

## A SHORT HISTORY OF THE NEXT THIRTY YEARS: GENETIC TESTING, CLINICAL CARE AND PERSONAL CHOICES

ROGER S MAGNUSSON\*

Danish physicist Niels Bohr is quoted as saying that 'prediction is very difficult, especially when it concerns the future'.<sup>1</sup> Lawyers usually prefer the safer ground of predicting the recent past. However, let me go way out on a limb and predict what the future will be like. Not the far-flung future, but a measured guess about how things will pan out over the next 20, 30 years or so. My aim is to identify some trends and influences that will shape the future of health care in Australia and, more specifically, the regulation of clinical genetics and genetic testing. One issue to watch will be the extent to which personal autonomy, and its equivalent in the market, personal choice, will remain the dominant values within health care settings, or whether the law will constrain the choices that genetic testing and therapies make available on the basis that they are perverse or against the public interest.

There is an enormous body of literature that considers how society *should* regulate genetic technologies.<sup>2</sup> Less attention has been given to how genetic technologies are actually *likely* to unfold, and how they are likely to be regulated. Frank Lewins argues that the disproportionate focus on normative ethics (what we should do) at the expense of sociological approaches to medicine means that the social forces precipitating debate, as well as the forces that will 'resolve' these debates in a political sense, tend to be ignored.<sup>3</sup> One thing we can say is that genetics is a highly sensitive political issue, as illustrated by extensive law reform work,<sup>4</sup> parliamentary debates and legislation.<sup>5</sup> To anticipate the future

---

\* Senior Lecturer, Faculty of Law, University of Sydney.

1 Jeffrey D Zajac, 'The Public Hospital of the Future' (2003) 179 *Medical Journal of Australia* 250, 251.

2 Outstanding examples include Allen Buchanan et al, *From Chance to Choice: Genetics and Justice* (2000).

3 See Frank Lewins, *Bioethics for Health Professionals* (1996) 53.

4 See Australian Law Reform Commission and Australian Health Ethics Committee, *Essentially Yours: The Protection of Human Genetic Information in Australia*, Report No 96 (2003) ('ALRC Final Report').

5 See, eg, *Research Involving Human Embryos Act 2002* (Cth). At the Commonwealth level, this Act restricts research on human embryos created by assisted reproductive technology ('ART') to embryos that were originally created for ART procedures but are excess to the needs of the woman and her spouse. It also imposes licensing requirements on persons carrying out such research. At present, such research can only be performed on embryos created before 5 April 2002, although these restrictions have a sunset date of 5 April 2005. See also *Prohibition of Human Cloning Act 2002* (Cth), which prohibits the creation of

regulation of genetics, we need to recognise that it has more to do with the trends that will influence individual choices and frame political action than with abstract, ethical arguments.<sup>6</sup>

## I HEALTH CARE IN THE FUTURE

In Australia, health care expenditure is slowly rising. It has risen from 7.9 per cent of Gross Domestic Product ('GDP') at the beginning of the 1990s to 9.3 per cent in 2001–02.<sup>7</sup> While the causes and implications of this are complex, future governments will be under increasing pressure to contain their share of expenditure on hospitals, pharmaceuticals, and medical services. Given voter resistance to paying higher taxes and competing spending priorities in high-cost areas like defence and education, the standard and scope of taxpayer funded services (such as Medicare and the Pharmaceutical Benefits Scheme) are likely to change.

We will see a gradual shift in the public–private funding mix for health care services. As with retirement income (increasingly funded through superannuation), the costs of medical care – or perhaps discrete components like pharmaceuticals or hospital care – will come to be seen as something for which individuals are expected to take personal responsibility in accordance with their economic capacity through mandatory forms of private insurance. Pharmaceuticals, hospital care and medical technology will remain expensive. The trend away from hospital care will continue. Community based care coordinators will oversee complex care programs for chronically and terminally ill patients, supported by home telecare (broadband links permitting videophone and monitoring of vital signs), and telemedical support as required.<sup>8</sup>

