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**TOWARD AN UNDERSTANDING OF GENETIC INFORMATION
WITHIN SOCIETY: THREE ESSAYS**

by

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B.A., Simpson College, 1996

presented in partial fulfillment of the requirements

for the degree of


Master of Arts

University of Montana

Spring 2000

Approved by


Chairperson, Board of Examiners


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Toward an Understanding of Genetic Information Within Society: Three Essays

Chairperson: Albert Borgmann **AB**

With the rapid advances being made in the field of applied genetics, it is imperative that society's understanding of these developments keep apace. Currently, there is no systematic framework in which to analyze the relative merits and demerits of genetic advances. Rather, work in the social and ethical implications of genetics has tended to be piecemeal, ignoring crucial distinctions and relying upon outmoded theories of decision-making.

In this portfolio, I attempt to provide the fundamentals of a framework for understanding the social implications of genetics and to clarify some of the confusions that arise as genetics is applied to our social institutions. I focus upon three areas of concern. First, using information theory, I distinguish between two types of meaning that may be found within genetic information: instrumental meaning and final meaning. Then through an analysis of Heidegger's theory of technology, I illustrate the reliance of the genetic enterprise on technology and how this partnership influences our use of genetics. Second, I elucidate two commonly misunderstood sets of concepts in efforts to protect genetic privacy: the two distinct prongs of privacy and the two kinds of genetic information. Once these misconceptions are clarified, the prongs of privacy are applied to the kinds of genetic information in order to protect more securely the fundamental liberties of persons. And finally, I address the thicket of ethical problems that surfaces in the context of genetic prenatal testing, and argue that before we bring traditional moral theories to bear upon dilemmas in prenatal decision-making we need to provide more substantial definitions of concepts that such decision-making will necessarily employ.

Through this series of papers, I hope to not only provide the fundamentals of a framework within which a more comprehensive, and thus effective, understanding of the developments might develop, but also to give some demonstration of how such a framework might be applied in different contexts.

Preface

When Francis Crick and James Watson proposed the double helical structure of DNA in 1953, it was hard to imagine the predictive power and the effects that their discovery would have at the end of the 20th century. After several decades of basic research on the structure of DNA, we are just beginning to realize the plethora of practical applications for genetic information. The study of genetics has revolutionized areas as diverse as medicine, law, agriculture, and environmentalism. Because of the wide range of uses for genetics, we in society are constantly inundated with reports of breakthroughs in genetic research and new applications for the principles of genetics. But in the deluge of updates, relatively little systematic commentary exists by which to understand these developments and their impact on traditional societal values. The three papers in this thesis portfolio are thus an attempt to provide a framework in which we may understand the myriad ways that genetics infuses society. Given the variety of societal issues surrounding genetics, these three papers are best understood as conceptual ground-clearing rather than an attempt to set out specific directives for action, although they do identify certain parameters within which future debate should focus.

Throughout the three papers, I often allude to a problem caused by the large number of news reports regarding genetic advances and applications, and thus, would like to clarify this problem at the outset. Because of the massive breadth of the genetic enterprise, the wide-ranging applications of genetics, and the predictive power of genetics, changes are occurring in our societal institutions perhaps faster than our understanding can keep pace. Lay readers and even isolated researchers are unable to

comprehend the full extent to which developments in genetics affect their lives. Lagging behind in this conceptual race leaves issues either ignored or inadequately addressed.

To provide some quantitative and qualitative support for the claim that the advances of genetics are proceeding faster than our ability to understand them, I have researched news articles related to genetics in the New York Times for the past 365 days. Within this one year period, 792 articles have been published that directly deal with advances in genetics or the application of genetics.¹ On average, 2.1 articles related to genetics appear in the daily New York Times. While the mere frequency is not astounding, when the specific content and pathos of these 2.1 articles vary, as they do, over the wide spectrum of genetic applications, we are left with mixed messages regarding the import of the “genetic revolution.”

For example, news articles can be positive and elicit hope (“Hint of Success In Gene Therapy” Mar. 2, 2000), or they can be negative and tragic (“Teenager’s Death Shaking Up Field of Human Gene-Therapy Experiments” Jan. 27, 2000). They can show concern (“Senators Press For Answers On Gene Trials” Feb. 3, 2000), or they can demonstrate apathy (“Concerns on Human Test Don’t Seem to Faze Biotech Investors” Feb. 19, 2000). News articles may focus upon political issues (“Study Questions Gene Influence on Male Homosexuality” April 23, 1999), or they might appeal to anthropological interests (“Study Alters Time Line For the Splitting of Human Populations” Mar. 16, 1999). Applications of genetics can be presented as overtly eugenic (“Scientist at Work: Joe Z. Tsien; Of Smart Mice and an Even Smarter Man” Sep. 7, 1999), or can be portrayed with a cautionary tone (“Cancer Gene Tests Turn Out

¹ All information referred to here, including a complete list of news articles for the previous 365 days, can be accessed at www.nytimes.com and doing a keyword search for ‘gene’ in the 365 day archive.

To Be Far From Simple” Aug. 17, 1999). And finally, the pathos of news articles can be serious (“PERSONAL HEALTH; Choosing to Test for Cancer’s Genetic Link” Aug. 17, 1999) or it can be comical (“Scientists Place Jellyfish Genes Into Monkeys” Dec. 23, 1999).

In combination with the steady frequency of genetic reporting, the diverse applications, goals, and opinions of the genetic enterprise can often mislead persons when attempting to understand how these developments affect their lives. One popular way of understanding modern genetics is to underestimate its particular potency. It might be argued that the use of modern genetics in fields like genetic engineering is no different than the use of selective breeding techniques. Humans have been genetically altering nature for over 12,000 years through the domestication of both plants and animals. But as Reiss and Straughan point out in their book, Improving Nature?: The Science and Ethics of Genetic Engineering, traditional biotechnology, i.e. domestication of plants and animals, differs from modern genetic engineering in three key aspects: relatedness of species, the pace of change, and the number of species implicated. First, while traditional biotechnology bred and crossed closely related species, modern genetic engineering exchanges genes between two or more widely dissimilar species, i.e. human genes in pigs, bacterial genes in plants, or jellyfish genes in monkeys. Second, traditional breeding and crossing occurs over the course of years and generations; changes occur within a matter of days or weeks in genetic engineering. And third, traditional biotechnology is mostly limited to only those species that provide food or drink, while no organism is beyond the reach of modern genetic engineering. (5) Thus, understanding the developments of genetics as merely extensions of past practices is foolish.

However, the impact of genetics upon our lives can also be overestimated. Reports of “smart genes” or “long-life genes” can usher in a utopian vision for the future of humankind devoid of suffering. But these visions overlook the acute suffering and sacrificing of persons that would be necessary to achieve such eugenic goals. We must therefore avoid either of these extreme interpretations of the impact of genetics, and come to a more reasonable understanding of the developments in genetics and the underlying values that drive them if we are to employ the benefits of modern genetics wisely.

In this thesis, I take up three issues in the much larger project of comprehending the impact of genetics on society. The first paper, “Finding Meaning in Genetic Information,” addresses two questions that arise as we await the completion of the Human Genome Project in 2003. First, what does it mean to know one’s genetic code? Drawing upon information theory, I try to demonstrate that the genetic code has no meaning outside of a mere causal relation to the development of organisms. Therefore, any meaning that is derived from genetic information is originally bestowed upon it by a collective agreement among persons. Since DNA lacks meaning in and of itself, we are then able to reconsider the meaning that we give to it. The second question that I address is why do we assign the meaning that we do to genetic information? An answer to this question can be found in Heidegger’s ontology of being in relationship to technology. Because our relationship to the genome is always mediated through technology, we have a predisposition to assigning meaning to DNA in a certain manner, namely as a resource. But this manner of making resources out of technologically mediated things has a tendency to extend to the manner in which we receive meaning from things unmediated by technology. I thus conclude that we must remain vigilant in our efforts to avoid

confusion between assigning meaning to the genetic code and receiving meaning from the persons and organisms that are expressions of a genetic code. Through this paper, I hope to establish parameters within which discussions of meaning can proceed, thus making available the possibility of directing the usage of genetic information.

