

## **Eugenomics: Eugenics and Ethics in the 21<sup>st</sup> Century**

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### **Abstract**

With a shift from genetics to genomics, the study of organisms in terms of their full DNA sequences, the resurgence of eugenics has taken on a new form. Following from this new form of eugenics, which I have termed “eugenomics”, is a host of ethical and social dilemmas containing elements patterned from controversies over the eugenics movement throughout the 20<sup>th</sup> century. This paper identifies these ethical and social dilemmas, drawing upon an examination of why eugenics of the 20<sup>th</sup> century was morally wrong. Though many eugenic programs of the early 20<sup>th</sup> century remain in the dark corners of our history and law books and scientific journals, not all of these programs have been, nor should be, forgotten. My aim is not to remind us of the social and ethical abuses from past eugenics programs, but to draw similarities and dissimilarities from what we commonly know of the past and identify areas where genomics may be eugenically beneficial and harmful to our global community. I show that our ethical and social concerns are not taken as seriously as they should be by the scientific community, political and legal communities, and by the international public; as eugenomics is quickly gaining control over our genetic futures, ethics, I argue, is lagging behind and going considerably unnoticed. In showing why ethics is lagging behind I propose a framework that can provide us with a better understanding of genomics with respect to our pluralistic, global values.

### **Introduction**

In 1883 the term “eugenics”, coined by Francis Galton, was used to describe the betterment of the overall quality of the gene pool. The common aim for eugenicists, as Buchanan et al. (2000) write, was to ensure that persons who come into existence are capable of enjoying better lives and contributing to the better lives of others.<sup>1</sup> In pursuit of human betterment, eugenic measures were taken to minimise undesirable genes (negative eugenics) and maximise desirable genes (positive eugenics) based on early theories of heredity. Negative and positive eugenic measures taken such as sterilisation and family planning gained epidemic-like popularity throughout the early 20<sup>th</sup> century. However, during the twenties and early thirties, many scientists, academics, and others, realising the scientific inaccuracies of the early theories of heredity, resisted “classical” or “mainline” eugenics, and either denounced eugenics altogether or supported what Daniel Kelves (1995) refers to as “reform eugenics.”<sup>2</sup> Reform eugenicists supported the view that there was an important, dialectical relationship between “nature” and “nurture.” However, it wasn’t until after World War II, when Nazi Germany eliminated thousands of genetically inferior people in the name of eugenics, that the word “eugenics” was rarely spoken. Nonetheless, the eugenics movement did not dissipate altogether; reform eugenics continued to receive support, especially when the mid-20<sup>th</sup> century sparked a resurgence of interest in genetics.<sup>3</sup>

While there were a number of historical events that can be attributed to a resurrection in eugenical thinking, eugenicists took a special interest in genetics when James Watson and Francis Crick announced at a local pub in Cambridge in 1953 they had found the secret of life. On the morning of February 28<sup>th</sup> they discovered the structure of deoxyribonucleic acid—the double helix of DNA. The mysteries of the double helix led to new discoveries in genetic engineering where eugenics was, not in name, but in theory, unleashed in new directions. The eugenic assumptions underlying the heritability of traits and the degeneration of the gene pool resurfaced. With developments in genetic engineering came infinite possibilities for eliminating undesirable genetic diseases and malformations and preserving, even enhancing, desirable genetic traits.

At the turn of the 21<sup>st</sup> century, an explosion of innovations in genetic research and technology was marked by the mapping of the human genome. Fifty years after the discovery of the double helix, a comprehensive sequence of the human genome was discovered, and with it even more grandiose possibilities for changing the biological, psychological, and social dimensions of mankind. However, with a shift from genetics to genomics—the study of organisms in terms of their full DNA sequences—the resurgence of eugenics has taken on a new form. Following from this new form of eugenics, which I have termed “eugenomics”, is a host of ethical and social dilemmas containing elements patterned from controversies over the eugenics movement throughout the 20<sup>th</sup> century.

In this paper, these ethical and social dilemmas will be identified as I draw upon why eugenics of the 20<sup>th</sup> century was morally wrong. Though many eugenic programs of the early 20<sup>th</sup> century remain in the dark corners of our history and law books and scientific journals, not all of these programs have been, nor should be, forgotten. The obvious horrors of the past, along with the more subtle controversies throughout the history of eugenics, remind us of the consequences of our unethical actions and beliefs, or what happened (and could happen again) when we exert too much genetic control over the lives of individuals and groups.

But, as Troy Duster points out, though many are aware of the abuses that took place in the name of eugenics, “current advocates, researchers, and celebrants of the putative link between genetic accounts and socially undesirable behavior (or characteristics or attributes) are either unaware of the social context of that history, or they are too quick to dismiss it as something that happened among the enlightened.”<sup>4</sup> While I seek to maintain historical accuracy, given the breadth of the history of eugenics, only the most notable events have been highlighted to give you a glimpse into the political, social, scientific, and ethical dimensions of eugenics. Furthermore, the history of the eugenics movement is rather complex and controversial. Philosophers, sociologists, historians, and others have provided us with a plethora of interpretations, competing definitions, and a vast amount of examples to support their theories.

My aim is not to remind us of the social and ethical abuses from past eugenics programs, but to draw similarities and dissimilarities from what we commonly know of the past and identify areas where genomics may be eugenically beneficial and harmful to our global community. In drawing upon these similarities and dissimilarities I show that our ethical and social concerns are not taken as seriously as

they should be by the scientific community, political and legal communities, and by the international public; as eugenomics is quickly gaining control over our genetic futures, ethics, I argue, is lagging behind and going considerably unnoticed. In showing why ethics is lagging behind I propose a framework that would bring the science and ethics of genomics together, thus giving us a better understanding of genomics with respect to our pluralistic, global values.

## **Eugenics Then**

Francis Galton published his eugenic ideas in a two-part article for *Macmillan's Magazine* in 1865, which was expanded into a book titled *Hereditary Genius* (1869) before the word "eugenics" had even been coined.<sup>5</sup> The subsequent history of eugenics is rather extensive; here, it is necessary only to highlight certain key elements of that history in order to understand the impact eugenics has had on current scientific and political programs and policies.

One could argue the overall aim of the eugenics movement in the early part of the 20<sup>th</sup> century was to improve the overall quality of the gene pool through negative and positive eugenic means. Eugenics during this time, also known as American Mendelian eugenics or mainline eugenics was a mix of scientific and pseudoscientific studies and beliefs, popularising the rediscovery of Gregor Mendel's work. Eugenic programs (e.g. immigration restriction) focused either on the elimination or fostering of heritable traits. Many followers of eugenics believed that compulsory sterilisation was the most effective way to rid a population of inferior peoples. Compulsory sterilisation involved removing or destroying reproductive organs and/or tissues from the human body. With the Darwinian theory of natural selection in mind, some members of the eugenics movement believed that it was possible to 'scientifically manage' society and eliminate undesirable characteristics to purify a population; the belief was partly based on heredity and evidence showing how inferior people cannot successfully raise a normal family.<sup>6</sup>

Two underlying assumptions were shared by most eugenicists during this time. The first assumption was the heritability of behavioural traits. Most eugenicists believed that all of our social problems were rooted in our inherited traits; thus, eliminating our social problems required the minimisation of undesirable traits and the maximisation of desirable ones. In 1907, Indiana was the first state in the United States to pass a law permitting the compulsory sterilisation of genetically inferior groups, including criminals, the mentally ill, epileptics, those with physical deformities, and others who were deemed "unfit". Thousands of people were forcibly sterilised in the United States as a way to prevent the "spread" of undesirable traits; most people who were sterilised lived in state institutions and prisons. Those who possessed desirable traits, such as high intelligence, a moral disposition, and physical beauty were encouraged (and even rewarded) to find partners with similar desirable traits.