Interest in alternative therapies, and other reactions to the overwhelming dominance of medical technology in treating disease will remain a visible, if somewhat peripheral, theme. The promise of extended life, improved resistance against disease and the recovery of capacity after trauma will sustain our appetite for medical technology and new therapies. We will remain a society that is passionately fixated upon the health of the body its maintenance, performance, and appearance. We will expect medical science to deliver and, to a considerable degree, it will. There will be modest increases in life expectancy. Each new achievement – be it custom grown replacement organs or artificial implants –

---

human embryo clones (other than by fertilization of human sex cells) and sets out a range of other prohibited practices. Some states are enacting equivalent legislation in accordance with the nationally consistent scheme agreed at the Council of Australian Governments meeting on 5 April 2002. See *Research Involving Human Embryos Act 2003* (NSW), which applies the Commonwealth embryo research law as a law of NSW. See also *Human Cloning and Other Prohibited Practices Act 2003* (NSW), which enacts mirror offences to those in the Commonwealth Act.

6 See Lewins, above n 3, 105–6.

7 Australian Institute of Health and Welfare, *Health Expenditure – Australia 2001–2002*, Health and Welfare Expenditure Series No 17 (2003) 8.

8 See Branko Celler, Nigel Lovell and Jim Basilakis, 'Using Information Technology to Improve the Management of Chronic Disease' (2003) 179 *Medical Journal of Australia* 242.

will subtly reinforce assumptions about the body as a malleable, replenishable personal project. On the other hand, the gap between rapidly expanding knowledge about the genetic contribution to disease and available therapies, will temper popular faith in medical science, deepen the already established theme of ambivalence within society about medicine, and stimulate existential questioning about the limits of health and the purpose of medicine.<sup>9</sup>

In its struggle to meet public demands for high quality health care, despite the 'hollowing out' of the welfare state,<sup>10</sup> cash-strapped governments will look to technology to deliver cost savings and efficiency gains. Health information networks will play a critical role. Over the next decade or so there will be a roll-out of integrated, electronic health care networks supporting longitudinal health records covering all points of care.<sup>11</sup> Integrated, digital medical records will be marketed to the public for their capacity to better coordinate the care delivered by multiple health care providers, particularly to chronically ill patients.<sup>12</sup> The crucial payoff for governments, however, will be the way in which health information networks facilitate the measurement of health system performance.<sup>13</sup> Health information networks will have capacity to capture life-long data about patients' illnesses and the care they receive. By monitoring the outcomes of the ways in which the health care system responds to the needs of the population it serves over time, health IT systems will permit comparison between institutions, administrative and clinical processes, and forms of treatment, both in terms of health outcomes and cost efficiency. This is just one example of how health information networks will permit 'real time' public health surveillance.<sup>14</sup>

Slowly, the distinction between clinical care, and public health functions, will become more difficult to draw. At one level, this is because 'multi-function' health records systems will serve the health needs of individual patients in a confidential manner while simultaneously drawing on clinical data as part of the information base for a range of public health and health management functions.<sup>15</sup> At another level, this is because there will be a shifting emphasis from a reactive,

---

9 See, eg, Renée C Fox, *Essays in Medical Sociology* (1988) 522–6, for discussion of the elements of 'post-modern medicine'.

10 See Derek Morgan, *Issues in Medical Law and Ethics* (2001) 26–7.

11 A national health information network that would encompass electronic event or separation summaries, called *HealthConnect*, is already under development: Commonwealth Department of Health and Ageing, *HealthConnect* <<http://www.health.gov.au/healthconnect/>> at 20 November 2003.

12 The elimination of adverse drug reactions caused by inadequate knowledge about all drugs the patient has been prescribed is one factor prompting the current development of an electronic medication record that would link prescriptions written by different doctors with dispensing pharmacists. Formerly known as the Better Medication Management System this system is now called *MediConnect*: Commonwealth Department of Health and Ageing, *MediConnect* <<http://www.medicconnect.gov.au/index.htm>> at 20 November 2003.

13 See Bruce Armstrong and Anne Krickler, 'Record Linkage – A Vision Renewed' (1999) 23 *Australian and New Zealand Journal of Public Health* 451, 452.