The second paper, "Challenges to Genetic Privacy," takes a more practical look at one issue that arises with the availability of genetic information: genetic privacy. As genomes are decoded and tests become available for certain genetic traits and diseases, the results of these tests render persons vulnerable to unwarranted scrutiny and discrimination. I attempt to clarify two sets of concepts that attend this issue and that confuse attempts to secure persons from infringements of their basic liberties.

The constitutional right to privacy is a difficult right to employ correctly. Partly, this is because it is an unenumerated right, and the argument for its establishment was muddled. And partly, confusion arises because there are two distinct protections that fall under the right to privacy. I then apply these two protections to another distinction between the two kinds of genetic information: the genotype and the phenotype. In this process, it becomes apparent that to truly protect persons from the infringement of their basic liberties, we need more than legal rules of conduct. Privacy law plays an important role in securing persons from genetic discrimination based upon their genomes, but it is inadequate to govern the subtle discrimination that occurs based upon phenotype. I thus partition off the realm of legal efforts to protecting against genotypic discrimination, and relegate the remaining issues to the realm of ethics.

It is within the realm of the ethical that the issues surrounding genetic information abound. The third paper, "Limitations of Morality in the Context of Prenatal Genetic

Testing,” thus attempts to explicate the thicket of ethical problems that attend one, relatively specific, application of genetics: prenatal testing. Because of the tangled web of ethical problems, we in society should not be too eager to apply traditional moral theories to the dilemmas that arise. Following Bernard Williams, I argue that we must concentrate upon identifying and delineating the issues involved in prenatal testing. The striking result of such an approach is that many of these issues rely upon substantive concepts, like “quality of life,” which are currently ill-defined. Only after fully understanding the issues involved will we be in a position to make the tough decisions that must be made regarding prenatal testing.

Although the three papers are separate and may be read in any order, I have arranged them so that certain common ideas might develop through the succession of papers. In “Finding Meaning in Genetic Information,” I give a broad, conceptual framework in which the other two papers can be understood. “Challenges to Genetic Privacy” applies the distinction between technologically mediated and unmediated things to the problem of genetic discrimination, yielding a realm of legal protections and a call to develop ethical protections. One of the challenges to creating these ethical protections is the tension between individual autonomy and the state’s pursuit of the public’s general welfare. The legal foundations of personal autonomy are addressed in “Challenges” while the state’s interests receive an interesting twist in “Limitations of Morality in the Context of Prenatal Testing.”

Through the distinctions and clarifications presented in these three papers, I hope to provide some basic conceptual tools to understand the impact that developments in genetics have upon our lives. While I have undoubtedly left important questions

unanswered, I hope to have developed a useful framework in which to address these questions, including some illustration of how we might go about resolving them.

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Finding Meaning in Genetic Information

I. Introduction

An inordinate amount of information is being amassed within genetic research, ranging from the isolation of drought-resistant genes in crops to a gene disproportionately found in women with breast cancer. However, within the deluge of news reports and research breakthroughs, the genetic enterprise lacks any sustained discussion of what this information means. What does it mean to know the gene for X? Or, what information is actually being conveyed in the sequences of DNA? It would be helpful to devise a method through which meaning is reliably and unequivocally extracted from a set of information. But more able persons than I have attempted to provide such a method and have been unsuccessful. In this paper, I resign myself to the more humble task of determining how we know when we have the wrong meaning of genetic information. I investigate the extent to which the meaning that is extracted can influence how we think about the referent. Specifically, I will focus upon the area of human genetic information and assign the boundaries for extrapolating meaning from our genetic code. My concern is the extent to which the information yielded by our genetic code can legitimately affect the way in which we think of ourselves in relationship to our origins, our identities, and our world, and why we sometimes insist that it will.

II. Defining the Problem

Based upon genetic differences, anthropologists are currently attempting to trace the migrations of human populations back in time to their origins. If we follow a reversal of the genetic clock, we could reasonably expect to find, in concert with archeological data, that the paths of native South and North Americans could be retraced across the

Bering Strait into Siberia. The paths of the Aborigines of Australia and the South Pacific would merge with the Native Americans and Northeast Asians somewhere in Central Asia, and converge upon the Middle East as the trails of the peoples of Europe sweep Southward. Ultimately, it may be found that it is most genetically plausible that the ancestral lineage of all humans traces back to one locale in East Africa.¹

Within academic circles, the response to this scenario might generally be one of detached interest. To academics, the importance of this information is determined by their interest in the subject and applicability to their particular field of study. For the most part, this information does not disrupt their fundamental understanding of the world. There are other sets of data, i.e. the archeological record and linguistic analyses, that have sufficiently illustrated this point. Its relevancy to their sense of identity and history has already been digested. Within other circles, however, the meaning of the information contradicts fundamental beliefs that give meaning and purpose to the lives of the members of those circles. Take for example the Native North Americans, whose oral tradition centers their community and provides a link to their heritage. In many of these oral traditions, it is said that the Creator placed the tribe upon the earth in their particular locale.² To locate their origin anywhere else would be to take away their connection to that locale, and likewise the identity they have formed with their historical and cultural surroundings. Because the results of the anthropological study might suggest a different origin, many tribes have vowed not to participate in the collection of the DNA samples needed to complete this study. Regardless of how one evaluates this situation, the

¹ See Cavalli-Sforza.

² See James Welch's Fool's Crow for a retelling of the Blackfeet's connection with the land of the Northern Rocky Mountain Divide (the Backbone of the World).

example shows that, at the very least, information has the potential to alter our basic understanding of the world.

Through this example, we see two very different ways in which the meaning of meaning can be construed. First, there is the way represented by the academic circle's response to the above scenario. I shall call this *instrumental meaning*. Meaning in this sense is useful for obtaining something else. It has relevance in relation to another set of information, and thus is useful only toward some other end. The response elicited by the academics reflects the fact that its usefulness in garnering other information is redundant. Other sets of information have already convincingly demonstrated the conclusion most likely to be reached by the genetic anthropologist. The deeper meaning of the study is easily digested and flows smoothly into the current worldview of the academics. This second type of meaning is what gives purpose to the life of a person. It constitutes a necessary part of the identity of an individual. In this deeper sense, meaning is an end in itself. I shall call this deeper sense, *final meaning*. But the integration of the anthropological study upon a person's worldview does not always flow so easily. It is precisely because some Native Americans interpret the projected results of the study as contradicting their final meaning that they refuse to participate.

With the help of the distinction between instrumental and final meaning, the focus of my paper becomes clear. I am not concerned with the instrumental meaning of genetic information. I am not directly concerned with the uses to which genetic information can be applied. In this paper, the questions regarding cloning and choosing the physical characteristics of a child are of secondary importance. Although these are interesting questions concerning what we can and should do with genetic information, I am mainly

concerned with the extent to which genetic information can impact the conception of ourselves as human beings. We will necessarily deal with instrumental meaning, but only to shed light upon final meaning, the latter lying deeper than the former. We must therefore excavate through the instrumental to understand the boundaries of final meaning. Ultimately, it is from these depths that the questions raised by the application of genetics will ultimately find answers. But let us postpone our concern over these matters and focus upon the limits to which final meaning is found within genetic information.

III. DNA as Information

If we are going to attempt a foray into the meaning that can and cannot be found in our genetic code, we must begin with examinations of DNA, information, and the extent to which the genetic code is information. Deoxyribonucleic acid (DNA) is a twisted ladder of molecules. The sides of the ladder are an alternating arrangement of phosphates and a sugar called ribose. The rungs are a combination of two nucleotide bases, each base branching from its respective single strand of ribose-phosphate complex and fusing in the middle. There are four nucleotide bases that make up the rungs of the ladder: adenine (A), guanine (G), cytosine (C), and thymine (T). Only A's bind with T's and vice versa, and only C's bind with G's and vice versa. Along one side of the twisted ladder, any nucleotide base can physically precede or follow any other.

