

Whither Morality in Genetic Tests?

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A. Introduction

In “Providing Genetic Testing Through the Private Sector: A View From Canada” decisions constituting a rational evaluation of genetic testing¹ for public funding or availability through private purchase were roughly organized into successive thresholds.² The first threshold required that a genetic test be assessed for its moral propriety. The morality of a genetic test may depend in large part on its accuracy, usefulness, social and psychological risks, yet most would agree that it is vital to assess genetic tests for their moral intent or nature prior to adoption into clinical practice, and before decisions are made related to public funding and private access. For instance, sex selection and testing for trivial genetic conditions or for genetic contributions to complex abilities such as intelligence might be ruled as morally inappropriate. What might constitute such a strong moral argument against a genetic test that it justifies a prohibition before the tests are even implemented and evaluated? The ethical arguments against genetics tests fall into four categories.

1. The special nature of the human genome is sacrosanct (e.g., God’s design, nature’s wisdom, “property” of the human race).
2. Developing genetic tests displaces funding opportunities to address conditions that are more common or of greater benefit to the least well-off (e.g., we could spend funds on environmental research rather than genomics).
3. The object of testing is discriminatory and excludes people from equal social status (e.g., sex selection, enhancement selection, testing for disabilities).
4. Genetic testing commodifies human life by treating reproduction and genetic knowledge as products to be manipulated and traded (e.g., pre-implantation diagnosis, prenatal testing and insurance risk for adult onset disease).

This review will explore each type of argument to assess criteria that might be used to evaluate whether there is a substantive moral objection to permitting access to a genetic test.

B. The Special Nature of the Human Genome

The incredible potential of the human genome and the genomes of other organisms has stimulated a sense of wonder and respect. Theists find the hand of God in the creation of the genetic code and our uniqueness, and question the wisdom of altering what God has created.³ Some ecologically-oriented perspectives consider the complex interactions over millennia that led to current and still evolving genomes, and question the hubris inherent in deciding that we can read and modify the human or other genomes.⁴ Rights-based humanitarian organizations and those emphasizing democratic participation in science and technology development (e.g., Council for Responsible Genetics,⁵ Genetics Alliance,⁶ Gene Watch UK⁷) sometimes emphasize the unique nature of the human genome. For instance, the UNESCO “Universal Declaration on the Human Genome and Human Rights” claims that the human genome “underlies the fundamental unity of all members of the human family, as well as the recognition of their inherent dignity and diversity. In a symbolic sense, it is the heritage of humanity.”⁸ These views seem to reflect a collective wisdom in avoiding a purely instrumental view of human nature reflected in the genome and detected through genetic testing. But how central to human nature, dignity and moral status are the human genome and genetic testing?

There is a growing literature that warns us not to overestimate genomic contributions to human nature and the potential to change our identity or destiny.⁹ In *The Triple Helix: Gene, Organism and Environment*, evolutionary biologist Richard Lewontin explains that although genes play an important role in development, it is a mistake to think of organisms as simply unfolding from their genome. “The organism is determined neither by its genes nor by its environment nor by even the interaction between them, but bears a significant mark of random processes.”¹⁰ Lewontin

explains that organisms interact with and change their environment, which in turn affects the organisms and how genes are expressed and change over generations. The oversimplified view of the genome as containing a blueprint of what a person will become is based on a few examples of diseases and characteristics with significant genetic components. The nature of an organism, or of persons, is no more or less located in the genome than it is in the environment or other components of the organism. Genomic knowledge will not bring us closer to an understanding of our “nature,” if by that we mean some essence of what makes us human. In fact, genomic research is demonstrating how similar humans are to other animals. It is therefore difficult to see how genomic knowledge merits protection as a special or sacrosanct portion of our being. This in no way denies (or affirms) the role of God or nature or the special moral status of humans. Rather, it is inappropriate to look to access to genomic knowledge (through genetic testing) as a basis of the special spiritual or moral nature of humans in relation to God, nature or each other. In fact, one of the key symbolic and politically powerful achievements of contemporary genomics is, to paraphrase Paul Rabinow, to identify the human genome with the human person and “spiritualize” genomics.¹¹ An assessment of the moral nature of genetic tests must consider the extent to which the apparent spiritual significance of the human genome is more a feature of social construction and avoid naively essentialist arguments.

