meaningful to the public, but also provides the continuity of science with a religious worldview.³³ What is so attractive about this view is not only that it offers hope,³⁴ It also gives science a stronger foothold in a society that has never lost such religious aspirations.

The acceptance of scientific agendas as fulfilling religious hopes poses the same ethical problem that occurred for 16th Century Reformed Christianity and then its later counterpart, secular utilitarianism.³⁵ Having accepted the basic tenets of the idea of justice embedded in such accounts, there is effectively no practical role for an ethic that values any struggle towards or activism involving social justice. The intent was always to make sure a person was a part of 'the elect'—that number predetermined by God or, as it came later, nature combined with a rational process—for whom the good may be realised. Justice, in this view, is satisfied by divine

retribution or natural/social selection, not by opening the doors to all. This form of justice is not social justice, because it comes at the price of denying a decent place in society to all. Equality amongst humans is supposed by it to be the outcome of this form of justice, not its prerequisite. For example, Hughes asserts that 'genetic technology does promise to create a more equal society in a very basic way: by eliminating congenital sources of illness and disability that create the most intractable forms of inequality in society'.³⁶ Thus, equality is the promised product of the salvific process—something accomplished by elimination of apparently unfavourable differences—that is, 'bad' genes. Yet, the very process maintains the normative discriminative order within society, whilst paradoxically rejecting the whole social order as 'the imperfect now' against which the future is framed. Presumably we are supposed to ignore present social inequalities and put our entire faith in a promised bio-utopia.

The deliberate screening out of a consideration of social inequalities, however, fosters harmful illusions. One is that scientifically advanced societies have already produced the system in which justice operates. For example Silver, as well as other writers³⁷, argues that since rich people already have the opportunity to enhance the wellbeing of their children through favourable education and lifestyles, the potential benefits of genetic enhancements is not only their right, it is unstoppable.³⁸ The view that the alliance of science with the rich is omniscient and beyond any further ethical consideration simply fosters another illusion—one that some scientists hold—that they are beyond a public discussion of ethics. For them, this interrupts the scientific research agenda.³⁹

Sectors of religion, hostile disability groups and recalcitrant governments are regarded as unwelcome impediments to science. But they are avoidable. Science is unstoppable. Science is in high demand, if not in one country, then in another, and scientists are mobile and dedicated to discovering the usefulness of the basic constituents of life. This is indicative of a worldview in which science is attempting, not only to eliminate social justice, but to produce the eugenic

master plan for human futures embodying a view of justice as whatever serves the interests of the strong.

The alternative, for those to whom such a pathway offers no resistance to elitist political regimes founded on Darwinian naturalism, is to start from a just appraisal of the social situation of all people. A worldview without this appraisal is highly likely to produce a system based on convenient lies and political manipulation. Ultimately, it gives way to a *laissez faire* regime in which the fittest and the rich are synonymous as a distinctly privileged and legitimised social class.

Conclusion

I have broad-brushed some plausible cultural underpinnings of the new eugenics of gene therapy. A better alternative to such eugenics begins as a moral engagement that considers human vulnerability as socially and systemically produced rather than as merely genetically predetermined. What follows next therefore, is a procedural recommendation rather than a substantive one. Advisory panels dominated by the bioscience establishment and biotechnology companies need replacing by inclusive public forums and decision making processes. This involves the creation and maintenance of what is referred to as 'moral space'. Peter Isaacs poses the critical questions that have yet to be answered:

The way forward in enhancing moral engagement lies, in no small way, in creating spaces in which many voices can be brought together in dialogue and collaboration. This is a critical ethical challenge for contemporary bio-technology and contemporary society. The challenge is a complex and imposing one. How do we ethically inform those who are engaged in bio-technological practice and how do we inform those who are excluded? How do we create public spaces within which these voices can meet and dialogue? How do we shape bio-technological agendas so that they

are responsive, responsible and inclusive? Furthermore, if there is no inexorable movement towards paradise and technological change is not wholly progress but a movement of gains and losses, how do we discriminate between that which we wish to preserve and that which we are quite happy to cast aside? How, too, do we balance between benefits and losses? The most crucial question we face is this. How can modern morality, modern political structures and modern technological processes continue to be validated in a post-modern world?⁴⁰