14 See generally Christopher D Mount et al, 'An Integrated Electronic Health Record and Information System for Australia?' (2000) 172 *Medical Journal of Australia* 25; Robert M Douglas, 'Disease Control in the Information Era' (2001) 174 *Medical Journal of Australia* 241.

15 See Roger S Magnusson, 'Data Linkage, Health Research and Privacy: Regulating Data Flows in Australia's Health Information System' (2002) 24 *Sydney Law Review* 5, 42–4, for discussion of 'patient centered' vs 'multi-function' health care records.

disease focused model of health care, to a proactive and pre-emptive health management model. Since the prevention and early management of disease is cheaper than the later treatment of chronic or degenerative illness, economic factors support this trend, although the real impetus will come from greater knowledge about the genetic contribution to degenerative diseases.

Health and vitality, like a person's financial assets, may increasingly come to be seen by individuals as resources requiring structured management. Perhaps by 2020 the healthier members of society will have individually tailored, possibly employer-sponsored health promotion plans encompassing genetic, environmental and workplace constraints, as well as physical, psychiatric and lifestyle elements. On a broader scale, the outcomes of these interventions will be closely monitored and evaluated in terms of their impact on health indicators and health-adjusted life expectancy.<sup>16</sup>

If this is a plausible description of how health care will evolve in the future, how will clinical genetics fit into the picture? Over the next couple of decades, genetics will be fully integrated into most areas of clinical practice. New genetic knowledge will translate into the routine use of a wide array of DNA tests to diagnose or confirm existing disorders, to assess whether a particular pregnancy carries a high risk for a genetic disease or abnormality, and to identify genetic variations (alleles) that will, or may, precipitate future illness. The dramatic expansion in diagnostic, prenatal and pre-symptomatic testing means that the current, largely publicly funded clinical genetics services attached to major hospitals will lose their de facto monopoly over genetic testing, diagnosis and counselling. By necessity, DNA testing will become a common part of primary care. The private sector will provide a growing proportion of genetic services. Assisted by online clinical decision supports, general practitioners will likely assume a 'gatekeeper' role, with referral to clinical geneticists, genetic counsellors, and other services as required.<sup>17</sup>

## II THEMES FROM THE PAST

Before exploring the social context of genetic testing in more detail, it is helpful to briefly consider some past trends that may offer clues to the future contest for regulatory control.

Much of the content of medical law – barely recognisable as a separate discipline in the middle of last century<sup>18</sup> – consists of an examination of the limits of personal autonomy and inviolability as foundational values within

---

16 See generally Colin D Mathers et al, 'Healthy Life Expectancy: Comparison of OECD Countries in 2001' (2003) 27 *Australian and New Zealand Journal of Public Health* 5.

17 Jon Emery and Susan Hayflick, 'The Challenge of Integrating Genetic Medicine into Primary Care' (2001) 322 *British Medical Journal* 1027; Kristine Barlow-Stewart and Clara Gaff, 'Working in Partnership with Support Services in the Era of the "New Genetics"' (2003) 178 *Medical Journal of Australia* 515.

18 Margaret Brazier and Nicola Glover, 'Does Medical Law Have a Future?' in David Hayton (ed), *Law's Future(s): British Legal Developments in the 21<sup>st</sup> Century* (2000) 371.

medical settings. The bureaucratisation of medical care, and the possibilities and uncertainties created by developments in medical technology, can be viewed as destabilising forces in medicine. One response to these developments was the rise, from the late 1960s, of the 'new discipline' of bioethics. Writing in 1974, American sociologist Renée Fox noted that medicine had reached 'a stage of development characterized by diffuse ethical and existential self-consciousness'.<sup>19</sup> This new medical introspection was evidenced by intense engagement with questions of biomedical regulation, not only by health professionals and academics, but by legislators and the popular media, and by the growth of professional codes and processes for resolving value-laden issues within health care settings.<sup>20</sup> Seen in this light, genetics is an important new arena for questioning: an arena which, because it will touch the lives of everyone, is both intensely political and of enduring public interest.