The second assumption was the fear of degeneration. Building on Darwin's theory that only the most "fit" survive, eugenicists believed that because we nurture and rescue unfit members of our population, our gene pool will degenerate with the spread of damaging hereditary traits. It was believed that to preserve our gene pool, sterilisation and other eugenic measures should be taken. The degeneration of the

gene pool may also be understood in racial terms.<sup>7</sup> Nazi eugenics, for example, aimed to preserve racial purity to prevent the degeneration of the gene pool through laws against interracial marriages, sterilisation, and finally through the brutal elimination of inferior racial stock. Although no eugenics program could compare to those initiated by Hitler, there were several immoral eugenics programs supported by governments in other parts of the world.

Prior to the Holocaust, in 1922, Harry Laughlin, director of the Eugenics Record Office at Cold Spring Harbor, published a draft law titled, “Eugenical Sterilization in the United States,” and advocated for the sterilisation of “socially inadequate” persons, which included individuals who were feeble-minded, insane, criminalistic, epileptic, inebriate, diseased, blind, deaf, deformed, and dependent (such as orphans and the homeless).<sup>8</sup> This publication led to a Virginia state law in 1924, which was found constitutional by the U.S. Supreme Court in the case of *Buck v. Bell* (1927).<sup>9</sup>

In the case of *Buck v. Bell*, members of the U.S. Supreme Court spoke in favour of preserving the gene pool through compulsory sterilisation. Justice Oliver Wendell Holmes stated, “three generations of imbeciles are enough”, referring to Carrie Buck, her mother, and her daughter, Vivian, and ruled that Carrie Buck was to be sterilised against her will to prevent the spread of idiocy. The *Buck v. Bell* case is particularly significant since neither Carrie nor any member of her family were mentally ill or possessed less than average intelligence.

Paul Lombardo has argued that the *Buck v. Bell* case was corrupt from the start. Dr. Albert Priddy, who ran the Virginia Colony where Carrie and her mother had been institutionalised for their “crimes,” had been sterilising patients under the guise of medical necessity for a number of years without legal justification.<sup>10</sup> Carrie Buck, though the victim of rape, was blamed for having an illegitimate child and deemed socially unfit, or “feble-minded,” by the U.S. government. But Carrie Buck was not subjected to compulsory sterilisation solely based on her lack of social status and moral values. Dr. Priddy testified that Carrie Buck’s mother had a record of “immorality, prostitution, untruthfulness and syphilis” and that the Buck family belonged to the “shiftless, ignorant, and worthless class of anti-social whites of the South.”<sup>11</sup> Dr. Priddy convinced the court that heredity played the key role in three generations of imbecility or feble-mindedness: “Carrie Buck, the product of a feble-minded, immoral mother produced yet another unfit member of society—her illegitimate daughter Vivian, the result of a rape.” However, Lombardo’s research revealed that Vivian had received As and Bs in school and had even been on the honour roll. David Pfeiffer has written that Justice Oliver Wendell Holmes’ decision “was incorrect on its facts, was based on now discredited scientific theories, relied upon inaccurate analogies, applied inappropriate constitutional standards, and was in conflict with many philosophical principles of the American governmental system.”<sup>12</sup> According to Lombardo, “legally mandated sterilization was the most radical policy supported by the American eugenics movement.”<sup>13</sup>

### *Resistance to Mainline Eugenics*

Despite a number of social policy successes such as the legalisation of compulsory sterilisation, the development and implementation of eugenic policies, practices and

laws did not occur without much resistance among academic and ethnic communities.<sup>14</sup> In the 1920's, reputable scientists, such as T. H. Morgan and Franz Boas, the immigrant community, and the media, among others "actively resisted popular eugenics,"<sup>15</sup> based on the central assumption that eugenics "could no longer stand on a nature *versus* nurture foundation,"<sup>16</sup> especially since the environment was shown to play a major role in biological development. For example, H. S. Jennings and his colleagues worked to "expose the fallacies, to disencumber the vocabulary, to cleanse the use of their science,"<sup>17</sup> arguing for the dialectical role of nature and nurture in biological development. In looking at the measurement of hereditary intelligence, Walter Lippmann, a journalist for the *New Republic* "argued that mainline eugenicists disregarded the findings of both biologists and social critics as to the importance and legitimacy of environment in physical, social, and intellectual development."<sup>18</sup>

Nevertheless, even with much academic and ethnic resistance based on well-founded research in biological and behavioral development, Sheldon writes that such factors were not nearly as effective in constraining eugenics as were others, including the economic collapse of the 1930s and the Second World War.<sup>19</sup>

But, it should be noted that even the First World War had influenced a significant withdrawal of public attention regarding eugenics, including an overt "stopping of the presses" for books such as T.W. Shannon's *Eugenics: The Laws of Sex Life and Heredity, Nature's Secrets Revealed* (1917), written for the purposes of guiding the public to maintain social purity. On the dust jacket of a replica edition of *Eugenics* (1970), John Alcorn writes, "World War I brought new freedoms, and Nature's Secrets were not so secret anymore. In 1920, after six successful printings, The S. A. Mullikin Company of Marietta, Ohio finally stopped the presses on *Eugenics*."<sup>20</sup> Some historians argue that eugenics came in two varieties: mainline eugenics and reform eugenics. Mainline eugenics—the kind of eugenics that was rejected by many scientists and resisted by ethnic communities—"lost its scientific legitimacy after the criticisms of the 1920s," according to Kelves.<sup>21</sup> Reform eugenics, meanwhile, was arguably less racist and "appeared as a benign source of 'nature' to the newly interactive vision of the nature-nurture debate."<sup>22</sup>

### *Reform Eugenics*

Though mainline eugenics was transformed into a "seemingly less racist movement,"<sup>23</sup> immoral eugenical programs continued throughout the 20<sup>th</sup> century, especially at the start of World War II, carrying over traditional mainline eugenical beliefs regarding human improvement. In 1924 Dr. Gustav Boeters, a German, racial hygienist and advocate of compulsory sterilisation programs, argued "What we racial hygienists promote is by no means new or unheard of. In a cultured nation of the first order—the United States of America—that which we strive toward [that is, sterilisation legislation] was introduced and tested long ago. It is all so clear and simple."<sup>24</sup>

National eugenics organisations in the United States continued to popularise the human betterment through controlled breeding. Some reform eugenicists, as Kelves describes, "rejected in varying degrees the social biases of their mainline predecessors

yet remained convinced that human improvement would better proceed with—for some, would likely not proceed without, the deployment of genetic knowledge.”<sup>25</sup>

Just two years after Germany passed a compulsory sterilisation law, in 1935, American geneticist Hermann J. Muller wrote that eugenics had become “hopelessly perverted into a pseudoscientific façade for advocates of race and class prejudice, defenders of vested interests of church and state, Fascists, Hitlerites, and reactionaries generally.”<sup>26</sup> Also in 1935, in a second Supreme Court case, *Skinner v. Oklahoma*, the state of Oklahoma attempted to legally sterilise Jack Skinner, a three-time felon for robbery. Though Oklahoma law prescribed compulsory sterilisation for criminals, Skinner was not sterilised due to the ruling in 1942 by Justice William Douglas, who stated: “We have not the slightest basis for inferring that...the inheritability of criminal traits follows the neat legal distinctions which the law has marked between those two offenses.”<sup>27</sup>

After the Second World War, the horrors of Hitler’s programs and death camps placed fear in the minds of many who practiced or were once in support of eugenics.<sup>28</sup> To show that they were not connected with Nazism (or in support of negative eugenics, in general), many scientific journals changed their names. In Britain, for example, the *Annals of Eugenics* became the *Annals of Human Genetics*. In the United States, *Eugenical News* was changed to *Eugenics Quarterly* in 1954, and then renamed again in 1969 to *Social Biology*. Knowing the journal’s history, Professor S. Jay Olshansky of the University of Illinois at Chicago and associate editor of the journal (March 2003), made the following statement: “You couldn’t find anyone better to run this society...I carry a potentially lethal genetic disorder. Plus I’m a Jew. I would be the exact target of any eugenics campaign. I hate what eugenics and the Nazis stood for.”<sup>29</sup>