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Endnotes

- 1 See articles published at www.qai.org.au
- 2 See: Abberley, P. The concept of oppression and the development of a social theory of disability, *Disability, Handicap and Society*, 2, 1987: 5-21. Also the many articles on the theme of oppression appearing in this and similar journals. See also: Oliver, M. *The Politics of Disablement*, Macmillan, 1990. For a searching examination of the intersection of social responses to disability with genetics see: Shakespeare, T. *Choices and Rights: eugenics, genetics and disability equality* *Disability and Society*, Vol. 13, No. 5 1998, pp. 665-681
- 3 My use of the term 'social justice' is in accordance with the principle of justice which "affirms fairness and equality in the allocation of resources, whereby everyone has the right to develop her or his potential and is provided with whatever is necessary to achieve individual and social well-being." See: Roehrer Institut, *Genome(s) and Justice: Reflections on a Holistic Approach to Genetic Research, Technology and Disability*, L'Institute Roehrer Institute, York University, Toronto, 1999: 2, 63. For clearly stated practical proposals concerning this form of justice in genetics see: Shakespeare, T. *Manifesto for Genetic Justice* *Social alternatives* Vol.18 No. 1, January 1999
- 4 Jennifer Fitzgerald argues that the value base

- 4 Jennifer Fitzgerald argues that the value base of current ethics involves four sets of values. She nominates these as materialism, monoculturalism, individualism and economic rationalism. Taken together, these value-sets point in the direction of a kind of consumerist perfectionism that implies exclusion and rejection of the presumed-to-be-imperfect at all stages of life. Fitzgerald says, "Our expectations for our own lives have become increasingly aligned with our expectations for our products. We demand the perfect product—and feel entitled to reject the imperfect." The difficulty for finding a participative approach to social justice is that these values are often unstated and therefore go unrecognised, so that, as Fitzgerald points out, "ethical dilemmas are frequently resolved in a laissez-faire manner by the unfettered and unguided interaction of social forces." See: Fitzgerald, J. *Values in End of Life Decision-Making: Some Implications for People with Disability*, in *Papers on Ethical Issues Facing People with Disability Vol 1*. Queensland Advocacy Incorporated 1996.
- 5 Galton said: 'The improvement of our stock seems to me one of the highest objects we can reasonably attempt.' (Galton, F. *Eugenics, Its Definition, Scope and Aims*. In *The Eugenics Society, Essays in Eugenics*, The Eugenics Society, London. 1909.
- 6 It involved selecting the most athletic and intelligent men and women to form a guardians' academy who would also be mated to breed new guardians. One noteworthy feature of this plan was the use of deception—the various couples were not to know they were being selected to mate-so they would not personally feel that their relationship was just about robotically breeding for the state.
- 7 Kitcher, P. *The Lives To Come: The Genetic Revolution and Human Possibilities*, Touchstone, 1996:203,204.
- 8 Diane Paul's scholarly work on eugenics spans over 20 years. Her most important collection of papers is in Paul, D.B. *The Politics of Heredity: Essays on Eugenics, Biomedicine, and the Nature-Nurture Debate*, State University of New York, 1998. Paul says "Eugenics has been variously described as an ideal, as a doctrine, as a science (applied human genetics), as a set of practices (ranging from birth control to euthanasia), and as a social movement. The word has been applied to intentions and to wholly unintended effects. It has been defined expansively, to include medical genetics, and narrowly, to wholly exclude it." (Paul 1998:95)
- 9 Because medical and reproductive practice desperately seeks to avoid the stigma of eugenics, many working in those fields avoid the term. Unfortunately there are a great many terms that apply to practices that have had an occasionally sordid past, or have been put to wrong or harmful purposes. But this is no reason not to apply the term to a continuing practice.
- 10 Eugenics should not be confused with attempts to prevent disabilities per se. The Roeher Institute maintains, "...not all attempts to prevent disabilities are based on eugenic values. Many countries have policies and programs that focus on preventative measures that address environmental risks or malnutrition, or that provide supports or biomedical treatments for people who have disabilities or are ill. ...(these) focus on making the lives of people better, not on creating better people..." Roeher Institute, op.cit. p.19 Yet it should not be assumed that the distinction between 'making people better' and 'making better people' is always easy to maintain in practice.
- 11 National health and Medical research Council, *Guidelines for Ethical Review of Research Proposals for Human Somatic Cell Gene Therapy and Related Therapies*, 1999: www.health.gov.au/nhmrc para 2.4.7 and para 2.8
- 12 Skene, L and Coady, CAJ. Genetic manipulation and our duty to posterity, *Monash Bioethics Review* Vol. 21 No 2 April 2002:20.
- 13 For the past twenty years or so, many books and articles have been written pointing out the abandonment of old, overtly coercive eugenic policies. Some claim that on these grounds we should stop talking about eugenics. But eugenics is not to be identified with overt coercion. Diane Paul also notes uses of the term 'eugenics' as "a way of ending, not promoting discussion." She says that "To assert that a policy with undesirable effects is also 'eugenics' does not add anything substantive to the accusation. What it does add emotional charge." (Paul 1998:97) In this

essay, I am not using the term to accuse, nor create emotional charge. I am using it to try to understand what produces eugenics, and engage in ethical dialogue about it. I take Paul's remarks to apply to a particular mode of debate, something that Janice Moulton terms 'the adversary method'.