In this thumbnail sketch of the structure of DNA, we are searching for the way in which DNA is information so that the meaning of the information can be understood. So within the orderly structure of DNA, we see at least one way in which it can be thought of as information. At its most basic, all information must have some orderly arrangement

or structure. But the fact that everything with structure is information in some way makes the structural sense of DNA a tautology, rendering this conception of DNA as information unilluminating. The particular way in which DNA is information cannot be discerned by its orderly arrangement.

However, if we connect the orderly arrangement of DNA to ideas in information theory, it is tempting to think that this structure could be quantified, thus giving us a measure of the information encoded by the DNA. Perhaps we might get a glimpse of the character of DNA in the process of knowing how much information DNA contains. In his paper, "The Mathematical Theory of Communication," Claude Shannon demonstrates the relationship between information and probability. He states that in order to maximize information, probability must be minimized. Extrapolating from this relation, in order to quantify information, one must first quantify improbability. One of the three methods that he uncovers is to look at the possibilities of various outcomes. If we take a randomly arranged single strand of DNA, the possibilities available for the first nucleotide base observed is four, since there are four possible nucleotide bases. The possible combinations for the first and second nucleotide bases are then 16; and for the first, second, and third are 64. Each new nucleotide multiplies the previous number of possibilities by four, thereby dividing the probability by four. The amount of information as measured by improbability thus grows at an exponential rate.

The number of possibilities quickly becomes incomprehensible, especially considering the millions of nucleotide bases along a strand of DNA. In order to render these quantifications of information manageable, we can use the logarithm to the base 4 of the possibilities. So for one nucleotide, there are four possibilities: $4 \log_4 4 = 1$; with

two nucleotides and 16 possibilities, $4 \log 16 = 2$; and with three nucleotides and 64 possibilities, $4 \log 64 = 3$, etc. The resulting numbers (1, 2, 3, . . .) are thus measures of information as a representation of the logarithm of possibilities. A strand of DNA can then be said to contain as much information as the number of nucleotide bases that constitutes its chain.

However, what must be noticed is that these numbers are essentially meaningless. The improbability that has been quantified is not a measure of information *qua* information, but information space. So when we talk about genetic information, we should note that this information is devoid of content. Whatever meaning is given to the genetic structure derives from how we impart meaning to it. We must therefore move to an examination of how content or meaning enters information space.

It should be remembered that meaningful information is not a structured object. Generally, meaningful information is a *relation* between a sign and a person and that sign and a thing. There are five component parts that make up this information relation: a sign, a thing, a person, intelligence and a context. A *person* must be present and aware of a *sign*. But the person must also have some background information or *intelligence* in order to connect the sign to the *thing* that it represents, and this connection between persons and things via signs occurs only within larger *contexts* of meaning.

Meaning thus presents a particularly thorny problem for understanding information. In our quest to find meaning in information, we have been reducing information to its constituent parts. But as we do so, we lose the context which is essential for grasping meaning. We must therefore shift our focus away from the structure of DNA and to the contexts in which we find DNA.

Opposed to the biological, structural sense of information, we can distinguish a cultural sense of information, in which information instructs our conception of reality. In his book, Three Scientists and their Gods, Robert Wright discusses two metaphors by which people understand DNA as information. Wright first designates DNA as information in much the same way that a blueprint is information. They are both plans that direct the construction of a major architectural project. Just as a realized blueprint is a building, so is a realized set of chromosomes an organism (97). Wright also likens DNA to information through the analogy of nucleotide bases (A, C, G, T) of DNA being like the letters of the alphabet. During replication, an enzyme unzips the two strands of DNA. The exposed sequence of nucleotide bases are 'transcribed' into a string of messenger RNA, which, for our purposes, is essentially a template of the original DNA sequence. This messenger RNA then travels outside of the nucleus and into the body of the cell where it encounters a cellular organelle, called a ribosome, and is 'translated' into a protein. In this process, the ribosome attaches to a particular three base sequence, called a triplet codon, and initiates translation. While attached, the ribosome facilitates the joining of an amino acid specifically configured to correspond with this triplet codon. The ribosome then moves down the chain to the next three and facilitates the joining of the next amino acid. This process continues until the ribosome attaches to a triplet designated as a stop codon, and punctuates the new protein chain. To complete the analogy, since nucleotide bases are like letters, triplet codons can be thought of as words, an amino acid like the meaning of a word, and a protein chain like the meaning of a sentence of triplet 'words' (98).

Looking at molecular genetics in this way is much like trying to decipher an unknown language. We need a translator in order to understand the meaning of the 'sentences' and their constitutive 'words.' The ribosome decodes the genetic triplets, and reveals the meaning of the triplet to be a specific amino acid. With this analogy, it thus seems that the meaning of DNA lies in the progression of DNA to RNA to amino acids to proteins. Taken further, the proteins go on to build the organism, so the ultimate meaning of DNA is the resultant organism. Like in the blueprint analogy, DNA directs the construction of the realized DNA, the organism. But a serious problem underlies both analogies. To use the word 'meaning' in this way is to broaden its definition to the point where anything within a causal relation has meaning. DNA is causally related to the production of proteins, but a protein is by no means that to which DNA refers. Something entirely different must be known in order for the genetic code to have meaning. Content does not enter into the genetic code just because it has a causal connection to the development of an organism.

This point can be supported in connection to our understanding of the information relation. With the letters of the alphabet analogy, there is no doubt that there is information, as information space, in the processes of transcription and translation, i.e. we can calculate the possibilities. However, this alone does not constitute information. There must be content that enters into the information space. Information becomes meaningful when the aboutness of some thing is relayed to an intelligent person by a sign within a context. We must then identify the parts of genetic processes that correspond to the parts of the information relation and inquire into the relationship within which the meaning of the DNA sequence is the resultant organism.

If we take DNA to be a set of signals or signs, we need the intelligence to recognize the thing(s) to which they refer. Without this, DNA has no meaning. But when we look at the processes of the nucleus, background information tells us that DNA is not a sign in any way. It does not represent any state of affairs within its environment. DNA is passive. It has an orderly structure, but it is not an agent of order in any active sense. Rather, the environment bumps into the double helix, chemical affinities determine which molecules will bind together, and a protein strand is produced. So DNA can be neither a sign that refers to something in the environment, nor the thing to which a sign refers. Rather, it is a processor of signs. Molecules in the nucleus are the signs that bump into the DNA. They deliver messages as to conditions within the nucleus or cell, such as low concentration of molecule X, meaning 'time to replicate.' In this way, DNA is not so much the subject of information, but a processor of it (Wright 109-110). At the microscopic level, it thus seems that DNA is best suited to play the role of person within the information relation. But since we necessarily find meaning within the information relation from our perspective, DNA cannot convey the meaningful information that we often assume. It therefore seems that DNA can have no meaning for us except within the broad notion of being causally connected to the construction of an organism.

So if no meaningful information, neither structural nor cultural, can be expected from DNA, why do we place so much importance on cracking its code? Is it to finally know which configuration, out of the possible billions, the sequences of adenine, guanine, cytosine, and thymine actually take? The Human Genome Project has been sequencing the nucleotides of DNA and unlocking the causal relationship between these sequences and the organism for over a decade. It is an international cooperative project

costing billions of dollars and hundreds of thousands of research hours. What are the underlying motives for undertaking such a massive project?

The Human Genome Project is a paradigm example of the implementation of modern technology. The research being done is made possible by the advances in microscopic technology, and would have been unimaginable prior to this technology. As such, an investigation into modern technology will provide some clues as to why we pursue a project of such magnitude. Along the way, the elusive question of the meaning of genetic information with which we have wrestled will also begin to take shape.

IV. Understanding the Essence of Technology

In “The Question Concerning Technology”, Heidegger explores the essence of technology. As he states at the beginning, “the essence of technology is by no means anything technological”, it is a way of being and thinking (4). Technology influences the way in which we see the world, and thus, how we interact with it. This conception of technology is in opposition to the instrumentalist school of thought, which holds that technology is simply a morally neutral tool. It is neither good nor bad. The instrumentalists define technology as a human activity in which the ends are already given, and technology offers the means to achieve those ends.