Many of those who did not defect from American eugenics in the 1920s, defected post World War II after recognising the slippery slope of eugenics. Edwin Black writes: “It took a Holocaust, a continent in cinders and a once great nation bombed and battled into submission to force the issue.”<sup>30</sup> Nevertheless, even after the Holocaust, some supporters of eugenics advocated to preserve the fit and eliminate the unfit by continuing the development and implementation of sterilisation programs. Black contends that “After Hitler, eugenics did not disappear. It renamed itself. What had thrived loudly as eugenics for decades quietly took postwar refuge under the labels *human genetics* and *genetic counseling*.”<sup>31</sup>

Whether the eugenics that took post-war refuge is entirely different from moral and social perspectives remains to be seen, however. Though the names of scientific journals changed along with the recognition of eugenics’ slippery slope, assumptions of heritability of unfit traits and the degeneration of the gene pool resurfaced. Throughout the United States, Europe, and Asia, thousands continued to be forcibly sterilised “for the good of society,” regardless of new scientific discoveries about human genetics. For instance, up until the end of the 1970s thousands of Native Americans were coerced into sterilisation and other measures for “appropriate” family planning through programs indirectly and directly supported by the U.S. government.<sup>32</sup> Reasons for sterilisation were partly based on the false assumption that diseases intrinsic to that population (e.g. alcoholism) would be eradicated, but a more

controversial reason stemmed from the Indian Health Service's desire to manage, or rather control, the Native American population.

Although sterilisation programs for the masses have ceased in the U.S. and Europe, governments still maintain the sentiment that genetic data contains all the information about health and disease, and if controlled, heritable diseases will not be passed onto future generations. For example, in *Mapping Our Genes*, the U.S. Congress's Office of Technology Assessment stated in 1988: 'Human mating that proceeds without the use of genetic data about the risks of transmitting diseases will produce greater mortality and medical costs than if carriers of potentially deleterious genes are alerted to their status and encouraged to mate with noncarriers or to use artificial insemination or other reproductive strategies.'<sup>33</sup>

North American and European governments generally recognise the unscientific and immoral basis for eugenical programs such as compulsory sterilisation for the masses, however such programs have not ceased in other parts of the world. For example, in 2002, BBC news reported a mass sterilisation scandal in Peru where more than 200,000 people in rural Peru were coerced or manipulated into being sterilised. The government of former President Alberto Fujimori pressured 215,227 women and 16,547 men to be sterilised with promises of "happiness and well-being" and economic and health incentives. Investigators found that there was inadequate evaluation before surgery and little post-operative care. Furthermore, only 10% of those sterilised voluntarily agreed to the surgery with the expectation that they would receive the promised incentives; others were told that if they refused, they would have to pay a fine.<sup>34</sup>

### *Newgenics*

As *in vitro* fertilisation has become a common reproductive therapy, and the cloning of animals and stem-cell technology offers promising hope for the preservation and maintenance of animal and human species alike, a whole new host of ethical and social issues have ensued.

Arthur Caplan writes: "...whether or not particular scientists or clinicians are serious or merely being prudent in publicly forswearing any interest in germline eugenics, the fact is that there is tremendous interest in American society and in other nations in using genetic information for eugenic purposes."<sup>35</sup> Sheldon (1999), on the other hand, seems to think that even though research into human behaviour raises many of the same eugenical issues, "there is no need for us to fall again into the ideological quagmire of that earlier period."<sup>36</sup> But have we not already fallen into that ideological quagmire? Chinese government has already passed a law, in 1995, to discourage people with low IQs from marrying, even though the word "eugenics" does not appear in the new law.<sup>37</sup> Such a law mimics the laws of the twenties and thirties regarding population eugenics, and "progress on ethical and social issues has been rather less dramatic."<sup>38</sup> What is even more disconcerting is that positive and negative eugenics can be pursued for both individuals and populations given our ability to manipulate genes on a genetic level. This sentiment is echoed by Black:

*'Newgenics may rise like a phoenix from the ashes of eugenics and continue along the same route blazed in the last century. If it does,*

*few will be able to clearly track the implications because the social and scientific revolutions will develop globally and corporately at the speed of a digital signal.’<sup>39</sup>*

That is, as Caplan (2004) reminds us, “Eugenic goals could be advanced through the use of embryo biopsy and the selective elimination of embryos or the selection of sperm or embryos known to be endowed with certain traits.”<sup>40</sup>

Though, as Gordon Graham points out, designing babies is an impossible dream, “entertained only by those who, whether in hope or fear, are ignorant of the real state of affairs in biological understanding and contemporary biotechnology.”<sup>41</sup> Graham wants to suggest the very thought of manipulating our genes for positive or negative eugenic purposes is currently something within the realms of fiction, but this only puts an end to the practical question and “does not entirely conclude the moral argument.”<sup>42</sup> The President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research recognised the public’s *exaggerated* concern regarding the recombinant splicing of genes, but did acknowledge genetic-engineering to be a powerful new tool for manipulating nature as well as “a challenge to some deeply held feelings about the meaning of being human and of family lineage.”<sup>43</sup> And, because of this challenge, Black, Kelves and Caplan, among many others, reveal our failure to keep up with the moral, legal and technical implications of genetic research and technology. As an appropriate summation, Kelves writes:

*‘...the more masterful the genetic sciences have become, the more they have corroded the authority of moral custom in medical and reproductive behavior. The melodies of deicide have not enabled contemporary men and women to remake their imperfect selves. Rather they have piped them to a more difficult task: that of establishing an ethics of use for their swiftly accumulating genetic knowledge and biotechnical power.’<sup>44</sup>*

So, with the development of genetic engineering in the late 20<sup>th</sup> century, including developments in genetic screening, gene therapy and enhancement, and various reproductive technologies, public fear and hesitation has ensued, especially since the ethical and social implications of this new science are not completely known. In trying to understand the ethical and social implications of genetic science, academics, scientists, and others began to discuss in great detail the moral wrongs of eugenics programs from the early 20<sup>th</sup> century as a way to prevent future moral injustices. In discussing why eugenics of the 20<sup>th</sup> century was morally wrong, I present, in brief, five theses developed in 2000 by Allen Buchanan, Dan W. Brock, Norman Daniels, and Daniel Wikler.<sup>45</sup> Though there are further ethical issues and dilemmas that characterise eugenics of the 20<sup>th</sup> century, I believe the following five theses capture the most essential moral wrongs of eugenics and are useful for looking at some of the moral concerns surrounding eugenomics today.



## Why Eugenics of the 20<sup>th</sup> Century Was Morally Wrong

Buchanan *et al* present five theses for why eugenics was morally wrong. These theses comprise 'Replacement, not Therapy,' 'Value Pluralism,' 'Violations of Reproductive Freedoms,' 'Statism' and 'Justice'. Although each does reveal the moral wrongs of eugenics, the authors endorse the fifth thesis on justice, which was the central moral problem of eugenics and, as I show, is a moral problem of eugenomics.

The first thesis, *Replacement, not Therapy*, suggests that in the aim to better the lives of individuals and groups, family planning and other programs were wrongfully designed to prevent the *possibility* of passing on undesirable traits to future generations. Instead of preventing the heritability of traits, persons or groups possessing undesirable traits should have been treated or cared for. For example, instead of sterilising alcoholic persons to prevent the "spread" of alcoholism to future generations, the morally right thing to do would be to treat the individual with alcoholism. Buchanan and others have shown that this effect is not unique to eugenics. Other policies and decisions such as conservation policies affect how "individuals will be conceived and born". Furthermore, this thesis does not support genetic screening for those serious conditions which are life threatening or greatly reduce the quality of life of a person born to those heritable conditions.