Some of the reactions to the concerns raised by bioethics have taken the form of social movements. For example, the death with dignity movement, and voluntary euthanasia movement, emerged in response to institutionalised, 'technology laden' forms of dying.<sup>21</sup> Over time, genetics will almost certainly provoke social movements of its own.

Consistent with the influence of the consumer movement and a growing 'rights consciousness' that extends beyond medicine, some of the questions raised by bioethics have spilled into the legal domain. By and large, courts have been highly protective of patient autonomy. This has helped to offset the power imbalance between patients and health professionals, an imbalance which is further exacerbated by the rapid development of medical technology and impersonal structures of care. Armed with legal rights, patients have become more assertive, and less willing to trust or to rely on the personal character traits of the doctor.<sup>22</sup>

The importance of personal autonomy is evident throughout medical law. Examples include legislation authorising the donation of tissue transplants,<sup>23</sup> common law recognition of the right to be informed of 'material' risks that would influence decisions about medical treatment,<sup>24</sup> the right to refuse medical treatment, even when one's life depends upon it or where refusal may harm a foetus,<sup>25</sup> the growing body of legislation protecting privacy and confidentiality,<sup>26</sup>

---

19 Fox, above n 9, 381.

20 Lewins, above n 3, 10–13 ff.

21 See Daniel Hillyard and John Dombink, *Dying Right: The Death with Dignity Movement* (2001) 5–8.

22 See Edmund D Pellegrino and David C Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (1988). Pellegrino and Thomasma argue that the overemphasis on rights and autonomy needs to be counterbalanced by a return to virtue-based ethics. They note that '[t]he more we yearn for ethical sensitivity [in the way that doctors respond to complex problems], the less we lean on rights, duties, rules, and principles and the more on the character traits of the moral agent': 122.

23 See, eg, *Human Tissue Act 1983* (NSW). Similar legislation can be found in other states and territories.

24 *Rogers v Whitaker* (1992) 175 CLR 479.

25 See *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *St George's Healthcare NHS Trust v S*; *R v Collins, ex parte S* [1998] 3 All ER 673.

26 Recently, this includes legislation covering the private sector: *Privacy Act 1988* (Cth) sch 3 ('National Privacy Principles'), and health specific privacy legislation in some states: *Health Records and Information Privacy Act 2002* (NSW); *Health Records Act 2001* (Vic).

and a consensus code on the protection of the rights of human research subjects.<sup>27</sup> Even when the patient is not fully competent, the law has applied an individual focused approach, keen to maximise opportunities for autonomous decision-making within the constraints of age or intellectual capacity.<sup>28</sup> Where this is not possible, the law has nevertheless applied a ‘best interests’ test that regards individual welfare as paramount, even when the decision might equally have been made by balancing the patient’s interests against those of third parties,<sup>29</sup> or by reference to community interests or resource considerations.<sup>30</sup>

Patient autonomy, therefore, remains the dominant value in medical law. At the same time, however, the landscape of medicine is changing. As financial pressures motivate a deeper interest in preventive health care, within a networked health information environment that encompasses whole-of-population concerns, it seems reasonable to ask: will we see a subtle cultural shift? Will there be a broadening of medicine’s focus beyond the individual patient, and a winding back of medical law’s preoccupation with the individual, and its protection of his or her choices within the clinical sphere and health care market?

If such a shift is likely, genetics might be one place where it will become apparent. Genes are often seen as irreducibly tied to a person’s identity and future prospects. At the same time, genes and genetic diseases run in families and ethnic groups, and more profoundly, as genetic epidemiology identifies the role of genes in multifactorial, non-Mendelian diseases, the clinical and public health implications will affect wide sections of the population.<sup>31</sup> In summary, several themes will be implicated in the contest for regulatory control over genetics in coming decades. First, as reflected in medical law, the dominance of personal choice as the foundational value in health care. Secondly, the possibility of a growing emphasis on public interests and population wide concerns that economic pressures, developments in genomics, and health information systems will make more pronounced. Finally, the historical theme of ambivalence in the face of rapid technological change, and scepticism about our capacity to wisely regulate the new possibilities of genetics, will also play a role.

