



# Faith & Genetics

Session 5:

Genetic Technologies and Social Justice

# Genetic Technologies and Social Justice

## Introduction

In her article entitled, “The Implications of Inheritable Genetic Modifications for Justice” Audrey Chapman concludes that:

The introduction of IGM (Inheritable Genetic Modification) in any form would have serious adverse implications for an egalitarian or needs-based approach to justice. IGM would be particularly problematic if it were to be introduced into a health care system that does not provide universal access to key health care services or regulate closely the packages offered and the practices of private insurers. Fundamental health care reform does not seem a likely option in the foreseeable future in our country, and even if it were to take place, IGM would still increase inequality and discrimination.’

It might be argued that all of the sessions preceding this one have been interesting but a bit on the esoteric side, dealing with brain twisting moral puzzles. This session may be a needed bucket of cold water, waking us up to the realities of the world we actually live in now. In the US, a country that spends more per person on health care than any other country in the world, 15% of the population has no insurance and many more are seriously under-insured. Minorities and ethnic groups bear the heaviest burden of this disparity in access. A study by the Institute of Health in 2002 concluded that even in cases where minorities have equal access to health care there is a differential in the quality of that care. Chapman calls this “therapeutic discrimination.” At a time when we desperately need to address fundamental health issues such as chemical exposure, obesity, inadequate prenatal care and drug use, genetic technologies may seem a luxury preoccupation for the rich. Some argue, like Chapman, that any introduction of IGM (and perhaps other genetic technologies) into a system which is discriminatory and class-based will only make things worse. In Canada, it is not so much this political question as that of scarce resources.

Given the amount of money spent on health care in Canada, and given the pressure to spend even more to address the issues in our health care system, it is possible that the use of genetic technologies should not be covered in a universal health care system such as ours. Even now, new and expensive therapies are being carefully assessed for their effectiveness and toxicity risks compared to established therapies that they meant to replace or add to. Decisions for approving funding should be based first on the most important outcomes such as improved survival or curability. Difficult decisions will have to be made that will likely exclude funding for some patients. Distributive justice will involve the criteria chosen to include and exclude different patients to receive government funding for a given new treatment. New therapies produced through genetic technologies should be scrutinized by similar criteria.

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We can ask what type of genetic testing should be admissible and who should be considered eligible for such testing? Should it depend on whether it is deemed life-saving (needed to determine urgent treatment)? What if it is requested for non-therapeutic reasons (e.g., demands of insurance companies for a battery of tests)? Would we think this latter type of testing worthy of public funding?

If expensive genetic technologies are publicly funded, thus making them more accessible, what health services would they displace? If privately funded, how would we regulate the worst effects of the disparity in access? Will the ability to screen for more and more diseases and disabilities more and more cheaply lead to changes in our attitudes toward disability? Will there be increasing pressure not to produce any child with a disability? Will health insurance, especially employer based health insurance, pressure employees to take genetic tests to find “pre-existing conditions? Will our knowledge of genetics change our ideal of equality since we may discover great differences in our “natural endowments? Some even argue that our species will eventually split because the disparities in these natural endowments will become so great.

While many questions are raised by the availability of new genetic technologies, in this session we will limit our discussions to three key questions raised by genetics for our concept of social justice. But first we need to articulate our understanding of social justice. Only then can we discuss questions raised by the use of genetic technologies that in some way affect social justice in our communities.



# Genetic Technologies and Social Justice

## Our Understanding of Social Justice

This session asks us to think about the intersection of genetics and faith from a social perspective. We have already considered some ethical questions from the point of view of the individual and from, for example, the point of view of couples thinking of marriage, who begin to realize that one's proposed spouse brings a specific genetic inheritance to the relationship. Parents are also faced with difficult situations when prenatal or pre-implantation genetic diagnosis indicates that their child, either at the embryonic or fetal stage, suffers from some serious illness or disability.

What are the implications of our personal values and decisions involving society as a whole? For example, we know from history what happens in societies where a policy of eugenics becomes acceptable, and where those who lead that society make ultimate decisions as to who should live, and who should die. The world judged Nazi Germany to be morally bankrupt in its eugenic campaigns against different sectors of society such as those with mental and physical disabilities. This was evident well before it went on to the wholesale slaughter of Jewish society in the concentration camps. While today's questions are different, the same possibility of controlling and shaping society that discriminates against citizens with certain characteristics now presents itself through the information that becomes available through genetic testing.