The second thesis, *Value Pluralism*, suggests that supporters of eugenics failed to acknowledge and appreciate the plurality of values in their attempts to characterise human perfection. Mainline eugenicists of the United States and United Kingdom, especially those of the elite, upper classes, looked down on those whose manners, appearance, and values were unlike their own. However, as evidenced by the pre-Nazi, eugenic views and practices, not all eugenicists failed to acknowledge value pluralism. The authors explain that although mainline eugenicists "despised the underclass for not resembling themselves, the traits the eugenicists believed heritable and worthy of cultivation were ones valued by people with widely varying ideals of personal development, plans of life, and family structure."<sup>46</sup> Furthermore, the authors suspect that in the future value pluralism will play an important role and constitute a significant challenge to ethical guidelines and policies; there will be individuals and groups who will hold unconventional values and who will chose to act upon them with the support of genetic technologies.

The third thesis, *Violations of Reproductive Freedoms*, refers to the way in which many of the eugenic programs were wrongfully forced upon people, thus inhibiting them from making informed, procreative choices, e.g. compulsory sterilisation programs. However, not all eugenic programs violated reproductive freedoms; many people, for example, were sterilised voluntarily. Although violations of reproductive freedoms were "the most notable wrongs done in the name of eugenics" and should be of moral concern, it is not the central moral problem defining eugenics. "[Diane] Paul has argued that, at least in the United States, reproductive freedoms are sufficiently well-established that we need not entertain serious fears about the return of a coercive eugenics in the wake of the Human Genome Project...the same may not hold in countries with weaker traditions that lack entrenched legal protections for reproductive freedom..."<sup>47</sup>

*Statism*, or state involvement, is the fourth thesis concerning the immorality of eugenics. Many of the large scale eugenics programs from compulsory institutionalism and sterilisation to the slaughtering of thousands “unworthy stock” were organised, implemented, and protected by the state. However, as Buchanan *et al* write, statism alone is neither essential for eugenics programs nor does it define its immorality. Eugenics programs have been organised and implemented by individuals and private institutions without any state support.

The fifth and final thesis, on *Justice*, is the central moral problem of eugenics. There was an obvious separation between the classes where people of the underclass possessed undesirable traits and, because of this, were subjected to unjust and intolerable cruelty. “The injustice of this distribution of burdens and benefits is evident, even when we make the effort to accept, for the sake of argument, the eugenicist’s warnings about degeneration and their promise of a better society to come.”<sup>48</sup> Not only was justice the central moral problem of eugenics during the 20<sup>th</sup> century, it appears to be the central moral problem surrounding genomic data and technologies today. Buchanan *et al* explain: “Control over genetic data is the single greatest concern among bioethicists and the general public concerning the new genetics. While this is usually conceived in terms of familiar from medical ethics—that is, as a right of confidentiality and privacy—its deeper significance is one of distributive justice.”<sup>49</sup> That is, there is a growing concern over not just whether our genetic information will be kept private, but also whether genomic resources will be distributed in ways that do not foster discrimination or inequality among different ethnic, racial, economic, and gender-based groups. However, I must emphasise that although genetic discrimination is not the same as eugenics, it can be a negative consequence of eugenics when individuals and/or populations are selected not on the basis of which genes should be enhanced or eliminated, but on factors other than gene selection (or any type of genetic and reproductive technology), such as race or economic status.

While there is a division between those who have a genetic disease or carry a deleterious gene(s) and those who do not, this division runs deeper than differences in health status. Those who have a genetic disease or carry a deleterious gene may not only encounter poor health but social and economic hardships as well. For example, by having genomic information accessible, employers may be so inclined to hire only “fit” employees, thus segregating the fit from the unfit through employment opportunities. Justice as one, though not necessarily the *only* central moral issues for eugenomics will be presented in the following section. I show that both justice and value pluralism are two significant theses for understanding the ethical dilemmas and issues surrounding eugenomics.

### **Eugenomics Now**

Defined as the study of the full DNA sequence of an organism, or genome, genomics has the power to do what most other interventions in health and disease cannot do. In understanding genetic material on a large scale, genomic researchers can detect genetic errors that cause or are factors of disease. Unlike the eugenic science conducted in the early 20<sup>th</sup> century, where hereditary diseases and deformities were determined by a person’s appearance, personality, behaviour, or genealogy,

eugenomic science focuses on the smallest units of heredity within the larger scale of the genome. Similar to eugenics, the aim of eugenomics is to improve the overall quality of the gene pool by minimising disease and deformity and by maximising, through enhancement, genetic features that will better a person's life. However there are several differences between eugenics then and eugenomics now.

The differences between eugenics and eugenomics not only lie in their histories, but in the sociocultural, political, economic, legal and ethical contexts through which their methodologies are examined and practiced. Duster reports that most commentators believe there are significant differences from the past when speaking of the dangers of eugenics.<sup>50</sup> Some have argued that vulnerable groups have the ability and resources to protect themselves from resurgence in eugenics. Because we know many of the factors that led to the ethical, social, and legal problems of eugenic programs in the early 20<sup>th</sup> century (e.g. inaccurate theories of heredity, disrespect for human life, the inability to identify and correct mental and physical abnormalities, etc.), some ethicists believe that the knowledge gained from the consequences of our past actions and beliefs will protect us from future immoral occurrences.

But, as Duster suggests, “[Despite this] there is a persistent search for ‘hard data’, for a biological or biochemical explanation for homelessness, mental retardation and mental illness, alcoholism and drug abuse, even unemployment, crime, and violent and abusive behavior.”<sup>51</sup> And, although much of the horrors of past eugenics programs (e.g. mass compulsory sterilisation practices) may be avoidable in the future, problems of justice and fairness will be just as difficult.<sup>52</sup> This is not to say that we are re-entering a eugenics movement similar to that of the 1920s. We are at the forefront of a whole host of genomic possibilities without a clear understanding of either *justice* or of *value pluralism*, an understanding that would arm us against potential eugenical abuses, which can lead to discriminatory practices, economic injustice, and social stigmatisation. So what are these eugenical abuses? What exactly are the differences and similarities between eugenics (mainline, reform, and new) and eugenomics besides the progression of scientific discovery?

Robert Proctor explains that eugenics is a relevant topic today: “At one level, it presents a dramatic case of how genetic knowledge (and genetic ignorance!) can be coupled with repressive state policy to deprive individuals of rights and liberties. It also illustrates how scientists may lend their support to political movements, giving them an air of respectable legitimacy.”<sup>53</sup> Many of the abuses associated with eugenics throughout history can be attributed to “genetic ignorance,” fixed with a social misuse of popularised theories and beliefs about heredity and the role of genes. Proctor argues that there is an equal danger from the abuse of genetic misinformation. This sentiment is echoed by the NIH working group coordinating research on the ethical, legal, and social implications (ELSI) of the Genome Project, which warns that “if misinterpreted or misused, these new tools could open doors to psychological anguish, stigmatization, and discrimination” for people who carry diseased genes.<sup>54</sup>

For instance, the vulnerable populations, once defined by race, religion, disease and deformity, will be those people who are unable to afford the luxuries of genetic engineering (genetic therapy or genetic enhancement) and those who will not be able to receive adequate healthcare and employment due to genomic discrimination.