---

27 National Health and Medical Research Council, *National Statement on Ethical Conduct in Research Involving Humans*, NHMRC ID 35 (1999).

28 See *Secretary, Department of Health and Community Services v JWB* (1992) 175 CLR 218, 237–8; *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819.

29 *Re Y (Mental Patient: Bone Donation)* [1997] 2 WLR 556 (donation of bone marrow by an intellectually disabled woman to her elder sister); *MAW v Western Sydney Area Health Service* [2000] NSWSC 358 (application for donation of sperm by comatose man).

30 *Airedale NHS Trust v Bland* [1993] AC 789 (patient in persistent vegetative state); *BWW* [2003] VCAT 121 (patient with advanced dementia; guardian appointed).

31 See Marieke C J Dekker and Cornelia M van Duijn, ‘Prospects of Genetic Epidemiology in the 21<sup>st</sup> Century’ (2003) 18 *European Journal of Epidemiology* 607, 615.

### III PREDICTING YOUR FUTURE: GENETIC TESTING AND HEALTH DECISIONS

Make no mistake: genetics will change health care. It will create a new market for knowledge about genetic influences upon the health of individuals, which will lead to a greater emphasis upon the preventive treatment of 'latent illness'. But I doubt that genetics will seriously interfere with market forces or the exercise of personal choices within health care settings, at least where genetic testing for health and reproductive purposes is concerned. To substantiate this prediction in more detail, I will distinguish between two grouped categories of genetic testing.

#### A Diagnostic and Predictive (Presymptomatic) Testing by Adults

In the future we will know much more about the role that genes play in the chronic and degenerative diseases that increasingly account for chronic illness and death, including cancer, heart disease, hypertension, diabetes, dementia, and schizophrenia. Progress in genomics will make genetic testing a familiar aid in the diagnosis of disease, while progress in pharmacogenetics and genetic pharmacology will make genetic testing an integral aid to treatment.<sup>32</sup> In many cases the genetic causes of disease will be linked in complex ways to biology, diet, exercise and lifestyle factors. Health outcomes will be linked in equally complex ways to socio-economic and demographic factors. Our knowledge of these pathways will emerge slowly.

Where genetic diagnosis serves a function in the sense that treatments, or prophylactic measures are available, then the risk that inherited mutations pose to health will encourage voluntary testing as an aspect of clinical care. For example, haemochromatosis can be treated by regular venesection, and regular colonoscopies can screen for familial, cancer causing bowel polyps. Testing for genes which predispose a woman to breast cancer, while confronting, can at least act as a trigger for regular screening in future.<sup>33</sup>

Not uncommonly, predictive or carrier testing will occur because there is a family history of genetic disease, or following the recent diagnosis of a relative. However, when the disease in question is a serious, adult onset, non-treatable disease, such as Huntington's disease or the familial form of Creutzfeldt-Jakob disease, predictive testing will continue to be an extremely confronting turning point in the life of the individual concerned. Unlike multifactorial diseases, predictive testing for certain autosomal dominant diseases generates a much clearer picture of what will happen in future. Studies confirm that such testing has profound implications for family functioning, as well as for those found to

---

32 By genomics, I am referring to the identification of the genetic bases for the molecular abnormalities causing disease. By pharmacogenetics, I am referring to the identification of the genetic basis for individual variations in responses to drugs. By genetic pharmacology, I am referring to the design of drugs to counteract either the lack of a required protein (caused by an inherited mutation) or the chemical effects of an undesirable, inherited genetic mutation: Buchanan et al, above n 2, 7.

33 G Rees, A Fry and A Cull, 'A Family History of Breast Cancer: Women's Experiences from a Theoretical Perspective' (2001) 52 *Social Science and Medicine* 1433.

have inherited the relevant gene.<sup>34</sup> In view of its psychosocial impact, there is unlikely to be any sudden surge in this kind of testing.