On a prima facie level, this seems correct. We do use technology in order to procure various predetermined ends. However, technology also has typical uses. As we put these technologies to typical uses we make basic material decisions as to what kind of society we will inhabit. As these decisions manifest themselves in society, individuals are prodded into making life decisions that are in concert with the way society is organized. For example, our society is organized around the automobile. Because of the

car, grocery stores are *super* markets, centrally located within a district; they are outside of neighborhoods and beyond walking distance. Our jobs almost invariably require a commute, and city planning is designed around the flow of the traffic. The effects of the automobile have altered the way we think about transportation to the extent that when we leave our house, the question 'By what means am I going to get there?' never crosses our minds. Technology is no mere means, but rather an infusion into our way of thinking.

For Heidegger, the instrumental definition of technology is correct, but not true. The truth of something makes itself present when its essence is revealed. Wherever something is used as an instrument to bring about an end, the rules of causality underlie this bringing-about. Heidegger refers to the Aristotelian four causes of *causa materialis*, *formalis*, *finalis*, and *efficiens* as being responsible for something coming into appearance or presence. These four causes bring forward an object as something that lies ready before us (6). The essence of causality is this setting something forward. It is the revealing of the concealed. So when we look into instrumentality as a means, which is generally regarded as the mark of technology, we see technology as something deeper, as a revealing.

Although all technology is a revealing, modern technology is of a special type. Heidegger distinguishes two types of revealing, or bringing-forth into presence. The first is a bringing-forth in which the Greeks used the term *poiesis*. In its highest sense, *poiesis* is "the arising of something from out of itself," and "has the bursting open belonging to bringing-forth, e.g., the bursting of a blossom into bloom, in itself" (10). In a lower sense, *poiesis* can also refer to the bursting open that is caused by a craftsman or artisan. But both senses of revealing as *poiesis* fail to account for that which occurs in modern

technology. The harsh coldness of modern technology does not set well with the poetical nature of *poiesis*. Modern technology is a bringing-forth, but unlike *poiesis*, it is a revealing as challenging. It challenges nature to “supply energy that can be extracted and stored as such” (14).

As a challenging, modern technology unlocks the secrets of nature and uses them to further the goals of something else. This information is then stockpiled, ready to be used at the moment it is called upon. Heidegger gives the example of a power plant set into the Rhine River.

The hydroelectric plant is set into the current of the Rhine . It sets the Rhine to supplying its hydraulic pressure, which then sets the turbines turning. This turning sets those machines in motion whose thrust sets going the electric current for which the long-distance power station and its network of cables are set up to dispatch electricity. In the context of the interlocking processes pertaining to the orderly disposition of electrical energy, even the Rhine itself appears as something at our command. The hydroelectric plant is not built into the Rhine River as was the old wooden bridge that joined bank with bank for hundreds of years. Rather the river is dammed up into the power plant. What the river is now, namely, a water power supplier, derives from out of the essence of the power station. In order that we may even remotely consider the

monstrousness that reigns here, let us ponder for a moment the contrast that speaks out of the two titles, “The Rhine” as dammed up into the *power* works, and “The Rhine” as uttered out of the *art* work, in Hölderlin’s hymn by that name. But it will be replied, the Rhine is still a river in the landscape, is it not? Perhaps. But how? In no other way than as an object on call for inspection by a tour group ordered there by the vacation industry. (16)

With the placement of modern technology into the river, the concealed energy of the Rhine was exposed, transformed, stored, and distributed in a form unrecognizable to its source. The energy of the river was extracted and set aside as a resource, immediately at hand. In like manner, modern technology orders everything to be always ready to be used. By turning an object into a resource, the object no longer presents itself to us; rather, it is a subject under our control. The most interesting change that occurs is not the transformation of concealed energy to usable energy; it is the alteration in how we *view* the river. The Rhine now refers to something different, namely a power supplier. By setting a piece of modern technology into the river, we have changed the meaning of that river. Likewise, whenever technology is set upon an object, it orders that object into a resource and changes its meaning.

V. Applying Heidegger’s Essence of Technology to Genetic Information

We left our discussion of genetic information with the conclusion that no meaningful information can be found within DNA. If we attempt to get meaning out of the information space of DNA, we end up not with meaning, but with a causal relation.

DNA facilitates the production of proteins by processing signs (molecules) referring to the state of affairs within its cellular environment. As a causal relation, the essence of DNA lies in its coming to presence. But in order to be aware of its presencing, we extend the powers of our observation through instruments of modern technology. Because the genetic sequencing is only possible within a highly technical enterprise, the revealing uncovers not the poetic blooming forth of DNA, but rather, DNA as a resource. The genetic enterprise reveals as a challenging-forth of the DNA to unlock its secrets, then sets them aside to be altered, manipulated, and ready to be at hand when needed. By setting technology upon the genome, we thus change our conception of the DNA. It becomes not that which processes information into instructions for the cell or that which facilitates the blossoming forth of an organism; rather, DNA becomes material to be reengineered and at our command. Even with this being so, it still might be said that DNA remains the basis for life. However, following Heidegger's response to the change in character of the Rhine, DNA is only the basis for life insofar as it is an object on call for inspection by a research group ordered there by the medical industry. By changing the way of revealing through technology, we alter the semantic relationship between DNA and ourselves.

The lingering question as to why we pursue the genome project seems to find an answer within the technological enterprise. With genetic technology, we are able to bring DNA under our control by setting DNA aside as a resource. But the essence of modern technology as a challenging revealing explains only half the answer. It explains how technology is related to DNA, but it does not fully explain how humans are then related

to technology. We must establish this relation if we are to complete the link between humans and their DNA.

For Heidegger, humans and technology are necessarily linked, but not in a common-sensical way. We might think that technology is dependent upon humans to invent and create it, but the essence of technology is actually the opposite. Humans are dependent upon technology as a fundamental way of being. We are talking about the essence of technology, and this essence calls us to set upon nature and challenge forth the real as an ordered resource. This essence of technology he calls Enframing, and asserts it as a primal disposition of humans. The essence of technology connects to something more primitive within human motivation: it sends humans upon a way to order the real as a resource. This sending upon a way is what Heidegger calls a destining.

By invoking the idea of destiny, Heidegger leaves us thinking that technology determines our course of action, namely ordering reality into a resource. We are left as slaves to some mystical notion of fulfilling the will of Enframing. Enframing as the essence of technology thus “threatens to sweep man away into ordering as the supposed single way of revealing, and so thrusts man into the danger of the surrender of his free essence” (32). We are threatened in two ways. First, as humans go along their way of ordering objects into resources, they will increasingly find themselves amidst a world of objectlessness. Everywhere humans go, things will seem to be mere artifacts; they will experience only their own presence. Ultimately, the disposition to Enframe must then turn inward and order humans themselves as resources. Second, Enframing as a destining limits humans to only that kind of revealing that is an ordering into a resource. Although Enframing reveals in one sense, it simultaneously conceals revealing as *poiesis*.

In its quest for order, it blocks out the bringing-forth into presence of an object. As the essence of an object is that which presences, and truth is found when essences are brought forth, Enframing thus blocks the coming of truth. When we pursue revealing as Enframing, we thereby distract ourselves from the coming to pass of truth (26-27).

We can see both of these dangers within the Human Genome Project, which has turned the scientific gaze inward to unlock the secrets of human biology. We are sequencing the nucleotide bases of our DNA, and setting aside these ordered packages of genes so that we can use them at our discretion. We extract them, store them, recombine them, and redistribute them as resources. But in this process of challenging forth the DNA, science has occluded the beauty of DNA as it presences itself. We have lost the wonder that we first felt when the structure and processes of DNA were discovered. And the efficiency of replication, transcription, and translation no longer inspire us. Instead, the structure and processes of DNA are things to be manipulated. Any mistakes (and even some of the successes) made by the DNA are things to be corrected. The brute explanatory force of Enframing drowns out the subtle blooming forth of truth.