While we need to respect the differing views about human nature and its origins in democratic societies, it is a mistake to identify these metaphysical issues with the physical human genome. If some groups believe that the genome has a special nature that merits protection, then it is appropriate to avoid forcing them to accept treatments or participate in research that they consider immoral. It is important to respect each community’s interests in the negotiation of how to study or utilize genomic knowledge related to that community, as well as to understand the very real interests of the public in directing genomic research and genetic testing.¹² However, social policy governing people who are interested in developing or accessing genetic tests must find a basis or justification that can be recognized across different communities. The special nature of the human genome will not serve this purpose.

Another claim for the special nature of genomic or genetic information is that such knowledge is by its nature more

than individual in scope. While “genetic information is familial” is a common refrain, it is important to understand that other kinds of information are also familial or follow ethno-cultural distinctions. Families and cultures provide meaningful environments that shape behaviour, and research into these influences also carries risks and benefits for the

studied groups. For example, anthropological knowledge about how particular communities behave can be used by governments and intelligence agencies to manipulate the groups.¹³ Knowledge that some groups have a propensity for health problems or useful abilities may lead to discrimination in the workplace. Although

genomic knowledge about a group may make the group or their genetic risks less private and more amenable to alteration, so can cultural knowledge about their practices and social organization. The concerns of aboriginal communities about genomic research are therefore very similar to concerns about anthropological research, and both kinds of research require ethical consideration of the acceptability of the research to non-participant people who are affected by the research.¹⁴ These moral concerns have to do with privacy and exploitation in general, and are not due to the special nature of genomic knowledge.

Once we get past the oversimplified view of the genome and specific genetic contributions, what then is a reasonable assessment of the special moral nature of genomic knowledge? To begin, the information gathered from genetic tests can be used to make medically useful distinctions between human beings, but can also be used for discriminatory purposes.¹⁵ Determining what characteristics or conditions to test for, and how the information will be used, is a product of our social institutions and practices. For example, insurance discrimination is a reflection of assumptions and choices embedded in the manner in which insurance shares risk and markets the resulting product. The use of genetic test information to predict risk by insurance companies, though, is not different from their rate-related use of social differences (i.e., gender, race, class, education, disability). Similar to complex social contributions to behaviour and health, genomic knowledge and genetic testing will contribute many pieces to the puzzle of human development and disease, but this will likely mean an incremental evolution rather than revolutionary advances in scientific understanding and medical treatment.¹⁶ Finally, the rapid growth in genomic knowledge and technology and genetic testing is due to the marshalling of enormous public and private resources, supported by breakthroughs in

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information management and in specific research areas where genetic contributions are particularly and unusually important. The particular moral importance of genomic research depends primarily on this dedication of resources, which will be discussed below. But the objection that a genetic test is immoral due to the special moral status of the human genome is unsupportable.¹⁷

C. Loss of More Valuable Opportunities

It might be objected that the availability of genetic testing displaces more important ways of pursuing health and other important social goods, and that some tests should therefore be prohibited.¹⁸ As the first marketable product of basic genetic research, genetic tests have helped drive research and commercial investment, even independent of establishing effectiveness. Public funding for the human genome project, the growing insistence on private partnerships within public funding programs, and commercial investment represent a considerable and unprecedented investment of public and private resources.¹⁹ It is inevitable that such an intense focus will have the effect of overshadowing other important areas of research and social needs, including some that may be more pressing or valued by persons who are already disadvantaged by the way social institutions and practices are organized.²⁰ For instance, research into early childhood development and appropriate programs would be of considerable benefit to the parents and children of the least well off in society and likely represent a more urgent social need.²¹ These programs of meritorious and socially desirable research and service fail to produce the kind of financial benefits for industry and venture capitalists that is produced through research related to biotechnology, however. The decision to spend limited public resources on genomic research programs and the resulting technology is therefore a moral insult giving priority to technological and financial development over greater social needs.²²