With multifactorial diseases, on the other hand, a particular genetic mutation may be identified as only one of several factors signalling an elevated risk of disease. The uncertainty created by this knowledge of future risk has the potential to create a culture of anxious introspection. In consequence, we are likely to see a greater emphasis on prevention and 'good health maintenance'. Some may interpret this trend as evidence of a new 'health fascism': a pervasive culture of health surveillance that brands ill-health and unhealthy living as a form of deviance. On the other hand, individualised 'health management' strategies will become popular precisely because they provide a constructive response to what, for some, will be a crippling uncertainty.

In the genomic era, the weight of knowledge of risk will be heavy, and will find social expression in many ways. Once the culture of anxious 'genetic introspection' is understood, however, it seems unlikely that law would, or could, do anything to impede individuals from accessing 'family genetic knowledge' that is relevant to their own health and reproductive decisions. One possibility is that, for those individuals who 'opt in', genetic registers will interface with electronic health records systems to flag the opportunity for testing when a genetic relative is diagnosed with a particular mutation or disease that carries significant risks for the individual concerned. Prompted by health managers, and advised by genetic counsellors, that person, and other family members, will need to decide whether they wish to be tested. This pattern of family based testing will be a more efficient and cost effective way of identifying pre-sick individuals than broad screening programs. It will also conserve genetic counselling resources and minimise the risk of false positive results.<sup>35</sup>

By monitoring the outcomes of these individual decisions, health departments will gather data on the risks and benefits of different ways of responding to different kinds of diseases and genetic risks within families. A graded series of protocols will evolve to deal with different conditions and levels of risk. Clearly, the desire of an individual to keep a genetic diagnosis secret from family members will become a casualty of the overriding theme of the right to know one's own health status, as already foreshadowed by law reform recommendations.<sup>36</sup>

A more serious challenge to the ethic of personal autonomy will arise when developments in genetic pharmacology provide the possibility of genetic enhancements offering increased protection against a range of common diseases.<sup>37</sup> Since these services are likely to be expensive (at least initially), they

---

34 Susan K Sobel and D Brookes Cowan, 'Impact of Genetic Testing for Huntington Disease on the Family System' (2000) 90 *American Journal of Medical Genetics* 49; Catherine A Taylor and Richard H Myers, 'Long-Term Impact of Huntington Disease Linkage Testing' (1997) 70 *American Journal of Medical Genetics* 365.

35 See Roger S Magnusson, 'Regulating Genetic Privacy in the On-line Health Information Era' (2002) 30(4) *Health Information Management Journal* <<http://www.himaa.org.au/members/journal/himj.asp>> at 20 November 2003.

36 ALRC Final Report, above n 4, Recommendations 21.1, 21.3.

37 See Buchanan et al, above n 2, 96–9.



are unlikely to be publicly funded. This will exacerbate health inequalities and provoke renewed debate about the role and largesse of the welfare state. Social movements will evolve around the belief that genetic enhancements, unlike vaccinations or vitamins, are 'unnatural', and will lead to a genetic underclass vulnerable to discrimination. This will be contested by those who argue that the demands of justice require broad access to genetic enhancement therapies, by rich and poor alike.<sup>38</sup> For their part, those with the ability to pay will see no reason why they cannot spend private capital to remain as healthy as possible. The risk is that if state funded health care services do not encompass a preventive 'good health care management' approach to genetic risks, and perhaps, eventually, 'health enhancement' services, then cultural assumptions about health will continue to change. Health will increasingly be seen as a form of private capital: to be managed and conserved, rather than as a form of public capital, and a right for all.

## B Prenatal Genetic Testing

In future, instead of screening for 20 or 25 life-threatening or disabling genetic conditions, intending parents will check for hundreds or thousands. Developments in foetal surgery and gene therapy will continue<sup>39</sup> but will be expensive. Since treatments will lag behind diagnostic capacity, parents will opt for carrier screening and prenatal screening, rather than newborn or childhood screening. Some of the genetic mutations identified will not be rational predictors of a life-threatening or seriously debilitating disease, but parents will want to minimise any risks within the boundaries of existing knowledge and their capacity to pay. The growth in prenatal screening is therefore likely to lead to more abortions performed for 'eugenic' reasons. Despite this, politicians will be reluctant to stir the hornet's nest of abortion law reform except, perhaps, to enact mandatory genetic counselling requirements.