So is this our fate? Is it to live in a world where objects do not make themselves present, but are instead set aside as resources for us? It may be the greatest danger to accept that we are determined by technology. But although humans cannot escape the primal condition of being sent forth into revealing, this destining is not a compelling force for preordained action. Within the realm of destining, we find ourselves truly free. We can choose which type of revealing we will embark upon, revealing as a challenging forth or as a blooming forth. So although Enframing threatens to lead us away from the

blossoming of truth, we are not resigned to follow blindly or to struggle helplessly against it (25-26).

VI. Finding Meaning in Genetic Information

The relationship between humans and technology thus seems to be one where modern technology sends humans on a way of revealing the world in which they live. Technology influences the ways in which humans experience the world. As beings in the world, we must undertake the revealing of essences. But then this revealing of essences is nothing but a search for meaning. According to Heidegger, when we search for the essence of something, we are inquiring into its truth, which is how an object presents itself to us. We inquire as to the meaning of the object. As part of the equation of truth, a subject must experience a coming to presence of the object. Only within this experience do objects come to have meaning for us. We must make sense out of the objects of our experience, but the question as to how we make sense of our experience remains.

Just as there are two ways of the coming to presence of a thing, as a challenging forth and as blossoming forth, so there are two ways in which we make sense of our experience. Revealing as challenging into a resource sets aside an object as something immediately at hand. It is there to be manipulated upon demand, and used as a means to achieve something else. The object as a standing reserve only has relevance in advancing some other end, which is only to say that it has instrumental meaning. In using modern technology to view humans on a microscopic scale, we predispose ourselves to revealing only instrumental meaning. Revealing as a challenging thus limits the extent to which meaning can be presented to us, for with instrumental meaning, the semantic energy runs only from us to objects. We impart meaning upon things.

We have seen that at the microscopic level, DNA has no meaning in itself. Once a researcher undertakes the investigation of DNA, we give instrumental meaning to it. With microscopic technology, the researcher challenges forth the DNA as a resource to be manipulated when she deems necessary. But at the same time, this revealing as resource clouds the presencing of the DNA itself, by which DNA shows us its true essence and illuminates its final meaning.

In contrast to instrumental meaning, whose semantic energy flows from subject to object, there is also meaning that flows from object to subject. It is this type of meaning that connects subjects to their surroundings, shapes their experiences, and thus shapes their identities. Because of this deep connection to our identities and the way we experience the world, I call this final meaning. In the blooming forth of things into presence before us, things impress meaning upon us. The coming to presence as a blooming forth of an object allows us to experience the final meaning of that object. There is something more poetic and primal to an object than what is revealed by ordering it into a resource. When we abandon attempts to order the object, the object will bring to our experience the beauty of its presence. The coming into beauty of an object is an end in itself, and impresses upon us its final meaning.

So when we experience the world as revealing, humans have a choice as to which direction the semantic meaning will flow. If we choose to mediate our experience through modern technology, we are predisposing ourselves toward revealing as a resource and imparting scientific meaning to things. This is not to say that we cannot appreciate the blooming forth of DNA, but it does make it more difficult. It is difficult because technology magnifies and amplifies our senses to a different scale. To

experience the world at this micro scale is to experience a world in which we do not live or have background experience. Because we do not know what it is like to experience the world at this scale, the blossoming into presence goes largely unrecognized. Instead, we attempt to assimilate our perceptions of the foreign scale into an order that we do recognize. This altered form of our perceptions then loses its connection to the world in which the objects of our perception present themselves. We can only experience a microscopic thing by assimilating it to the scale in which we live. Because we extract the thing from its scale to ours, we create a void of meaning as it loses connection to its microscopic environment. We must therefore impart meaning upon it to fill the void. It is this response that develops into our disposition to order technologically mediated reality into a resource.

Meaning is therefore dependent upon scale. When we experience the world at the scale in which we live, the presencing of objects make sense, without having to order them in some way. By experiencing DNA at the microscopic scale, we experience DNA as an ordering because it is the only way we can make sense of it. Therefore, the only meaning that DNA can have for us is what I have termed instrumental meaning. It has no bearing upon final meaning, as we do not experience DNA in the way we experience the world. We experience and have evolved to experience the world of things unmediated by modern technology.

So with this understanding of instrumental and final meaning, let us return to the practical problem with which I first identified the distinction between the two senses of meaning. Should Native American tribes concern themselves with the results of the genetic anthropological study? The answer is both yes and no. It remains a danger to

forget or confuse the difference between instrumental and final meaning. This danger is made all the more real, considering humans' disposition toward confusing the two, when our experience is mediated by modern technology. Therefore, Native Americans must concern themselves with the practical dangers of confusing instrumental meaning with final meaning. However, if Native Americans remember that the meaning of genetic information is limited to instrumental meaning, and that they receive fundamental meaning from their experiences of the world around them, then genetic information poses no threat to cultural or personal identities. Even if there is overwhelming evidence that all groups of humans originated in Eastern Africa, the cultural and personal experiences that have developed their identities and connections to a specific locale remain.

As beings that experience the world as revealing, we must consciously work to exercise our freedom in deciding when it is appropriate to order the world and when it is better to receive the presencing of the world. The challenge that faces not only Native Americans, but all humans, is how to practically apply the scientific knowledge that orders our world in such a way that the beauty of the world is not concealed, but rather, bursts forth. By fostering a world that bursts forth into bloom, we foster our connection with the world. Genetic information will never be able to tell us who we are or what we should be; these questions can only be answered at the scale in which we live. Genetic information is something to which we give meaning. But we must make sure that the meaning we impart to it is consonant with the final meaning that gives purpose to our lives. Although opinions differ on what exactly constitutes this final meaning, it is clear that we cannot find the answers through a microscope. We must focus ourselves upon

arriving at some consensus regarding who we are before we can wisely decide what to do with genetic information.

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Challenges to Securing Genetic Privacy

I. Introduction

Current efforts to protect the genetic privacy of persons have been focused upon restricting access to a person's genome -- the full sequence of nucleic acids that prescribe certain physical characteristics of individuals. Fears of genetic discrimination are justified given past practices by insurers and employers that have denied coverage or employment to individuals based upon criteria derived from a person's genome. However, in the race to regulate access to genetic information, several confusions have arisen which mitigate against the success of anti-discriminatory measures. In this paper, I will clarify two crucial distinctions that are implicated in the protection of genetic privacy. First, the term 'genetic information' is often misconstrued to refer only to the genome, which has recently become accessible through new technology. But there remains another type of genetic information, the phenotype, which has always been accessible to our gaze, and eludes current anti-discrimination efforts. Second, since the right to privacy is not an enumerated right in the U.S. Constitution, this discovered right has also been mistaken to be a monolithic entity. However, as legal scholarship demonstrates, there are actually two forms of the right to privacy: one governing the access of information and the other guaranteeing certain zones of privacy in which to make autonomous decisions. Application of the nuances of privacy law to the richer notion of genetic information thus presents a more complex situation for the protection of genetic privacy. By respecting the intricacies of genetic privacy laid out in this paper, we shall see that privacy law is limited in its ability to protect persons from all genetic discrimination. But these limitations do not call for the abandonment of efforts to protect

genetic privacy. Rather, they merely signal that we must consign certain areas of genetic privacy to ethical rules of conduct as opposed to forcing all protections to be legal. It is through an appeal to the ethical underpinnings of privacy that a resolution to genetic discrimination may be found.

II. Two Types of Genetic Information

As we interact with one another on a daily basis, we unwittingly have access to one type of genetic information. At a glance, we can discern certain genetic characteristics of the person who we walk past on the street. Their sex, their skin color, their height, and, if natural, their hair color are all manifestations of that person's genome and readily observable. This type of genetic information has been coined the phenotype of a person. The phenotype is the observable expression of genes and it is the form of genetic information that is most familiar to us, although often not recognized as having genetic implications.