Two additional features of this argument are important in order to understand its force. First, funds withheld from genomic research or genetic testing may not become available or be assigned to a more important social activity. In particular, funding for health care services such as genetic testing would rarely be made available for social or educational programs such as early childhood development. Rather, an additional strategy (e.g., lobbying) is required to get the funding assigned to the preferred activity. Second, by the time there are genetic tests to be evaluated, the genomic or genetic research necessary to establish the tests' validity, benefit and safety should have already been completed. The earlier decisions to fund genomic and genetic research are

what established increased research and expertise and related technology. It is certainly true that permitting access to genetic tests encourages the market and health care system to develop and dedicate resources to these technologies, and often causes serious further financial implications related to the additional costs of complications arising from the use of the technologies (e.g., genetic counselling to promote realistic expectations and assessment of possible harms). But prohibiting access to the tests after they have been developed is less relevant to changing the priorities of research and health care than challenging the research priorities directly. The most that could be made of the objection from lost opportunities in relation to the morality of specific genetic tests is that some genetic tests should not be publicly funded because there are more important funding priorities.²³ This is not a moral objection to genetic testing *per se*, but an objection to the *public funding* of genetic tests when compared with other more valuable services. This evaluation will be based on sound economic and epidemiological information to determine the best use of public funds, as well as a participatory scheme for determining social priorities. So at most that can be made of the moral objection to spending public funds on genetic tests is an objection to research funding priorities or public funding, and it does not provide a moral criterion for the evaluation of genetic tests themselves. The moral objection is not to the testing, but to how research dollars are spent and resources are allocated — not to the tests but to how we establish funding priorities.

D. Discrimination and Inclusiveness

Limits on access to a genetic test might be supported on the basis that it would lead to exclusion of some people from social institutions or benefits to which they believe they are entitled, such as life itself, health care, insurance, equality in employment or the basic institutions of society. Genetic tests can be used as a basis for exclusions from services or account for experiences of discriminatory social attitudes. For example, the widespread acceptance of a prohibition on sex selection is one example.²⁴ Prohibiting parents and service providers from limiting reproduction to male offspring seems a reasonable extension of the dedication of social resources to correct a lack of sensitivity and equality that discriminates against women. Disability activists have argued that consideration needs to be given to which disabilities should receive similar protection as part of a social commitment to addressing discrimination toward persons with disabilities.²⁵ Resistance to childhood testing for late onset disease or susceptibility is based on concerns that children will have significant limitations placed upon them by their parents or social institutions. Genetic testing can be used to increase rates or exclude coverage under health, life and disability insurance, with economically

crippling effects on people who require insurance as a condition of employment or mortgages. Such exclusionary effects of genomic knowledge and genetic testing seem to be a good basis for policy considerations about whether to prohibit or severely restrict certain genetic tests.

The nature of the moral harm of exclusion is difficult to describe without detailed attention to theories of justice and evaluation of specific instances of discrimination.²⁶ The exclusionary moral concern is primarily a claim that genetic testing will deny certain groups their fair opportunity to participate in the social institutions of a society. Of course, social institutions should be modified to be less discriminatory, and such reform is important independent of the issue of genetic testing. As Buchanan *et al.* have argued, perhaps the most important social program of a society with considerable reproductive freedom related to genetic tests and interventions will be the efforts to make society's institutions as inclusive as possible.²⁷ It is unclear that even the prohibition on sex selection is justified on grounds of exclusion, although a prohibition might be justified if sex selection results in significant harmful effects on society, such as a severe imbalance in the distribution of sex in the population, thereby threatening reproductive opportunities. The precautionary argument that we must avoid harms that might result from patterns of use requires evidence of the effects of actual utilization of genetic tests. The most important ethics-related activity related to genetic testing is social science research to describe the reinforcement and re-invention of harmful social attitudes and discriminatory institutional practices.

Discrimination and inclusiveness will likely be key issues in evaluating the morality of a genetic test, and together with the lost opportunities to address non-genetic components of health and welfare, constitute concerns that are related to the notion of geneticization as discussed earlier.²⁸ These issues will become more complicated as genome research develops an understanding of the genetic contributions to valued characteristics and more comprehensive genomic technologies. The extent to which we can provide actual access to society's institutions for marginalized persons will influence whether they feel sufficiently included in society to trust that genetic testing is not an attempt to reduce diversity or a failure to appreciate the very wide range of contributions from persons with different abilities. In this sense, the moral problems associated with genetic testing are

not about genetic testing, but about genetic testing in the context of our current social institutions, attitudes, and practices.²⁹ The moral objection from exclusion may rarely justify prohibiting a genetic test. The arguments do suggest, however, that permitting access to tests that threaten exclusion brings with it has the corollary responsibility of assuring that appropriate safeguards are in place to prevent discrimination based on genetic tests, and to evaluate whether private genetic testing promotes discriminatory social policies, attitudes and practices.