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Some people still believe that society should be cleansed of its mentally and physically unproductive members. This can come in the form of pressure to abort fetuses with physical or genetic evidence of mental or physical disabilities or to threaten not to subsidize their care with public funds if they are allowed to live. These messages speak volumes about the kind of society that some people want, i.e., free of anyone who is disadvantaged, disabled and, therefore, perceived as a liability. Yet most of us become disabled in some way if we live into old age in any event, no matter how strong and vigorous we have been in our youth. Will we, in turn, be perceived as “liabilities” and users of scarce resources, as some proponents of euthanasia point out? This has obvious implications for a society in which the proportion of elderly citizens is steadily increasing.



The question of scarce resources does concern us all, however. With shrinking budgets and expanding medical and surgical possibilities, how do we decide who get funding for what treatments in a universal health care system? Most of us see the system as operating on a fairly equitable basis, but some circumstances pose problems. For example, how do we decide who should receive donated organs when there are not enough to go around for those in need? For example, should younger people have priority as occurs in the UK? Is this outright discrimination against older people and if so, what other eligibility criteria be added? This type of question has to be dealt with in an overloaded health care system.

Even deeper questions of social justice are raised by those who favour a fee for service system, or privatized health care, where a treatment may be prioritized on the basis of the ability to pay rather than urgency of need. Even in Canada, of the inability of poorer citizens with no extra insurance coverage to pay for certain drugs or dental care is an ongoing problem involving social justice. No health care system is perfect and these issues are real and ongoing. This is the background to our discussion of faith, genetics and genetic testing



# Genetic Technologies and Social Justice

## Main Question for Scenario 5.1

Will genetic technologies affect ethnically related social problems? If so, how?

There is widespread belief that ethnicity is a genetic rather than social characteristic, and, while it is true that certain ethnic groups are carriers of some specific diseases, it is not the case that such diseases are confined only to those ethnicities. There is the danger that certain groups could be stereotyped or that, for example, intermarriages would be looked at askance out of fear of passing on such genetic problems. Questions arise as to how best to address these issues with the sensitivity required, yet with the need for prudential advice. Francis Collins writes that "...race is an imperfect surrogate for ancestral geographic origin, which in turn is a surrogate for genetic variation across an individual's genome." (<http://www.nature.com/ng/journal/v36/n11s/full/ng1436.html>) He notes that many think that race and ethnicity are too flawed as concepts to be helpful in working out race-health concerns. The message for us is that, while there are some diseases specific to some races or ethnicities, we have to be careful not to presume too much, nor to perpetuate stereotypes or prejudices linked to some diseases.

### Scenario 5.1

#### The Use of BiDiI

##### Narrative

For the past two years you have been a member of a Health Canada committee that approves the testing of new drugs. You are currently charged with making a recommendation regarding the drug known as BiDiI (isosorbide dinitrate and hydralazine hydrochloride). You are convinced that the drug is sufficiently safe and effective to be approved. You are concerned, however, about how the drug is to be marketed. Its maker NitroMed intends to market this drug to a particular ethnic population, based on studies that show it to be particularly effective in that group. Little was done to isolate the particular genetic profile that might make this drug more or less effective. You have done enough reading to understand the debate that approval of this drug will raise since it is being targeted for use in a particular group as though it were established that ethnicity is a genetic rather than social category. Further, studies show there is more genetic variation within that group than there is in other ethnic communities. Overall, further studies show that BiDiI has been effective in treating African-Americans, but it is feared that since only African-Americans participated in clinical trials, some think it is only effective within that group, whereas it may be more universally beneficial.



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## Questions

1. What considerations would you bring to bear in formulating a recommendation to Health Canada with respect to the manufacture and use of this drug?
2. Even though you understand that there is a preponderance of evidence in favor of BiDiI's safety and effectiveness, you also understand that the science behind the marketing decision is shaky. You know that the marketing will inevitably reinforce the dubious idea that ethnicity is a genetic category. You also understand that there will no doubt be a public controversy about the decision should the drug be approved for use in that particular community. How will you weigh these considerations? Is your role on this committee **ONLY** about the safety and effectiveness aspect of drug approval?