Rather than test how 'lucky' their foetus was following natural conception, there will be rising pressure for reproductive procedures to be made available to paying, fertile parents who want to improve their chances by choosing the 'best' embryo from a group of embryos fertilised in vitro. Embryos that are screened and found wanting will be discarded. Access to assisted reproductive technology will therefore remain a battleground for anti-abortion groups.

The motivation of parents to have the healthiest child possible will be a powerful political force that will mesh both with the interests of the state in reducing the economic burden of disease and with the interests of physicians in avoiding lawsuits for failure to diagnose foetal abnormalities. So long as prenatal eugenics remains the sum of individual decisions, rather than a result of state policies, genuine debate about the meaning of these developments may be delayed. By funding a wider selection of prenatal tests, however, the state will

---

38 See Mirko Bagaric, 'Eugenics – So What's Wrong with Improving the Quality of the Human Species?' (2001) 20 *Monash Bioethics Review* 11, 15 ff. As Bagaric argues, 'a full commitment to equality in fact drives us towards eugenics – for all people': 17.

39 See, eg, Diana Farmer, 'Fetal Surgery' (2003) 326 *British Medical Journal* 461.

unintentionally buy into the abortion debate.<sup>40</sup> On the other hand, failure to do so will compound the inequalities between the rich, who can afford to pay for private services, and the poor, who must rely on publicly funded services. While some might regard it as an abdication of moral responsibility to leave prenatal genetic testing to market forces, an approach built on individual choice may have the benefit of discouraging any policy drift towards ‘public health’ approaches to reproduction that would treat the risk of giving birth to a child with a hereditary disease as akin to transmission of an infectious disease.<sup>41</sup>

Over time, social movements will emerge to resist the ‘appropriation’ of natural birth and women’s reproductive experiences by the coercive culture of genetic risk management. These movements will find natural allies in other movements promoting a return to a pre-technological, ‘natural’ era, for example, the movements resisting genetically modified foods and those advocating home births and homeopathic remedies. A central theme in the debate about prenatal eugenics, however, will be *disability*. Is it possible for society to devote so many resources to preventing those with genetic disabilities from being born, while simultaneously respecting the dignity of those who – for whatever reason – *are* disabled? To what extent should the elimination of genetic disability and disadvantage be an aim of medicine, or at least publicly funded medicine?<sup>42</sup> So long as prenatal genetic testing remains a private moral choice to be made by parents we may be able to duck these questions but only for so long. The ‘disability critique’ overshadows many debates in bioethics, including euthanasia, and it will remain central to ethical evaluation of genetic testing policies.<sup>43</sup>

As medical science moves beyond identifying genetic factors that contribute to disease, to ‘positive’ factors that protect *against* aging and disease or that boost intelligence or embody aesthetic qualities such as height or skin tone, the eugenics debate will take on a new urgency. Will a culture that has given pre-eminence to personal choice make a distinction between an abortion performed on the basis that the foetus carries a cystic fibrosis gene, a gene that boosts immunity against respiratory infections and a gene that causes short stature? Some see the distinction between positive and negative attributes as fundamental, but this does not mean that society will in coming decades. After all, trying to maximise positive genetic attributes before birth hardly seems arbitrary when aggressive social engineering after birth (in education and lifestyle) is tolerated without dissent.<sup>44</sup>

---

40 See, eg, James Mickle, ‘NHS Urged to Widen Genetic Screening’ *The Guardian* (London), 3 September 2003. This article recommended that the National Health Service increase genetic screening programs for pregnant women to include fragile X syndrome.

41 See Buchanan et al, above n 2, 12.

42 See, eg, Tom Shakespeare, ‘Parental Diagnosis, Disability Equality and Freedom of Choice’ (2001) 79 *Reform* 19. Shakespeare argues that ‘it is vital that we do not see disability as a problem which can and should be prevented’: 19.