E. Commodification

Commodification is a social phenomenon that is woven through multiple institutions and social practices whereby value is assigned to things for the sake of being able to trade or barter different kinds of goods. The objection to commodification of human life is that any trade in human life or materials fails to pay appropriate respect to human life. Slave trade, prostitution, child labour, mail-order brides, and other social practices are condemned for their failure

to give appropriate respect to the inherent dignity and invaluable nature of human life.³⁰ Critiques of reproductive technologies that provide information permitting the evaluation and termination of a fetus *in utero*, *in vitro* fertilization, and gamete donation creating human life independent of natural conception are the historical roots of this concern, now extended to genetic testing.³¹ The ability to evaluate and manipulate reproduction encourages a trade in reproduction and children through the sale of gametes or embryos, or the use of women as surrogate mothers.³² Genetic tests that permit the evaluation of gametes, embryos and even parents further contribute to this slide toward evaluating and improving upon reproduction and children.

Commodifying reproduction encourages evaluation of human potential in order to determine whether the purchase of screened gametes or embryos or the related services is worth the investment of time and money. Failure to meet the standards implicit in the evaluation implies a defective product, with subsequent termination of pregnancy. Although perhaps not strictly within the concept of commodification, the evaluative attitude toward human abilities and characteristics is a necessary component of marketing or purchasing commodifying services or

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products. In this extension, the effects of commodifying technologies are also experienced in adult genetic testing in the case of the loss of social goods such as insurance or employment due to an evaluation that one is genetically a “bad risk.” Parents who elect to have a child without using the predictive technologies or despite particular test results may thereby be seen to fail to avoid costs to society, with the result that the costs of raising these “defective” products are privatized, i.e., family instead of state or social responsibility. People with genetic risks are viewed as the source of increased product costs or insurance costs against which companies and consumers may seek to protect themselves. This ties in with the moral objection of inclusiveness through the hazard of reduced emphasis on efforts to increase the inclusiveness of social institutions. But the effects of commodification are more dependent on social attitudes and practices than the exclusionary design of some institutions, although the latter certainly influence the former.

Commodification is a complex and ongoing social activity. Preventing the use of specific genetic tests is unlikely to significantly reduce commodification because no single use of a genetic test requires that those involved evaluate human life as if it were a commodity. Rather, genetic tests are lightning rods for attention to commodification, drawing notice to how people and institutions use genetic information. While commodification definitely presents serious moral problems at the level of institutions and social practices, restricting evaluation on a test-by-test basis seems likely to have a minimal effect on the problem. The best moral criterion that can be derived from concerns about commodification is that genetic tests be evaluated for evidence of harms related to commodification, and specifically to track social attitudes toward reproduction and children. It is unlikely, though, that any test will have such a strong commodifying influence that it would be justified to prohibit it. Further, with the access to genetic testing that is available internationally and through the internet, limiting tests to avoid commodification is unlikely to be effective.³³

F. Moral Criteria

The resulting moral criteria according to which genetic tests can be evaluated are not so much bases for prohibition, but social concerns related to the discriminatory uses of the tests

in particular contexts (e.g., insurance) and to their overall effect on attitudes and practices (e.g., commodification). These moral concerns require ongoing evaluation of the actual use of genetic tests. To summarize, there are two criteria relevant to the moral evaluation of genetic tests, neither one of which would justify prohibition of a genetic test.

Whether for adults in the context of reproduction for childhood testing, genetic tests must be implemented in a way that considers how best to ensure that test results cannot be used to unfairly exclude people from social institutions. Although there is unlikely to be a reason to prohibit genetic tests, it will be important to identify specific interests related to a particular genetic test and evaluate how best to protect privacy for those affected. It is vital that genetic

counselling and the information provided prior to consent disclose the risks of discrimination, but this is not sufficient³⁴ and the threat of discriminatory use requires the evaluation of the use of genetic tests by social institutions.