See Moulton, J. A Paradigm of Philosophy: The Adversary Method, (149-164) in Sandra Harding and Merrill B. Hintikka (eds.) *Discovering Reality*, D. Reidel Publishing Co. 1983

In my own work I seek to create a 'third space' for dialogue. See David Turnbull, *Genetics and Disability: Exploring Moral Space*, Queensland Advocacy Incorporated (QAI) October 7, 2002 Workshop *Genetics and Disability: Exploring Different Spaces, Different Futures* (Brisbane Convention and Exhibition Centre) www.qai.org.au

Jayne Clapton notes "the predominant critique offered by disability rights activists is to question biotechnology as a eugenic process for the implicit power within it to negatively discriminate against people and potential people with disability (see, for example, Parens & Asch, 2000; Vehmas, 1999; Shakespeare, 1998). Not surprisingly though, such an accusation is rejected by scientists and clinicians alike who defend their practices as being based upon ethical principles of seeking the good, and offering beneficence and compassion to those who suffer or will potentially suffer (see for example, Gillon, 2001; Gillott, 2001). I argue, though, that to engage in such a polarised debate merely presents a smokescreen to ethical deliberation." See: Clapton, J. *Disability, Ethics and Biotechnology: Where are we now?* Queensland Advocacy Incorporated Newsletter, July 2002. www.qai.org.au

Endorsing Clapton's remark in the last sentence, I think that the problem is with the polarised style of debate that comes with a particular kind of activism and also from entrenched defensiveness in the established professions, not with the terms used, or in posing challenges for dialogue.

See also:

Parens, E. & Asch, A. (Eds.) *Prenatal testing and disability rights*. Washington, DC: Georgetown University Press. 2000

Vehmas, S. Discriminative assumptions of

utilitarian bioethics regarding individuals with intellectual disabilities. *Disability & Society* 14, (1), 1999: 37-52.

Shakespeare, T. Choices and rights: Eugenics, genetics and disability equality. In *Disability & Society* 13, (5), 1998: 665-681.

Gillon, R. Is there a 'new ethics of abortion'? *Journal of medical ethics*, 27, Supplement, 2001:115-119

Gillott, J.

Screening for disability: A eugenic pursuit? *Journal of medical ethics*, 27, Supplement, 2001: II 121 - II 123.

14 Tracing out relations to past and past and future complements tracing out relations within culture, such as colonial relations particularly within race and gender. See, for excellent contrasts: Jayne Clapton 2002, op.cit.

15 The ability of Skene and Coady to be very sanguine about social conditions and population compliance is disturbing from the point of considering eugenic trends. There are obviously two kinds of choices involved in what they propose: reproductive choices and the lifestyle choices available to future people. They appear to think that reproductive choices are very easy to manage, oversee and control medically speaking, and that others' lifestyle choices are none of their concern. The mere claim of 'choice' however fails to acknowledge material and political factors influencing eugenic social trends that make the notion of choice, as it appears from their neo-liberal perspective, less value-neutral.

16 See: Keller, E. 1995. *Refiguring Life: Metaphors of Twentieth Century Biology*, Columbia University Press, New York.

17 Addressing fears of genetic determinism has been a primary concern of the Australian Law Reform Commission—Australian Health Ethics Committee Inquiry into The Protection of Human Genetic Information. See: ALRC-NHMR, *Protection of Human Genetic Information*, Discussion Paper 66, Commonwealth of Australia, 2002