The underlying genetic structure that is expressed as the phenotype is called the genotype. The 'instructions' for human development are encoded in some 100,000 genes. The genotype is that specific sequence of nucleic acids that make a particular gene, and ultimately, a particular human unique. At the level of daily social intercourse, the genotype is hidden from us, and has historically been unavailable to us.¹ But with the techniques of modern genetics, our genes, and the sequence of nucleic acids that constitute them, are no longer necessarily hidden. We are able to uniquely identify persons through DNA fingerprinting, as well as identify abnormalities in the genetic

¹In this paper, I will be referring specifically to molecular as opposed to allelic genotypes. While allelic genotypes have been known since the 19th century, our current understanding of molecular genotypes provides us with a more detailed access to the underlying genetic structure.

sequence through testing of tissue samples. It is the advent of our ability to 'see' the genetic make-up that has sparked the call for genetic privacy.

Following the completion of the Human Genome Project in 2003, it is possible that the genotype of every gene in the human body could become subject to scrutiny. The entire sequence of nucleic acids that has been concealed for so long will finally come under our gaze. From the front page of the newspaper to the President's State of the Union Address, the promise of this ability has captivated the public's imagination. Underlying the excitement surrounding knowledge of genotypes is the notion that through an understanding of the molecular basis of genes, we can manipulate and control the genome to achieve certain prescribed results. Undoubtedly, genetic research and technology will provide needed relief to those suffering from severe genetic maladies. Medical doctors are already testing gene therapies that will correct diseased genes. But these advances in genetic technology and medicine necessarily introduce the availability of genotypic information into a society unfamiliar with the power of genetic information. Because a person's genotype becomes available through this new technology, a series of legal and moral implications are introduced as well.

Once genotypic information is available, i.e. once the sequence of nucleic acids is recorded, access to this information becomes a key question. If knowledge is indeed power, then whoever has knowledge of a person's genome has a unique power over that person. When employers or insurance companies obtain this genotypic information, they also obtain power over that individual – the power to deny coverage or employment. The availability of genotypic information should thus be seen as a new possibility to rigidify power structures within society and perpetuate certain practices of discrimination and

oppression. The reality of this possibility is supported by the history of discrimination based upon the other type of genetic information: the phenotype.²

Since phenotypes are the observable expressions of the genotype, it is quite possible, and seemingly natural, to make judgments/evaluations of others based upon their particular expression of their genes. We tend to shy away from confrontations with persons of large stature and assert ourselves when the difference is to our advantage. Like genotypic information, phenotypic information can be used in wonderful ways. Phenotypes provide us with basic information necessary to organize the altos and sopranos in a harmonious quartet or to position players on a successful football team. However, while these evaluations can be used to celebrate the uniqueness of individuals, phenotypes can also be the basis for the denigration of persons. Over the course of the history of phenotypic evaluations, we, as a society, have favored certain phenotypes over others, i.e. male over female, fair skin over dark. These phenotypic differences have then been used to justify preferential treatment toward individuals with the favored phenotypes. Evaluations of this sort have thus instantiated systems of oppression and discrimination, whether they be overt, as in slavery, or covert, as in opportunities available to women.

If we are to understand the threat of genetic discrimination, we must understand the parallel between genotypic and phenotypic discrimination. While the emergence of genotypic information presents challenges for the protection of persons, the challenges are not new. Discrimination based upon phenotype is as old as societal interaction. The attention given to genetic information qua genotype thus provides an opportunity to

² See Kevles for a history of eugenic discrimination in early 20th century America and Britain.

correct old injustices based on phenotype as well as to address the challenges peculiar to genotypic information.

III. The Right to Privacy

One of the key tenets of liberal democracies like the United States is the protection of persons from unwarranted intrusions into their private lives. If we are to understand how the right to privacy can act to protect persons with respect to their genetic information, we must delineate the two distinct strands of privacy. Through a historical analysis of the 'discovery' of the right to privacy, I hope to illustrate how the two strands of privacy can act to mitigate the use of genetic information in restricting the fundamental freedoms of persons.

As a matter of general legal interpretation, there are two types of rights in the U.S. Constitution. Enumerated rights are those explicitly stated in the Amendments of the Constitution, i.e. the rights to a free press, free speech, and the free exercise of religion. Although these rights still require judicial interpretation as to their particular meaning and bearing within certain contexts, their status as strong rights is uncontested. The right to privacy is not such a right; it is an unenumerated right discovered in the Constitution. The very existence of this right is a matter of judicial interpretation. But over a series of Supreme Court decisions, the right to privacy now enjoys a secure place among our fundamental rights.

The U.S. Supreme Court first recognized the right to privacy in 1965 with the decision in *Griswold v. Connecticut*. At issue in this case was the state's ability to infringe upon the liberties of persons under the substantive due process clause of the 14th Amendment. Connecticut had passed a state statute that criminalized the use of

contraceptives. In his majority opinion, Justice Douglas argued that the term 'liberty' in the due process clause should be interpreted as meaning the fundamental liberties of persons, and followed that the right to privacy is one such liberty. In support of this right, Douglas appealed to the "penumbras" of several of the enumerated rights, suggesting that the right to privacy is the underlying foundation for our set of enumerated Constitutional protections. This discovered right to privacy, in combination with the 14th Amendment, was then used to strike down the Connecticut statute.

In arguing for the right to privacy as a fundamental liberty, Justice Douglas pursued two lines of reasoning, ostensibly meant to establish the same right. However, each line of argument has come to be understood as a distinct prong of the right to privacy. Justice Douglas first argued that if persons are to be able to exercise their fundamental liberties, there must be certain "zones of privacy" in which persons are free from state intrusion. Within this private sphere, persons are free to make the decisions that will affect their lives. Douglas' first argument has come to be understood as establishing our right to make autonomous decisions.

In his second line of reasoning, Douglas appeals to the decision in *NAACP v. Alabama*, which ruled that the state of Alabama could not require the state chapter of the National Association for the Advancement of Colored Persons to disclose its membership lists. Requiring the disclosure of these lists violated the members' right to free association, and hidden within this right was a protection of the privacy of those individuals. But the privacy being protected was not the privacy to make autonomous decisions for which he had earlier argued. Instead, there seemed to be an implicit understanding that in publicizing the membership lists, the state was subjecting the

members to unwarranted, and perhaps hostile, scrutiny by the public given the social climate of Alabama in the late 1950's. In order to protect persons from the hostile gaze of the public, Douglas argued that the Court must protect the information used to subject persons to scrutiny. The unwarranted disclosure of personal information was thus a violation of the right to privacy; it was the right of persons to decide who has access to one's personal information. Although it seems clear that Justice Douglas intended that his second argument support his first, we now understand his reasoning to establish a distinct right to privacy: the right to informational privacy.

The foundations of the two prongs of privacy, autonomy and informational, were thus established in the Supreme Court decision of *Griswold v. Connecticut*, but because of Douglas' muddled arguments, the right to privacy remained an ill-defined concept. It was only through a series of later cases that the right to privacy was refined into its distinct strands. I will follow the evolution of each strand separately, noting its developments and presenting the current understanding of both prongs so that the application to genetic privacy will follow naturally.

Douglas' argument establishing "zones of privacy" and protecting the right to make autonomous decisions was, for the most part, unambiguous. Therefore, the development of this right has less to do with clarifying and refining the constitutional guarantee of autonomy than of determining the limits of its protections. The extent to which the state can pursue the general welfare against the fundamental liberties of persons is a common theme within constitutional democracies. In the case of autonomy, the Supreme Court has had to weigh a person's right to make decisions without the intrusion of state regulation against the state's legitimate role of protecting persons from

harm. Perhaps unsurprisingly, this debate has been focused upon the right of autonomy in medical decision-making.

One of the most famous attempts by the Court to define the limits of the autonomy prong of privacy came with the decision in *Cruzan v. Dir., Missouri Dept. of Health*. In the early 1980's, a young woman, Nancy Cruzan, was in a car accident. Paramedics resuscitated her, but the lack of oxygen left her in a coma. Despite appeals by parents and friends that Nancy would wish to be taken off of nutrition and hydration support, the Missouri Department of Health would not withdraw the feeding tubes. After 8 years of legal appeals, the Supreme Court ruled in favor of the Cruzan family and mandated that the equipment be withdrawn. Through its decision, the Court strengthened the right of privacy qua autonomy finding that the individual's right to refuse medical treatment trumped the state's duty to provide for the health of its citizens.