The use of genetic tests and related institutional policies may provide evidence of harms of commodification and other objectionable attitudes and practices. The modest contribution of any single use of a test to social attitudes or patterns makes it difficult to criticize that particular test as used by individuals on a case-by-case basis. However, the influence of the health care system and commercial interests on individual choices may contribute to patterns of use that may reinforce commodification and discrimination. It is vital to develop research into measures of these deleterious social effects and to seek a detailed understanding of how they are generated in order to determine how best to counter them, although such research should be based on the assumption that many of the social effects of technology will be perennially contentious and require ongoing public debate.³⁵

The remaining moral issues for genetic testing have to do with whether to use public funds or insurance to support access to testing, and whether it is appropriate to permit private access alongside the health care system. These are not objections to tests as immoral, but to the effect of using public funding to provide access (and the effect of permitting private purchase) on the public system as well as

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on the pattern of utilization and social effects. These issues need to be considered in the context of particular theories of justice in health care, but are not likely to result in moral prohibitions on a particular genetic test.

Thus, the moral evaluation of genetic tests is likely to fail to justify a prohibition on any particular test or the research to develop it. It does not follow from this that any test must be publicly funded or privately available, only that moral grounds do not provide a basis for such a prohibition. Recognizing that the primary ethical concerns related to genetic tests are associated with their use by institutions and their effect on social attitudes and practices strongly supports the need for social science research as a basis for ensuring vigilance over inclusiveness and justice in society. Clinical evaluation of genetic tests, usefulness or safety is not sufficient to ensure that the tests are morally appropriate, but must be supplemented by research into the social effects of patterns of genetic test utilization on institutional practices and social attitudes.

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1. Genetic testing refers to the detection of a genetic change for the purpose of assessing the tested person's chance of developing the condition or characteristic associated with the genetic change. The various technologies used to detect genetic changes and the range of genetic changes known to have some degree of

influence on phenotype are both rapidly proliferating based on scientific research on the human genome, as well as genetic and other research into the etiology of particular diseases and conditions. This paper restricts the discussion to the genetic tests as the first and likely the least controversial application of genomic and genetic knowledge.

2. T.A. Caulfield *et al.*, "Providing Genetic Testing through the Private Sector: A View from Canada" (in review) *ISUMA: Canadian Policy Research Journal*.

3. J.F. Keenan, "Genetic Research and the Elusive Body" in L.S. Cahill & M.A. Farley, eds., *Embodiment, Morality, and Medicine* (Boston: Kluwer Academic Publishers, 1995) 59; A. Verhey, "The Body and the Bible: Life in the Flesh According to the Spirit" *ibid.* at 3.

4. Cf. Nuffield Council on Bioethics, *Genetically Modified Crops: The Ethical and Social Issues* (London, 1999) online:

<<http://www.nuffield.org/bioethics/publication/pub0000000310.html>>.

5. Council for Responsible Genetics online:

<<http://www.gene-watch.org>>.

6. Genetics Alliance online:

<<http://www.geneticalliance.org>>.

7. Gene Watch UK online:

<<http://www.genewatch.org>>.

8. UNESCO, *Universal Declaration on the Human Genome and Human Rights*, UNESCO Gen. Conf., 29th Sess., 29 C/Resolution 19 (1997), online: <<http://www.unesco.org/ibc/uk/genome/projet/index.html>> at

2.

9. P.A. Baird, "Will Genetics Be Used Wisely?" (2001) 2:1 *ISUMA: Canadian Policy Research Journal* 94; T.A. Caulfield, "Underwhelmed: Hyperbole, Regulatory Policy, and the Genetic Revolution" (2000) 45:2 *McGill L. J.* 437; D. Nelkin & M.S. Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: Freeman, 1995); R. Hubbard & E. Wald, *Exploding the Gene Myth: How Genetic Information is Produced and Manipulated by Scientists*,

Physicians, Employers, Insurance Companies, Educators, (Boston: Beacon Press, 1999).