Jeremy Rifkin, author of *The Biotech Century*, writes: “Our notions of sociality and equity could be transformed. Meritocracy could give way to genetocracy, with individuals, ethnic groups, and races increasingly categorized and stereotyped by genotype, making way for the emergence of an informal biological caste system in countries around the world.”<sup>55</sup> Vulnerable populations may not be identified by physical appearance or mental capabilities but by what is contained in their genomes. For instance, recently developed genetic databases may subject people to discrimination because of defects within their genomes. Instead of a person being forcibly sterilised because his or her parent committed repeated crimes of petty theft, was “feebleminded”, or raped, for example, a person today may not receive healthcare or be able to find employment because his or her entire DNA sequence, including a family history of “defective genes”, was recorded in a national database and disclosed to employers and insurance companies. Proctor explains that the stigma against genetic disease may lead to an extension of coercive powers of public health, such in the case of state and federal laws requiring notification of health conditions.<sup>56</sup> Black writes:

*‘Humanity should also be wary of a world where people are once again defined and divided by their genetic identities... In the twenty-first century it will not be race, religion, or nationality, but economics that determines which among us will dominate and thrive. Globalization and market forces will replace racist ideology and group prejudice to fashion mankind’s coming genetic class destiny...First, newgenics will create an uninsurable, unemployable and unfinanceable genetic underclass. The process has already started.’<sup>57</sup>*

The public is not the only group subject to discrimination and hardship. Scientists may run the risk of losing their science to the control of corporations and to the state—a potential moral wrong under the thesis of statism. In 1988, Jeremy Rifkin predicted that big businesses would capitalise on genetic and genomic research. Genes, he said, will become the “green gold” of the biotech century and customised babies could pave the way for the rise of a eugenic civilisation in the 21st century.<sup>58</sup> Furthermore, Rifkin purports “the very practice of biotechnology—gene splicing, tissue culture, clonal propagation, and monoculturing—is likely to result in increased genetic uniformity, the narrowing of the gene pool, and loss of the very genetic diversity that is so essential to guaranteeing the success in the biotech industry of the future.”<sup>59</sup>

Proctor (1992) suggests that among all the potential dangers of human genomics, “to my mind the most all encompassing is the danger of its confluence with a growing trend toward biological determinism.”<sup>60</sup> He argues that the biological determinism characteristic of the eugenics movement in the early 20<sup>th</sup> century has not disappeared and suggests that genetics continues to remain a “science of human inequality.”<sup>61</sup> And, in part, this inequity is based on a misunderstanding of genomics and the assumption that everything is genetic. Proctor finds that “If there is a disconcerting continuity between genomics and eugenics, it is the fact that both have take root in a climate where many people believe that the large part of human talents and disabilities are heritable through the genes.”<sup>62</sup>

With the current and potential moral problems of eugenomics there is little global effort into developing ethical policies and regulations that protect people from such eugenomic injustices while, at the same time, showing support for genomics research. In the next section I describe why ethics lags behind genomics and suggest how we can put ethics and genomics into a dynamic framework that provokes collective discussion and deliberation and guides our ethical decision- and policy-making.

### **Ethics Lags Behind**

In recent genethics literature, George Annas examines the division between scientists and non-scientists and how this division creates obstacles for serious moral deliberation and critical developments in policy-making involving the social and economic implications of genetic research and technology. Annas explains how non-scientists believe that scientists “underestimate the danger in their work, and vastly overestimate its importance”. Scientists, on the other hand, believe the fields of social policy and ethics “lag behind” science, failing to keep up with advancements and progress in science and technology.<sup>63</sup>

The field of genomics is as complex and mysterious as the human genome itself, and attempting to unlock the secrets of our biology does not follow without ethical and social implications. In determining what these implications will look like, non-scientists must work with and not against the scientific community by keeping up-to-date with what researchers are thinking and doing, the technologies they are using, and their immediate and future goals. Likewise, scientists have a moral obligation to consider potential harmful, social and psychological consequences of their research and technology; they must work with non-scientists to achieve a better understanding of the plurality of values held by the global community.

I believe Annas is correct in saying that social policy and ethics “lag behind” science. Non-scientists and scientists need to work together to achieve a collective understanding of the social and ethical implications of genomics. However, there are several reasons why ethics lags behind science besides the lack of effort and responsibility by scientists and non-scientists in trying to understand and predict the potential benefits and harms genomics research and technology may bring to the community.

Social policy and ethics lag behind because, first, there is a lack of public discourse and deliberation. While many scientific and non-scientific groups may discuss the social and ethical issues surrounding genomics, much of their discourse lacks critical evaluation and reflection. Even with a diverse representation, committees, though able to address significant social and ethical considerations for genomics, find it difficult to deeply analyse and evaluate these considerations given the plurality of values within their national and global communities. For example, when deliberating whether genomics will give more reproductive freedom to women, we need to consider the variety of social, cultural, and moral values and attitudes women may have regarding prenatal screening, birth control, health and disease, and so forth. Women may feel that they will have less reproductive freedom if groups, in following a particular set of values and beliefs that *seem* universally applicable to all women, expect them to conform to their standard system of values and beliefs.

Public deliberation provides an open forum for pluralistic values and interests to be discussed and evaluated. Before stopping the progress of science through bans and moratoriums, we should collectively address genomics and its social and moral implications. In the United States, for example, there is a ban on federally funded embryo research. Parens and Knowles believe that this ban should be lifted, for “we cannot have responsible oversight of reproductives research and practice, nor of embryo research generally, if we do not first acknowledge that we already support those activities in a wide variety of ways.”<sup>64</sup> The ban on embryo research, or any future ban imposed without public deliberation, prevents open discourse between researchers and non-researchers. Furthermore, creating an open forum for public deliberation should not entail a separation between the private and public sectors; the gap between private and public sectors should be closed, especially among those private government sectors that disclose very little, if any, of their genomic research for military applications to the public (e.g. biowarfare research). Proctor writes:

*‘Whether the NIH ELSI group tackles this problem remains to be seen. If, however, as some predict, biology supersedes physics as the “science of the twenty-first century,” and if the militarization of science continues unchecked (nearly 70 percent of all U.S. federal research and development funding presently goes to the Department of Defense), then one can certainly expect the science of life to assist in the science of death.’*<sup>65</sup>

If the militarization of genomics goes unchecked in the United States or anywhere in the world, if it does not filter into public discussions, deliberations and resolutions, genomics, and corollary eugenomic policies worth developing, it could be masked by public fear and global misunderstanding.

Second, there is a general lack of understanding of justice and the moral principles that follow. Justice was the central moral problem of eugenics and is quite possibly the central moral problem of eugenomics. There was and still remains an obvious separation between classes. While many of the people of the underclass were targeted as having undesirable traits in the early 20<sup>th</sup> century, today members of the underclass are not afforded the same opportunities in receiving insurance benefits and employment and are often subjected to unjust treatment in the healthcare sector. Genomics can be translated into healthcare benefits such as better, reliable diagnostic procedures, early detection, prediction and elimination of disease and illness, and the identification of genes that contribute to good health and healthy living. However, in practice, genomics may only deliver these benefits to those who can afford them or to those who are deemed “unfit” and who may be forcibly required to eliminate heritable disease for “the good of the gene pool.”

To avoid unjust eugenomic practices that discriminate, segregate, disrespect and avoid issues of confidentiality and privacy, subjecting persons to unfair and intolerable treatment, we need to understand which moral principles ought to guide our decisions and actions. In developing a better understanding of our current (and future) moral problems we can begin to determine which decisions and actions we ought to make so that eugenomics does not mirror the past problems associated with the eugenics movement throughout the 20<sup>th</sup> century.