18 Silver, L.M. *Remaking Eden: Cloning, Genetic Engineering and the Future of Humankind?* Phoenix, 1999: 275

19 Silver, op. cit. p. 273, 274

20 Silver, op. cit. p. 276

21 Silver, op. cit. p. 277

22 See: Plato, *Republic*, I, 338c-339a, in Plato,

- volumes. New York: Random House, 1937.
- 23 Note the emphasis on the assertion of justice by 'decree' rather than by continuing dialogue.
- 24 See: Fitzgerald, J. *Geneticizing Disability: The Human Genome Project and the Commodification of the Self*, *Issues in Law & Medicine*, 1998.
- 25 The National Statement on Ethical Conduct in Research Involving Humans (Commonwealth of Australia, 1999:46) notes, "Genetic research can reveal information about an individual's susceptibility to disease and hence about the individual's future health." The idea of a genetic susceptibility to disease gives rise to the term used in genetic research circles: 'susceptibility genes'.
- 26 Christopher Newell calls for "the increased use of resources for the prevention and amelioration of disease amongst the peoples of the world by primary health care measures, rather than the use of much more high tech and invasive intervention..." See: Newell, C. *Critical Reflections on Disability, Difference and the New Genetics*, in O'Sullivan, G., Shaman, E., Short, S., (eds.) *Goodbye Normal Gene*, Pluto Press 1999: 70
- 27 See: Carter, L. The ethics of germ line gene manipulation—a five dimensional debate. *Monash Bioethics Review* Vol. 21 No 4. Ethics Committee Supplement. October 2002:66-81. Carter says, "if germ line manipulation proves to be a safe and effective procedure, then the principle of beneficence imposes on the medical profession a moral duty to pursue the technology." (p.66)
- 28 See: Buchanan A., Brock D.W., Daniels N., Wikler D., *From Chance to Choice: Genetics and Justice*, Cambridge, 2000 for a philosophical attempt to argue that "both justice and our obligations to prevent harm make interventions to prevent disabilities not only permissible but also obligatory." (p.302) These authors take seriously critiques from 'the disabilities rights movement' as creating "some of the most radical and disturbing challenges to the whole enterprise of genetic intervention" (p.302)
- 29 Including the consideration of all those spheres in which fairness must operate simultaneously.
- 30 See: Noble, D. 1999. *The Religion of Technology: The Divinity of Man and the Spirit of Invention*, Penguin, New York.
- 31 See: Hindmarsh, R. 2001. Molitor's Technodiscourse: Rhetoric Unconvincing, *Journal of Futures Studies*: 6(3): 117-124, p. 121.
- 32 The Gospel of John Ch. 3
- 33 Peter Isaacs writes: 'For the first one thousand years of Christianity the spiritual pursuit of perfection disdained the mundane technology of the artisans. However, as Noble (*The Religion of Technology*) has argued, from the early Middle Ages a tradition emerged in Christianity which valued technology as a means of recovering that perfection lost in the fall of Adam. Technology came to be seen as an instrument of salvation and that salvific role gained greater emphasis with the passage of time and the growth of technological inventiveness. Technological progress was sanctified and legitimated as humankind's participation in God's restoration of creation through salvific history. The Christian theology of history provides both the justification for, and ultimate goal of, the technological imperative.' Isaacs, P. 2002. *The Technological Imperative and the Ethical Impulse - Exploring the Interface*. Paper presented to *Towards Humane Technologies: Biotechnology, New Media and Citizenship* conference, 15-17 July, University of Queensland, Queensland.
- 34 In the contemporary world, genetic science provides hope, using the same conceptual framework as a particular brand of theology that offers a new birth. Genetics offers one too, not because it avows publicly divine authorisation, but because it believes it has independently discovered the genetic 'secrets of life'. But politically speaking, science is embedded within a consensual culture, authorised by those people willing to accept such agendas as truth, and as the fulfilment of religious hopes, dreams and expectations, even if much of the latter is unconscious or subliminal.
- 35 The problem is not that 'science is playing God'. Neither is the claim that there ought to be, in principle, no biotechnological remedies to various forms of illness, and other experiences of pain or loss.
- 36 Hughes, J. 1996. *Embracing Change with All Four Arms: A Post Humanist Defense of Genetic Engineering*, *Eubios Journal of Asian and International Bioethics*, 6(4): 94-101.

and *International Bioethics*, 6(4): 94-101.
<http://www.changesurfer.com/Hlth/Genetech.html>

- 37 For example John Harris argues, "I wonder why, if it is legitimate to try to educate our children to acquire the ability to do mathematics, it is not legitimate genetically to engineer into them a like ability." See: Harris J. and Dyson A. *Ethics and Biotechnology*, Routledge 1994:221
- 38 Silver, op. cit. p.264
- 39 A developmental biologist, in declining an invitation to speak at a recent public forum on genetics and disability, expressed his feelings and his strategic reaction to a variety of social forces threatening to undermine his team's research this way. "I spent all this morning being berated and threatened by a Catholic group. Last week I was attacked by a cabal of deaf people for being part of a conspiracy to perpetrate genocide on them. I really am no longer of a mind to be set up for yet more attacks just presently-time for somebody else to carry the can, for a while. I'm just a scientist trying to work out whether stem cells might be useful some day. I'll leave the metaphysics to others. Sorry if I sound jaded-I am. I'm currently thinking that if Parliament votes down the current stem cell bill, I will take my lab of 15 overseas as soon as I am able-we are currently in high demand. If my country doesn't want me to stay, I don't feel inclined to tarry." (Email correspondence with the author, September 2002)
- 40 Isaacs, P. *The Technological Imperative and the Ethical Impulse—Exploring the Interface*. op. cit.