The autonomy of persons would receive its most explicit formulation in *Washington v. Glucksberg*. In this case, the underlying issue was physician-assisted suicide, a matter that perfectly illustrates the conflict between individual autonomy and the state's role of protecting persons from harm. The State of Washington enacted legislation that made it illegal to assist in another person's suicide. In response to this statute, a group of physicians who regularly treat terminally ill patients sued the State, claiming that they would violate the law if asked by their patients and the severity of the situation called for such a humanitarian act. In her concurring opinion, Justice O' Connor clarified the right of privacy qua autonomy as "the individual's right to make certain unusually important decisions that will affect his own, or his family's, destiny", and protects those matters "central to personal dignity" (*Glucksberg* 2307). But ultimately,

the Court found in favor of the State of Washington, that the statute outlawing physician-assisted suicide was within its 14th Amendment powers. The Court argued that the right of autonomy can be limited if the state had a “compelling state interest,” and thus, physician-assisted suicide was not protected by the right to privacy given the state’s compelling interest in guarding against the involuntary hastening of death.

Interestingly, just as the refinement of the right to privacy qua autonomy evolved through a string of medically related cases, so can the development of informational privacy be traced through issues surrounding medicine. In 1977, the Supreme Court revisited the question of the disclosure of personal information with the case *Whalen v. Roe*. The State of New York passed a statute requiring that the dispensing of potentially harmful drugs be registered with the State Health Department in order to prevent creating a market for these drugs through over-prescription, multiple fillings, and obtaining prescriptions from multiple doctors. Patients who regularly received these drugs and doctors who regularly prescribed them contested the constitutionality of the statute as invading the “zones of privacy” protected by the right to privacy qua autonomy. They did not specifically argue for the right to informational privacy. The confusion that attended the argument of the appellees in *Whalen v. Roe* is thus a prime example of the need to separate the prongs of privacy, and explicate their respective domains.

Justification for the right to informational privacy, or selective disclosure of information, is found in the need to have certain aspects of our lives free from the public gaze. Although this may entail demarcating certain “zones” that are strictly private, what is essential to these zones, i.e. what these zones are meant to protect, is the personal

information that may be used by the public to limit our other liberties. The control of personal information is thus essential in order to protect our basic liberties.

So when the physicians and patients contested the New York statute, they were essentially concerned with the restriction of other basic liberties that would attend the mandatory disclosure of this information. The appellees legitimately argued that the statute required the release of private medical information that could potentially subject both physicians and patients to public scrutiny. Concern for their reputations might have disposed some patients to refuse beneficial medications and may have rendered doctors reluctant to prescribe drugs that fall under the criteria of the statute. However, the argument brought to the Court (and eventually accepted by the Court) was that the New York statute was an infringement of autonomy, not of the selective disclosure of private information. The confusion within this argument is illuminated by the fact that the State of New York was not making important decisions for the physicians and patients, as was evident in the case of physician-assisted suicide. The State only required the individuals to register their decisions with a state agency. Instead of appealing to the right of autonomy, the appellee's argument provided support for the security of personal information and the right to engage in activities free from the judgment of others. To understand the New York statute as a breach of autonomy was to stretch the meaning of autonomy to the general idea of liberty, and thus, to lose its usefulness in making distinctions within our rights of privacy (Huff 793).

Whether or not a clarification of the two prongs of privacy would have had a bearing on the outcome of the case is a matter of debate. But it seems likely that a more explicit appeal to informational privacy would not have been enough to sway the Court in

favor of the appellees. The Court ruled that the statute requiring the registration of certain drugs with a state health agency was a reasonable exercise in maintaining public health, and that this interest superceded the right of patients and physicians to avoid “disclosure of personal matters” (*Whalen* 599).

However, the right to informational privacy received a crucial refinement by the Second Circuit of Appeals in *Doe v. City of New York*. The issue facing the Court of Appeals was the degree to which certain forms of medical information were strictly personal. In this case, Doe had filed a discrimination claim based upon his homosexuality and positive HIV status to the City of New York Commission on Human Rights. The commission later released information regarding Doe’s HIV status to the press, subjecting him to the possibility of discrimination by his employer, co-workers, and insurance company. Although the state had a legitimate interest in accessing this information, given the infectious nature of the disease, the Court of Appeals found that the state should not have had access to this medical information. Because of the uniquely personal nature of the information, the individual’s right not to be scrutinized trumped the state’s public health interest calling for the disclosure of the information. The key factor that allowed the selective disclosure of information to override the state’s health interest was thus the uniquely personal nature of the medical information.

These court cases reveal the two distinct strands of privacy that protect two distinct domains of privacy. The right to privacy qua autonomy guarantees our right to make the fundamental decisions that affect our lives and dignity, especially in the most intimate spheres of our lives. On the other hand, the right to informational privacy protects us from unwarranted observation, and therefore, evaluation by others. In

combination, these two domains of privacy act to secure the fundamental liberties of persons, so that we are able to pursue our interests without the undue interference of others. But this analysis of the right to privacy has also elucidated another issue that is pertinent to the application of privacy to the concerns surrounding genetic information. In the discussion of both strands of privacy, the interests of the state offer certain limitations to the protection of privacy. As we consider the right to genetic privacy, we must keep in mind the lessons learned in the analysis of privacy. A person's right to privacy is not absolute; compelling state interests can restrict it. The interesting questions are thus when and how.

IV. The Right to Genetic Privacy

The application of the right to privacy to genetic information can be divided into two main concerns, roughly corresponding to the two prongs of privacy. First, the availability of genetic information immediately exposes uniquely personal information about persons to the evaluation of others. Second, the state has a demonstrated interest in public health, militating against the individual's right to make decisions based upon their genetic information. In this section, I will consider these two issues separately, outlining the various issues that arise, and will conclude, in the final section, with suggestions as to how to interpret the confluence of the two prongs of privacy with the two types of genetic information.

Genetic Informational Privacy

As the decision in *Doe v. City of New York* demonstrates, in order for medical information to be protected under the right to privacy, it must be of a uniquely personal nature, i.e. the release of such material must directly threaten to limit a person's

fundamental liberties. Likewise, if genetic information is to be protected, we should be able to show how genetic information is uniquely personal, and thus how any unwarranted release of genetic information renders persons exposed to scrutiny by the public. There are three ways in which genetic information is uniquely personal. First, a person's genome can predict an individual's likely medical future for a variety of conditions. This ability to predict likely medical problems has likened the genome to a "future diary," a concept that we will explore shortly. Second, genetic information implicates the genetic status of persons other than the individual to which the information directly refers, namely biological parents, siblings, and children. Released information can thus subject uninvolved persons to public scrutiny and a limitation of their rights. And third, genetic information has historically been used to stigmatize and victimize persons (Annas 360). Expounding upon each one of these reasons separately, I hope to demonstrate that without a doubt, genetic information is uniquely personal information, and thus, requires protection under the informational strand of privacy.

The enterprise of medical research occupies itself with establishing the causation of disease. Once the causal link is identified, treatments, therapies, and behaviors can then be modified to eliminate, mitigate, or avoid the causes of disease. However, genetic diseases currently present quite a conundrum to the enterprise of medicine. Researchers are often able to identify the diseased, or abnormal, gene that causes the particular disease, but too often this diagnosis produces little that can be used to treat the disease.³ The affected individual thus is aware of a scenario that will likely play itself out in the

³ There are many efforts that are now using genetic techniques to rid persons of 'bad genes,' and some of these efforts have had celebrated success, even more showing promise. But it still remains that there are more identifiable genetic diseases than curable genetic diseases.

future, but may be paralyzed from doing anything to alter its probability, time of onset, or severity. For this reason, information about one's genome has been called one's "future diary" (Annas 360).