Third, we lack a dynamic, ethical framework to understand the key social and ethical issues surrounding genomics and its effects on the global community. Like many ethicists and social policy makers, Buchanan *et al* offer no ethical framework for regulating genetics and genomics: “Instead, our aim is to explore the resources and limitations of ethical theory for guiding deliberations about public policy. To borrow a metaphor from molecular genetics, we only hope to produce a map featuring the most important moral markers, nothing like a complete sequence of ethical steps into the genetic future.”<sup>66</sup> Though exploring the resources and limitations of ethical theory is essential, ethicists and policy makers need to develop a dynamic framework through which we can begin to make ethical decisions and policies that cohere with the theories and applications of genomic research as well as with the values and beliefs held by our global community. This framework would encourage moral discourse and deliberation among scientists and non-scientists and would identify and critically reflect upon moral theories and principles, namely justice, and their limitations with respect to our pluralistic values and beliefs. The framework I propose is similar to the Theory of Wide Reflective Equilibrium (WRE), introduced by John Rawls and developed by Norman Daniels<sup>67</sup> and Kai Nielson<sup>68</sup> to address questions of ethics and justice. In working through our moral rules and principles, our background beliefs and theories, and our particular moral judgments (the three elements of WRE), we are able to achieve some coherence among each of these elements.<sup>69</sup>

The framework—a coherence framework—is dynamic in that at any time we are able to make adjustments to any three of the elements and restore coherence. By making the moral judgment, for example, “genomic data ought not to be given to employers”, we can look at those moral rules and principles concerning equal opportunity, respect for persons, and so forth, and the particular cultural and social values of the working class, along with what we know about genomic theories, practices, and applications. By working back and forth among each of these elements we are able to achieve a coherent fit, while developing ethical policies and standards from the results of this dialectical interplay. Just as the coherence framework is itself subject to revision, so are the ethical policies and standards that are created from it in the process.

Although no such ethical framework has been fully established and implemented, several working groups have begun to look at genomics from multiple perspectives (or the elements of the framework I have briefly described), picking up the pieces of its implications and uses for science, medicine and society. In examining how these components relate to each other, several challenges have been documented. In the following section I will describe how members of the US National Human Genome Research Institute have begun to understand the implications for genomics research and the challenges these pose for scientists, clinicians, ethicists, policy makers and others. Though the authors’ analysis is at its primary stage, I believe it is an important step for determining which elements need to be placed within a framework such as the one I propose. The coherence framework is significant because it fosters collaboration, a sharing of different ideas and perspectives, and does not limit ethical analysis to a set of competing principles or rules that merely define and guide our moral actions and beliefs. With a coherence framework, moral theories and principles are critically examined in light of our individual, community, and global values, as well as with what we currently know about genomics within political, scientific, economic, and social spheres. The danger we face in trying to understand the ethical

and moral impact of genomics on the individual and on the population involves limiting ourselves to a specific set of principles, laws and policies, and to a particular knowledge base. In other words, just as Proctor fears, misunderstanding or misinformation could threaten our belief systems, and thus compromise public deliberation and open discourse.<sup>70</sup> We may find ourselves limited in the way we develop and implement policies and ethical guidelines, leaving us open to future eugenical abuses.

Now, a coherence framework is not necessarily the “magic bullet” for opening lines of communication and creating a better forum for ethical deliberation and resolution. There are serious limitations such as governmental or political resistance for openly discussing all aspects of genomics, notably genomic knowledge used for offensive or defensive military action. Furthermore, the coherence framework may not be useful when there are power struggles among individuals who assume “expert roles” in ethical deliberation and resolution. Yes, I am talking about my own kind—the bioethicists—who have been trained in a variety of disciplines ranging from law to medicine to philosophy, but who, unfortunately, as Black puts it “are of little help in this hurtling new world.”<sup>71</sup> With my lack of objectivity about this issue, I disagree; bioethicists *can* be useful in formulating new approaches to moral deliberation, contributing personal and hypothetical case scenarios that challenge our critical thinking about genomics and eugenomics, and synthesising a variety of perspectives among several areas of thought so that discussion is ethically based and not politically driven. But, I can also see where Black (and others) has difficulty supporting bioethicists and the discipline of bioethics. Black writes:

*‘The still emerging field of bioethics includes self-ordained experts who grant interviews to television talk shows and newspapers even as they consult as scientific advisors to the very corporations under question. The do’s [sic] and don’ts of genetic tinkering are being revised almost daily as the technology breeds an every-evolving crop of moral, legal and social challenges that virtually redefine life itself. It will take a global consensus to legislate against genetic abuse because no single country’s law can by itself anticipate the evolving intercollaborative nature of global genomics.’<sup>72</sup>*

While I agree with Black that there needs to be a global consensus, in order to achieve this goal, a framework such as the one I recommend needs to be in place, as a starting point, to organise our ethical, legal, social, economic, and scientific ideas, theories, and knowledge, while eliminating our biases, fears, misunderstandings, misinformation, and the like—that which contributed to past abuses, including those associated with eugenics.

### **Picking up the Pieces**

In a recent paper published in the journal *Nature*, on behalf of the US National Human Genome Research Institute, Francis Collins *et al* describe three major themes and six cross-cutting elements characterising a vision for genomics research.<sup>73</sup> This vision for genomics was the result of lengthy discussions, workshops and consultations involving scientists and members of the public over a two-year period. The themes include genomics to biology, genomics to health and genomics to society; the six cross-cutting elements include resources, technology development,



computational biology, training, ethical, legal and social implications (ELSI), and education. For each of the three themes the authors also present a list of challenges.

Each of the themes and cross-cutting elements are significant to genomic research. However, my interests lie in one particular theme and one cross-cutting element: genomics to society and ELSI. Genomics to society refers to the promotion of genomics to maximise benefits and minimise harms. Collins *et al* write:

*'In the next few years, society must not only continue to grapple with numerous questions raised by genomics, but must also formulate and implement policies to address many of them. Unless research provides reliable data and rigorous approaches on which to base such decisions, those policies will be ill-informed and could potentially compromise us all.'*<sup>74</sup>

Disguised within this theme is the notion of eugenomics; in order to maximise benefits and minimise harms, significant efforts are required to understand the possible ethical, social and cultural effects genomics has on our global community. Presented within this theme are four grand challenges including 'Genomic Policy,' 'Genomics, Race and Ethnicity,' 'Uncovering Genomic Contributions,' and 'Defining Ethical Boundaries.' Before disseminating each of these challenges, it is important to answer the question of why *this* vision for genomics research is significant. Collins *et al* and those working closely with NIH ELSI have made a significant step toward a collaborative effort in informing eugenomic policies grounded in ethical considerations. And though this is a monumental contribution worth commending, further expansion is needed to include not only the recognition, evaluation and resolution of difficult eugenomic problems (past, present or future), but also critical reflection of how global communities interpret ethical values such as justice and value pluralism, and how these values may (or may not) play a significant role in the development, implementation, and changes of future ethical policies and guidelines. The need for expansion and organisation within a framework similar to the one proposed is clear after delving into each of the four challenges presented by Collins *et al*.

### *Genomic Policy*

The first challenge is to develop policy options for the uses of genomics in medical and non-medical environments. The authors indicate that the primary concern involves discrimination in health insurance and employment. Though many US states have passed anti-discrimination legislation, enforcing this legislation may be difficult. Because anti-discrimination legislation has not been enacted and supported nationally, a division has been created between those who are and those who are not protected from discrimination. The authors indicate that the US Equal Employment Opportunity Commission has ruled that the Americans with Disabilities Act should apply to discrimination based on predictive genetic information; however the legal status of that construct remains in some doubt.<sup>75</sup> Furthermore, an executive order was made to protect US government employees against genetic discrimination, but unfortunately this order does not apply to non-government workers. Discrimination in employment and health insurance is not concentrated within the United States. Current laws in the

United Kingdom do not protect employees from genetic discrimination as well; employers may use genetic test results as a basis for denying employment to people.