10.R. Lewontin, *The Triple Helix: Gene, Organism and Environment*, (Cambridge, Mass.: Harvard University Press, 2000) at 38.

11.P. Rabinow, *French DNA: Trouble in Purgatory* (Chicago: University of Chicago Press, 1999) at 201.

12.M.M. Burgess & F. Brunger, "Negotiating Collective Acceptability of Health Research" in M. McDonald, ed., *The Governance of Health Research Involving Human Subjects (Hrihs)* (Ottawa: Law Commission of Canada, 2000) 117; R.E. Sclove, *Democracy and Technology* (New York: Guilford Press, 1995); A. Kerr, S. Cunningham-Burley & A. Amos, "The New Genetics and Health: Mobilizing Lay Expertise" (1998) 7 *Public Understanding of Science* 41.

13.J.N. Hill, "The Committee on Ethics: Past, Present and Future" in J. Cassell & S.-E. Jacobs, eds., *Handbook on Ethical Issue in Anthropology*, (Arlington, VA: American Anthropological Association, 1987) special publication 23, online:

<<http://www.ameranthassn.org>>.

14.Burgess & Brunger *supra* note 12, at 124; D. Davis, "Groups, Communities, and Contested Identities in Genetic Research" (2001) 30:6 *Hastings Center Rep.* 38; M.W. Foster, D.

Berensten & T.H. Carter, "A Model Agreement for Genetic Research in Socially Identifiable Populations" (1998) 63 *Am J. Human Genetics* 696; R.C. Fox, "Commentary 1: Contract and Covenant in Ethnographic Research" in N.M.P. King, G.E. Henderson, & J. Stein, eds., *Beyond Regulations: Ethics in Human Subjects Research* (Chapel Hill: The University of North Carolina Press, 1999); P. O'Neill,

"Communities, Collectivities, and the Ethics of Research" (1998) 17:2 *Can. J. Mental Health* 67; C. Weijer, G. Goldsand, & E.J. Emanuel, "Protecting Communities in Research: Current Guidelines and Limits of Extrapolation" (1999) 23 *Nature Genetics* 275; C. Weijer, "Protecting Communities in Research: Philosophical and

Pragmatic Challenges" (1999) 8 *Cam. Q. Health Ethics* 501.

15.T. Lemmens & P. Bahamin, "Genetics in Life, Disability and Additional Health Insurance in Canada: A Comparative Legal and Ethical Analysis" in B. M. Knoppers, ed., *Socio-Ethical Issues in Human Genetics* (Cowansville, Que.: Yvon Blais, 1998) 115; D.C. Wertz, "Patients' and Professionals' Views on Autonomy, Disability, and 'Discrimination': Results of a 36-Nation Survey" in T. A. Caulfield & B. Williams-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal and Policy Issues* (New York: Kluwer Academic / Plenum Publishers, 1999.) 171; T.H. Murray, "Genetics and the Moral Mission of Health Insurance" (1992) 22:6 *Hastings Center Rep.* 12; N.A. Holtzman & M.S. Watson, *Promoting Safe and Effective Genetic Testing in the Unites States: Final Report of the Task Force on Genetic Testing* (Washington, D.C.: Task Force on Genetic Testing, 1997).

16. Baird, *supra* note 9.

17.I do not mean that the beliefs of individuals that to test for a condition is immoral should not be respected through individual counselling and consent. But the individual's belief that a test is immoral is unlikely to win sufficient support to justify a social policy restricting access for those who think the test moral and desirable. Of course, tests might be restricted for reasons of accuracy, ineffectiveness, or due to the harms that result from providing the test, but this is not an objection to the morality of the test per se.

18.Canada, *Proceed with Care: Final Report of the Royal Commission on New Reproductive Technologies 2* (Ottawa: Minister of Government Services Canada, 1993) [hereinafter *Royal Commission 1993*] at 695; A. Lippman, "Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequities" (1991) 17:1&2 *Am. J. L. & Med.* 17.