43 See, eg, Jennifer Fitzgerald, ‘Bioethics, Disability and Death: Uncovering Cultural Bias in the Euthanasia Debate’ in Melinda Jones and Lee Ann Bassler Marks (eds), *Disability, Divers-ability, and Legal Change* (1999) 267.

44 See Bagaric, above n 38, for an interesting discussion of these issues.

Where pregnancy follows in vitro fertilization, parents who want their child to have particular 'positive' traits will merely need to choose the most appropriate foetus for implantation from those available. In vitro fertilization thus gives parents a wider choice from a range of 'possible children' embodying a range of 'positive' and 'negative' genetic traits. In these circumstances, the preference for particular 'positive' attributes may be seen as a trivial, parental self-indulgence and nothing more. When conception occurs naturally, however, in order to avoid the birth of a child who lacks a crucial positive attribute the parents' desire, the foetus would need to be aborted. As long as a significant proportion of the community have moral objections to abortion, this distinction may have regulatory significance. It is conceivable that prenatal eugenic decisions might be permitted where parents have paid for assisted reproductive services, but restricted where conception occurs naturally. What is more likely, however, is that women will continue to seek medical assistance to terminate pregnancies for many and varied reasons. In general, the lawfulness of an abortion depends upon it being a necessary and proportionate response to a serious risk to the woman's physical or mental health. Even so, since abortion will remain a confidential medical service, some abortions will be performed because the parent does not want a child who lacks a desired attribute.

#### IV CONCLUSION

While the changing structure of health care will spark ambivalence, debate, and resistance, I have suggested that a qualified guess about the future is still possible. Perhaps the most important message is that as the welfare state contracts and patients become health care consumers managing an important resource (their health), the theme of individualism and personal autonomy will continue to dominate. There will be a market for genetic testing, and for the knowledge testing will generate. Testing for the genetic contributors to multifactorial diseases will contribute to a culture of genetic introspection and preventive 'health management'. Ultimately, I expect that the future shape of clinical genetics services will be shaped far more by the aggregate impact of individual choices than by interventionist government policies. This is not necessarily a bad thing: a culture that values personal choice may immunise its members from any trend towards coercive, state sponsored eugenics policies.<sup>45</sup>

Resistance to this dominant culture will be voiced in many ways. Most tiresomely, we will be admonished not to 'play God': an empty criticism, since from anaesthetics to prosthetics, '[a]ll medicine is about playing God'.<sup>46</sup> A lesser god medicine may be, but in time genetic technology will give us freedom to

---

45 This is not to deny the importance of a normative approach. Callahan asks '[w]hen all our free choices are put together, what kind of a society will we get? Why should we think that the sum total of our self-interested genetic choices will result in a decent society?': Daniel Callahan, 'The Genetic Revolution', in David C Thomasma and Thomasine Kushner (eds), *Birth to Death: Science and Bioethics* (1996) 13, 19.

46 Australian IVF pioneer Alan Trounson quoted in Cameron Stewart, 'The God of Very Small Things', *The Weekend Australian Magazine* (Sydney), 22–23 June 2002, 17. See also Buchanan et al, above n 2, 4.

shape and choose, rather than just accept, our genetic constraints and thus, ultimately, our human destiny.<sup>47</sup> This will not happen overnight, and whether we choose to exercise this freedom is another matter. Genetic knowledge will be a source of continuing anxiety, particular in societies that are not united by a single, shared vision of humanity's purpose. The rapid expansion of genetic testing for health and reproductive purposes will signal a broadly based and public conversation encompassing the mainstream media, legislatures, medical organisations and the academy. Importantly, however, the 'resolution' of these debates will be a political process that reflects themes embedded in our culture, and in the structure of health care. We will be best placed to contribute to the public policy debates that will arise around genetics if we pay careful attention to the social context in which they arise and leave science fiction scenarios for the movies.

---

47 See Hugo Tristram Engelhardt, *The Foundations of Bioethics* (1996) 414–18.