Some may argue that ethics and social policy do not lag behind since organisations, public forums, state and country statutes are imposing bans, moratoriums, regulations, laws, recommendations, etcetera to govern how research ought to be practiced and to determine which outcomes and aims are acceptable. Various regulation and oversight committees have been developed to govern research conduct. For example, the Recombinant DNA Advisory Committee (RAC), a National Institute of Health Committee in the US, advises the Secretary of Health and Human Services on all matters relating to DNA research and reviews certain genetic experiments.<sup>76</sup> Presidential Bioethics Advisory Commissions have taken up both the safety and well-being issues raised by reproductive, embryo technology. However, these issues are raised on an *ad hoc* basis. Parens and Knowles explain that the *modus operandi* of President Clinton's National Bioethics Advisory Commission (NBAC) was to respond to the President's specific requests.<sup>77</sup>

Though the intentions behind these governances are respectable, they are nationally and globally inconsistent and deleterious for those who remain uninformed and unaware of both the benefits and possible dangers resulting from genomic research and public policy. For example, although Parens and Knowles believe that many groups, commissions, and agencies have influenced policy and regulation over aspects of reproductives, "there is, at best, a patchwork system of oversight." They write: "There is no standing body to promote public conversation about both the safety and well-being issues that arise in the context of new reproductive technologies."<sup>78</sup>

One example of the ineffectiveness of regulatory oversight occurred in 2000 when the American Association for the Advancement of Science (AAAS) took the position that "no genetic modifications affecting the germ line, whether intentional or inadvertent, should be undertaken until the technology's safety, efficacy, and social implications had been subject to widespread public discussion."<sup>79</sup> In addition to widespread public discussion, the AAAS believed that a system of public oversight was needed to look over private and public research. It recommended that science should slow down until such a system was established. Only six months after the recommendation, a fertility clinic reported a human germline modification in normal, healthy children whereby mitochondrial DNA (in ooplasm) from donated material was introduced into recipient eggs. The modification, Mark Frankel explains, was viewed as unethical and even illegal in parts of the United States and United Kingdom.<sup>80</sup>

### *Genomics, Race, and Ethnicity*

The second challenge is to understand the relationships between genomics, race and ethnicity, and the consequences of uncovering these relationships. ELSI programs identify and discuss the ethical, legal, and social implications of genetic research, guides research conduct, and develop public policies. The challenges of ELSI are explained in *Human Genome News*, where it is purported:

*'A continuing challenge is to safeguard the privacy of individuals and groups who contribute DNA samples for large-scale-variation studies. Other concerns are to anticipate how the resulting data may*

*affect concepts of race and ethnicity; identify potential uses (and misuses) of genetic data in the workplaces, schools, and courts; identify commercial uses; and foresee impacts of genetic advances on the concepts of humanity and personal responsibility.’<sup>81</sup>*

Collins *et al* propose that additional research ought to be done for determining how persons and cultures understand and value concepts such as race and ethnicity.<sup>82</sup> It is important to determine whether genomics affects our understanding and uses of these concepts (race and ethnicity) and the limitations genomics has in giving us a clearer or better picture of what these concepts mean and their significance in community—and self-identity.<sup>83</sup> The challenge is to conduct clinical and scientific genomics research in a way that does not lead to wrongful interpretations, discrimination, prejudices or biases. The beliefs and values of our pluralistic world community must be addressed and understood as genomic research moves forward.

### *Uncovering Genomic Contributions*

The third challenge is to understand the consequences of uncovering the genomic contributions to human traits and behaviors. This very challenge speaks to the moral wrongs that were done throughout the early eugenics movement. Research conducted in behavioural genetics (e.g. intelligence) “has been poorly designed and its findings have been communicated in a way that oversimplifies and overstates the role of genetic factors.”<sup>84</sup> As we have experienced in the past, such research has had a negative impact on individuals and groups. Further research on the interactions between genes and their environments is one important step in understanding genomic contributions to human behaviours and traits, as suggested by Collins *et al.*<sup>85</sup> But another important step is to understand the link between culture and behaviour to gain further knowledge about the various systems of values and beliefs that often shape the way people think, feel, and behave, and to distinguish, if possible, these connections from those that are biological in nature.

### *Defining Ethical Boundaries*

The fourth and last challenge is to assess how to define the ethical boundaries for uses of genomics. Defining ethical boundaries is a difficult challenge that requires a deeper understanding of not just genomic theories and applications but also of our individual and collective values. While it is important for us to determine when genomics is useful and when it is not, while attempting to be fair and respectful of difference, how we define the uses of genomics as a global community really depends on the flexibility of our ethical framework and not on where or when to draw the line. By defining ethical boundaries, we are assuming that there is some ethical line to be drawn, when, in reality, the judgments we make cannot always be determined as morally right or morally wrong. Our moral judgments are as dynamic as the values they represent and the boundaries we attempt to create will not always be, nor should be, clear. There should always be room for reflection and refinement when making ethical decisions and policies. The true challenge is to determine when our moral judgments and decisions ought to be refined or changed and to predict the impact those changes have on individuals and groups.

## Concluding Thoughts

Though highlighting these ethical and social challenges is an important development for the future of genomics research, we must identify ways to meet these challenges as I have briefly indicated: collective moral deliberation; developing a deeper understanding of the past moral wrongs of eugenics and comparing and contrasting with current (and possible future) wrongs of eugenomics; creating a dynamic ethical framework for making moral decisions and policies; and developing a better understanding of the values that contribute to our pluralistic global views. In meeting these challenges we can bring ethics up to speed with genomic science and medicine and support the positive goals of eugenomics while protecting individuals and groups from its possible dangers. The eugenics movement cannot be captured in a single event at the beginning of the 20th century, or defined as a static goal over the course of a century. Though that which eugenics describes remains the same—human betterment through the minimisation or maximisation of our genetic materials—eugenics has evolved over time with balanced support and resistance. The goals of today's eugenomics are certainly not unethical, but the paths we have followed in the past to meet those goals have been. In order to move toward eugenical goals without resistance and without moral harm, we should, as a collective, develop a comprehensive understanding of what would make us better and why. In the end we may find that eugenomics has no attainable goals because all of our human differences and similarities, whether defined as “good” or “bad,” capture the true meaning of “human betterment” in and of themselves.

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<sup>1</sup> A. Buchanan, D.W. Brock, N. Daniels, and D. Wikler. 2000. *From Chance to Choice: Genetics and Justice*. New York. Cambridge University Press: 42.

<sup>2</sup> D.J. Kelves 1995. *In the Name of Eugenics*, Massachusetts. Harvard University Press.

<sup>3</sup> Eugenic theories and practices can be traced on a continuum, however, eugenics lost its popularity due to the atrocities of Nazi Germany and quite possibly due to the slower progression of genetic science immediately following the war.

<sup>4</sup> T. Duster. 2003. *Backdoor to Eugenics*, 2<sup>nd</sup> edition. New York. Routledge: 140.

<sup>5</sup> Kelves, op cit. note 2, pp. 37.

<sup>6</sup> See H. Goddard 1912. *The Kallikak Family: A Study in the Heredity of Feeble-mindedness*. New York. Macmillan.

<sup>7</sup> Buchanan et al, op. cit. note 1.

<sup>8</sup> H.H. Laughlin 1922. *Eugenical Sterilization in the United States*. Chicago, IL. Psychopathic Laboratory of the Municipal Court of Chicago.

<sup>9</sup> A. Wellerstein. Harry Laughlin's 'Model Eugenical Sterilization Law'. Harvard University. <http://www.people.fas.harvard.edu/~wellerst/laughlin/> accessed 19 May 2005.

<sup>10</sup> P. Lombardo, “Eugenic Sterilization Laws” in Image Archive on the American Eugenics Movement, Dolan DNA Learning Center, Cold Spring Harbor Laboratory [www.eugenicsarchive.org/html/eugenics/essay8text.html](http://www.eugenicsarchive.org/html/eugenics/essay8text.html) accessed 19 May 2005.

<sup>11</sup> Ibid, pp. 2

<sup>12</sup> D. Pfeiffer. *Eugenics and Disability Discrimination*. *Disability and Society* 1994; 94: 481-99 (pp. 482).