19. T.A. Caulfield, "The Commercialization of Human Genetics: A Discussion of Issues Relevant to the Canadian Consumer" (1998) 21

- J. Consumer Pol’y 483; M.J. Malinowski & R.J.R. Blatt, “Commercialization of Genetic Testing Services: The FDA, Market Forces, and Biological Tarot Cards” (1997) 71:4 Tulane L. Rev. 1211; M.J. Malinowski & N. Littlefield, “Transformations of a Research Platform into Commercial Products: The Impact of United States Federal Policy on Biotechnology” in T.A. Caulfield & B. Williams-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal and Policy Issues* (New York: Kluwer Academic / Plenum Press, 1999) 29.
- 20.N. Daniels, “Justice, Health, and Health Care” in M. Battin, R. Rhodes & A. Silvers, eds., *Health Care and Social Justice* (New York: Oxford University Press, forthcoming).
- 21.M. Watanabe, “A Call for Action from the National Forum on Health” (1997) 156 CMAJ 999.
- 22.Baird, *supra* note 9; Lippman, *supra* note 18.
- 23.*Supra* note 2.
- 24.Canadian College of Medical Geneticists and the Society of Obstetricians and Gynaecologists of Canada, “Canadian Guidelines for prenatal diagnosis of genetic disorders: An Update” (1993) March Supp. J. Soc. Obs & Gynae. Canada 15; *Royal Commission 1993, supra* note 18, at 695; Bill C-47: *An Act Respecting Human Reproductive Technologies and Commercial Transactions Relating to Human Reproduction*, 2nd Sess., 35th Parl., 1996.
- 25.A. Asch, “The Human Genome Project and Disability Rights: Thoughts for Researchers and Advocates” (1993) 13:3 Disabilities Studies Q. 3; D. Kaplan, “Prenatal Screening and its Impact on Persons with Disabilities” (1993) 8:Supp 1 Fetal Diagnosis & Therapy 64; S.M. Pueschel, “Ethical Considerations Relating to Prenatal Diagnosis of Fetuses with Down Syndrome” (1991) 29:4 Mental Retardation, 185; J. Retsinas, “The Impact of Prenatal Technology Upon Attitudes Toward Disabled Infants” (1991) 9 Research in Sociology of Health Care 75.
- 26.Cf. A. Buchanan “The Morality of Inclusion” (1993) 12:2 Social Philos’y & Pol’y 105.; A. Buchanan, D. Brock, N. Daniels & D. Wikler, *From Chance to Choice: Genetics and Justice* (Cambridge: Cambridge University Press, 2000) at 258.
- 27.Buchanan *et al.*, *ibid.* at 329.
- 28.Lippman, *supra* note 18.
- 29.T. Lemmens “Selective Justice, Genetic Discrimination, and Insurance: Should We Single Out Genes in Our Laws?” (2000) 45 McGill L J. 347.
- 30.A. Kimbrell, *The Human Body Shop: The Cloning, Engineering, and Marketing of Life*, 2d ed. (Washington, D.C.: Regnery Publishing, 1998); J. Rifkin, *The Biotech Century: Harnessing the Gene and Remaking the World* (New York: Jeremy P. Tarcher/Putnam, 1999).
- 31.B.K. Rothman, *The Tentative Pregnancy* (New York: Viking Press, 1986); B.K. Rothman, *Recreating Motherhood* (New York: WW Norton, 1989); M. Stanworth, “Birth Pangs: Conceptive Technologies and the Threat to Motherhood” in M. Hirsch & E.F. Keller, eds., *Conflicts in Feminism* (New York: Routledge, 1990) at 288.
- 32.D. Nelkin & L.B. Andrews, “*Homo Economicus*: Commercialization of Body Tissue in the Age of Biotechnology” (1998) 28:5 Hastings Center Rep. 30.
- 33.B. Williams-Jones, “Re-Framing the Discussion: Commercial Genetic Testing in Canada” (1999) 7 Health L.J. 49.
- 34.M.M. Burgess, “Beyond Consent: Ethical and Social Issues in Genetic Testing” (2001) 2:2 Nature Reviews: Genetics 147.
- 35.M.M. Burgess, “Marketing and Fear-Mongering: Is It Time for Commercialized Genetic Testing?” in T.A. Caulfield & B. Williams-Jones, eds., *The Commercialization of Genetic Research: Ethical, Legal, and Policy Issues* (New York, NY: Kluwer Academic / Plenum Publishers, 1999) 181.