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## Main Question for Scenario 5.2

Will genetic technologies affect socio-economic problems? If so, how?

It seems to be an axiom of history that those who have power and advantage maintain that power and advantage if they can, often at the expense of those without power or advantage. In the film, *Gattaca*, we find ourselves in a world that has divided into two groups, the genetically engineered who are designed for the highest skilled jobs and the “invalids” who are given menial tasks to support the work of the engineered class. Is this an extension of the logic of our economic system today, especially if we throw genetic technologies into the mix? According to Neal Postman every technology has winners and losers, those that benefit and those that suffer. Who will benefit from the genetic revolution? Who will suffer? What choices will shape how we use genetic technology?

### Scenario 5.2

#### Narrative

Janet is applying for a job at Applesoft, a large computer manufacturer in Mississauga. She is excited about this opportunity and looks over the job application very carefully. They have extraordinary benefits, particularly in the area of health. They pay 100% of all health related costs for employees and all immediate family members. There is just one caveat. The “health history” portion of the application includes genetic testing. All her immediate family members must be sequenced and profiled. The job is not dependent on the outcome of this test unless it reveals a life threatening or seriously debilitating disease which would affect Janet’s job performance in the near future and cost the company a good deal of money. If the tests reveal the presence of a genetic marker linked to the high probability of less serious illnesses or disabilities Janet will still be offered a job, but her health premium and those of her family members will be based on the actuarial tables for the set of probabilities—the “risk pool” revealed in the genetic profiles. Janet seems to be in good health and she is not aware of any major health issues on either side of her family or that of her husband. Janet decides to discuss the situation with her husband, the kids, and you, her close friend.

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## Questions

1. This case is similar to the GenLife case discussed in session two. In this case Janet and her family are being asked to disclose genetic information in exchange for a potentially good situation, a good job with great health coverage. As a close friend, what response would you make to Janet?
2. It is a common, and some would argue reasonable, request that insurance applicants disclose pre-existing conditions. Physical exams and family health histories are sometimes part of the process of assessment and the assignment of a risk pool. How is genetic testing different, if at all, from this kind of risk assessment process?
3. What are the risks Janet and her family take when they take these tests? Apart from the possibility that Janet may be turned down by Applesoft, what other problems could arise for them?
4. Some argue that genetic technologies will either accelerate the demise of private insurance as a way of delivering health care or further isolate those with less than ideal genetic inheritance. What do you think?
5. Does genetic testing have ANY place in assessing suitability for employment?



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### Main Question for Scenario 5.3

Will the promise of genetic technologies affect the allocation of health care resources?

Demands for testing for genetic information may affect health care budgets, and, if driven by fear rather than fact, not all requests are likely to be reasonable. Certain situations will demand such testing, e.g., the daughters of women with breast cancer traceable to the BRCA1 and BRCA2 genes. This has prompted many women to request pre-emptive mastectomy surgery based on probabilities of their developing breast cancer in the future. Not all women would develop cancerous tumours, but one can understand the internal pressures which lead to such requests. As more research uncovers genetic sources of disease, more of us will find ourselves anticipating outcomes and undergoing preemptive treatments where available. Since this will be statistically based, our health care resources may be further stretched, in some cases unnecessarily.

### Scenario 5.3

#### Narrative

A 50 year old man has surgery recently to have a malignant tumour removed from his colon. All visible tumour was removed but certain features of the tumour suggest that there is a high risk of the cancer recurring in the next five years. A treatment with some potentially troublesome side effects is available that can reduce that risk by 20% for patients with similar cancers. However, patients whose resected tumour possesses a certain mutation are much more likely to benefit from the treatment; that is, the tumour recurrence rate is reduced by 60% in patients whose tumour had the mutation while the rate is less than 5% in patients whose tumour does not have the mutation. A reliable test for this mutation is available but is very expensive due to patent protection. Colon cancer is a relatively common cancer. Clearly more lives can be saved by preventing cancer recurrence in patients whose tumours have the mutation. In addition, considerable health care funds are saved or deferred among treated patients whose tumours had the mutation. Therefore, the ministry of health decided to fund the genetic test that can discriminate which patients are more likely to benefit from the treatment.