<sup>13</sup> Lombardo, op. cit. note 10, pp. 1.

<sup>14</sup> S. Sheldon, 1999. *Inheriting Shame: The Story of Eugenics and Racism in America*, New York: Teachers College Press at Columbia University (pp. 107).

<sup>15</sup> Ibid, pp. 109.

<sup>16</sup> Ibid, pp. 108.

<sup>17</sup> Kelves, op cit. note 2, pp. 128.

<sup>18</sup> Sheldon, op. cit. note 5, pp. 121.

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- <sup>19</sup> Ibid, pp. 110.
- <sup>20</sup> T.W. Shannon. 1917 (1970 copy). *Eugenics: The Laws of Sex Life and Heredity, Nature's Secrets Revealed*. Marietta, Ohio: S.A. Mullikin Company. John Alcorn is quoted from publisher's notes on page 1 and the dust jacket.
- <sup>21</sup> Sheldon, op. cit. note 5, pp. 125.
- <sup>22</sup> Ibid, pp. 125
- <sup>23</sup> Ibid, pp. 120
- <sup>24</sup> G. Boeters, "Die Unfruchtbarmachung der geistiger Minderwertigen," *Sachsische Staatszeitung*, July 9-11, 1923; RN Proctor. 1988. *Racial Hygiene: Medicine under the Nazis*. Cambridge, Mass: Harvard University Press, pp. 98.
- <sup>25</sup> Kelves, pp.173.
- <sup>26</sup> Kelves, pp. 164.
- <sup>27</sup> Proctor, op. cit. note 24.
- <sup>28</sup> A.L. Caplan. The meaning of the holocaust for bioethics. *Hastings Center Report* 1989; 19:2-3.
- <sup>29</sup> E. Black. 2003. *War Against the Weak: Eugenics and America's Campaign to Create A Master Race*, New York, Four Walls Eight Windows Publishers, pp. 425.
- <sup>30</sup> Ibid, pp. 411.
- <sup>31</sup> Ibid, pp. 411.
- <sup>32</sup> M.S. De Fine. *A History of Governmentally Coerced Sterilization: the Plight of the Native American Woman*. 1997; University of Maine School of Law, <http://www.geocities.com/CapitolHill/9118/mike2.html> accessed 6 July 2005.
- <sup>33</sup> United States Congress Office of Technology Assessment 1988, *Mapping Our Genes*, US Congress; Washington, DC. pp. 84.
- <sup>34</sup> BBC News. *Mass Sterilisation Scandal Shocks Peru*. 24 July 2002; <http://news.bbc.co.uk/1/hi/world/Americas/2148793.stm> accessed: 5/19/2005.
- <sup>35</sup> A.L. Caplan. 2004. What's Morally Wrong with Eugenics? In: *Health, Disease, and Illness: Concepts in Medicine*, Washington, D.C.: Georgetown University Press. pp. 280
- <sup>36</sup> Sheldon, op. cit. note 14, pp. 154
- <sup>37</sup> M. Bobrow. *Redrafted Chinese Law Remains Eugenic*. *Journal of Medical Genetics* 1995; 32:409.
- <sup>38</sup> Ibid, pp. 409.
- <sup>39</sup> Black, op. cit. note 29, pp. 428.
- <sup>40</sup> Caplan op. cit. note 35, pp. 280.
- <sup>41</sup> G. Graham. 2002. *Genes: A Philosophical Inquiry*. New York. Routledge: pp. 173.
- <sup>42</sup> Ibid, pp.174.
- <sup>43</sup> Kelves, op. cit. note 2, pp. 290
- <sup>44</sup> Ibid, pp. 301
- <sup>45</sup> Buchanan et al, op. cit. note 1.
- <sup>46</sup> Ibid, pp. 48.
- <sup>47</sup> Ibid, pp. 50.
- <sup>48</sup> Ibid, pp. 52.
- <sup>49</sup> Ibid, pp. 58.
- <sup>50</sup> Duster, op. cit. note 4.
- <sup>51</sup> Ibid, pp. 132
- <sup>52</sup> Buchanan et al, op. cit. note 1, pp. 43.
- <sup>53</sup> R.N. Proctor. 1992. *Genomics and Eugenics: How Fair Is the Comparison*. In *Gene Mapping: Using Law and Ethics as Guides*. G. Annas and S. Elias, eds. New York. Oxford University Press: pp. 61.
- <sup>54</sup> Ibid, pp. 59.
- <sup>55</sup> J. Rifkin. 1998. *The Biotech Century*, New York, Penguin Putnam Inc.: pp. 3.
- <sup>56</sup> Proctor, op. cit. note 53.
- <sup>57</sup> Black, op. cit. note 29, pp 428-9.
- <sup>58</sup> Rifkin, op. cit. note 55, pp. 3.
- <sup>59</sup> Ibid, pp. 108.
- <sup>60</sup> Proctor, op. cit. note 53, pp. 76.
- <sup>61</sup> Ibid, pp. 83.
- <sup>62</sup> Ibid, pp. 83.
- <sup>63</sup> G.J. Annas. 2002. *Mapping the Human Genome and the Meaning of "Monster Mythology."* In *A Companion to Genethics*, Justine Burley and John Harris, eds. Massachusetts. Blackwell Publishers: pp. 136.

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- <sup>64</sup> E. Parens and L.P. Knowles. Reprogenics and Public Policy. Special Supplement to The Hastings Center Report 2003; 33(4): S1-S24.
- <sup>65</sup> Proctor, op. cit. note 53, pp. 75.
- <sup>66</sup> Buchanan et al, op. cit. note 1, pp. 21.
- <sup>67</sup> N. Daniels. Wide Reflective Equilibrium and Theory Acceptance in Ethics. *Journal of Philosophy* 1979; 76(5): 256-82.
- <sup>68</sup> K. Nielson. Relativism and Wide Reflective Equilibrium. *Monist* 1993; 76(3):316-332; K. Nielson. Reflective Equilibrium and the Transformation of Philosophy” *Metaphilosophy* 1989; 20(3 and 4): 235-246.
- <sup>69</sup> By working back and forth between the elements of the coherence framework, we begin with our considered moral judgments about particular cases or situations and then match these judgments with equally secure moral principles and background beliefs including scientific beliefs, beliefs about culture and society, and so on. Working to find coherence means working to get each of the elements together as a mutually supportive, coherent whole.
- <sup>70</sup> Proctor, op. cit. note 53.
- <sup>71</sup> Black, op. cit. note 29, pp. 443.
- <sup>72</sup> Ibid
- <sup>73</sup> F.S Collins, et. al. A Vision for the Future of Genomics Research. *Nature* 2003; 422, online publication on behalf of the US National Human Genome Research Institute: 12.
- <sup>74</sup> Ibid
- <sup>75</sup> United States Department of Energy Human Genome Program 1999. US HGP on Fast Track for Early Completion. *Human Genome News Archive Edition*; 10( 1-2): 1-5.
- <sup>76</sup> Annas, op. cit. note 63, pp. 138.
- <sup>77</sup> Parens and Knowles, op. cit. note 64
- <sup>78</sup> Ibid, pp. S12.
- <sup>79</sup> M.S. Frankel. Inheritable Genetic Modification and a Brave New World: Did Huxley Have It Wrong? *Hastings Center Report* 2003; 33(2): 31-36.
- <sup>80</sup> Ibid, pp.31.
- <sup>81</sup> ELSI/US Human Genome Project Archive News 1999, pp. 1
- <sup>82</sup> Collins, op. cit. note 73.
- <sup>83</sup> P. Mazumdar. 1992. *Eugenics, Human Genetics, and Human Failings: The Eugenics Society, Its Sources and Its Critics in Britain*. New York.Routledge Press.
- <sup>84</sup> Collins et al, op. cit. note 73, pp. 14.
- <sup>85</sup> Collins et al, op. cit. note 73