Consider the example of Huntington's Disease, a harrowing affliction striking most often during one's 40's or 50's. Once popularly known as Huntington's Chorea because of the wild involuntary movements associated with the disease, this genetic disease leads to a slow deterioration of mental abilities, i.e. intelligence, emotional control, balance and speech. Since the Huntington's gene is a single dominant gene, children of an affected parent have a 50% chance of also expressing the disease. With the availability of a genetic test to identify the presence of this gene, children can know, with high probability, whether or not they will suffer the same fate as their parent. If the test returns positive, the scenario of deterioration that crippled the life of their mother or father morbidly awaits the child. Although treatment in this area is progressing, there is little, if anything, that such a person can do to alter the course of the disease, yet they must anxiously live the next twenty or so years before any symptoms begin to appear.

The uniquely personal nature of genetic information can be illustrated through the concerns of a diagnosed individual. Knowledge of one's diseased genetic status can cut deep into the self-perception of persons. Akin to the sense of moral powerlessness felt by the ancient Greeks in the face of Moira, or Fate, persons are often powerless to alter the course of their disease, leaving them grasping to understand their situation. They may come to wonder if they somehow deserve such a disease, that they are somehow less worthy of a full life. Beyond such anxious thoughts, affected persons must contemplate how the disease will affect their life plans. And to aggravate the sheer gravity of coping

with such news, they must worry about how they will be received by society, if they will be subject to discrimination, and whether the liberties they have so enjoyed might be limited given this new knowledge. If the information were to reach their insurance companies, what kind of coverage would be available to them, and at what price? And if their employers were to obtain this information, what future do they have in their careers? Such possible restrictions on a person's liberties necessitate understanding genetic information as a highly personal form of information, and thus clamor for protection under the right to informational privacy.

The second reason that genetic information is uniquely personal has already been intimated in the discussion of the first reason. Because genes are hereditary, certain anomalies in one's genome imply a probability that the same anomaly will be present in the genomes of biological relatives. The aforementioned concerns that arise for those persons directly affected, both existential and practical, also affect family members. Although the right to informational privacy can do nothing to protect persons and their families from the reality of the disease, it can do much to protect them from the possibility of scrutiny and discrimination based upon the disease.

One concern that separates the position of the positively diagnosed from the position of family members is the *knowledge* that one will express the particular genetic disease. Whereas diagnosed persons already know their status and must begin coping with their situations, the confirmed status of family members is unknown, necessitating a different kind of coping. Especially in cases where no cure currently exists, the knowledge of one's probability of expressing a genetic disease, yet not knowing for sure if one's future has a diseased script, is undoubtedly a daunting state of existence. Does

one take a genetic test to confirm or eliminate the probability? Or is it better to live one's life ignorant of one's future health? (This unique position of family members raises further issues regarding the right to privacy, such as the right not to know one's status vs. a duty to know, but this discussion will be better served within the context of autonomy, which we shall explore shortly.)

But before we consider the prong of privacy qua autonomy, let us first address the final reason that genetic information is of a highly personal nature: genetic information has historically been used to stigmatize and victimize individuals. In a famous 1927 Supreme Court case, *Buck v. Bell*, the enforced sterilization of persons thought to carry 'bad genes' was ruled constitutional. A young woman, Carrie Buck, herself born of a mentally deficient mother, gave birth to a daughter while institutionalized at the Virginia Colony for Epileptics and Feebleminded. The ruling of the Supreme Court permitted the state to pursue their eugenic program in the name of public health, ending with the state-sanctioned sterilization of Ms. Buck. In his opinion, Justice Oliver Wendell Holmes uttered the famous eugenic words, "[t]hree generations of imbeciles are enough" (*Buck* 201-202). Tragically, the daughter of Carrie Buck later showed signs of being especially bright before her death from an intestinal disorder in the second grade (Kevles 112).

Institutional discrimination such as that illustrated in the case of *Buck v. Bell* has largely been eliminated since the heyday of the social eugenics movement in the first thirty-five years of the 20th century. However, discrimination based upon genetic information continues to threaten persons in two ways. First, as I have alluded to above, employers and insurance companies have large incentives to deny employment or coverage to individuals known to carry a genetic disease. Training employees costs

companies large amounts of time and money. If persons known to be turnover risks can be weeded out in the hiring process, the company can maintain a more efficient workforce, saving dollars in the long term. Likewise, if insurance companies can identify current or prospective clients as high risks, they too can financially benefit from genetic information. Depending on the severity of the genetic disease, premiums could be adjusted to account for expected medical care, or coverage could be denied altogether. Either way, those individuals who most need the protection will either be without insurance or forced to pay incredible premiums to receive coverage. The threat of discrimination against those carrying abnormal genes will only be exasperated by current trends in the insurance industry, which are steadily shifting from a community rating system to a system based upon individual risk and experience, without making the distinction between voluntary and involuntary risks (Wolf 347).

The other area in which discrimination threatens the freedoms of persons is in the area of reproductive rights. As the case of *Buck v. Bell* demonstrates, the right to bear children can be withdrawn if genes deemed unworthy are likely to be passed on. But *Buck v. Bell* is not merely an antiquated court case, remaining only as an aberration in the history of jurisprudence. Twenty-four states still have sterilization laws in effect, albeit highly regulated (Kevles 111). That such laws exist attests to the threat against personal liberties created by the institutional bias against persons with genetic maladies. Given the degree to which this discrimination has limited the freedoms of persons, the highly personal nature of genetic information must be asserted to protect persons from harmful uses of their genetic information.

The successful application of the right of informational privacy to genetic information hinges upon its uniquely personal nature. As the case of *Doe v. City of New York* suggests, in order for genetic information to be secure against the state's interest in pursuing public health, there must be a demonstrable threat to the restriction of a person's fundamental liberties. In fleshing out three reasons why genetic information is of such a uniquely personal nature and why unregulated access to it poses such a threat to liberty, I hope to have secured the information of one's genome under the guaranteed right to informational privacy. We can now turn to the issues surrounding the application of privacy qua autonomy to genetic information.

Issues of Autonomy in Decisions Regarding Genetic Information

Through our discussion of court cases, we have refined the right to privacy qua autonomy as protecting those important decisions that will affect our, or our family's, life plans. But as we have noted, this right is not absolute and can be limited by compelling state interests. The interesting questions that surround the application of privacy qua autonomy to issues involving genetic information thus arise at the intersection of the state's compelling interests and the individual's right to make autonomous decisions. In this subsection, I will explicate the opposing interests in issues of personal autonomy in order to provide a framework by which to understand and engage in the numerous debates that attend the issue of personal autonomy in decisions regarding genetic information.

Public health, including the health of future persons, is the most often cited state interest that challenges individual autonomy. If we are to understand how personal autonomy can be limited by the interests of public health, we must first grasp the basic

nature of genetic diseases. Because all genetic diseases display some pattern of inheritance, it is, in principle, possible to eradicate them through manipulation of reproductive behavior. It would then be consistent with the state's interest to pursue programs which aim to bring about this elimination of disease. But a key component of any program that attempts to eliminate genetic disease through manipulation of patterns of inheritance must alter reproductive habits. One method of covertly achieving this end is through a "duty to know" (Laurie 91-93). It is argued that if persons know the high probability of passing on a genetic disease to their children, they will readily alter their reproductive behavior. The state thus achieves the change in behavior necessary to break the patterns of inheritance through the decisions of individual persons.

However, several difficulties challenge the establishment of any duty to know. First, there are practical objections to the effectiveness of this duty. Knowledge of one's genetic status does not guarantee that persons will in fact alter their reproductive behavior (Laurie 92). Second, certain constitutional questions might be raised, i.e. personal or religious beliefs may keep persons from taking birth control, having a selective abortion, or even accepting the goal of the public health program. And as *Roe v. Wade* demonstrates, there is good reason to believe that the limiting of an existing person's rights does not supercede the rights of future persons to good health (Laurie 93). Third, we must ask whether the very establishment of a duty to know infringes upon the rights of persons. In direct opposition to the duty to know, there exists a good argument for the establishment of a right not to know one's genetic status. Whereas the duty to know finds its justification in the state's interest to secure the general health of its citizens, the right not to know is grounded in the interests of individuals, expressed specifically in the

right to privacy qua autonomy of persons. If a right not to know can be legitimated under the right to privacy, then a duty to know is unacceptable.

Let us thus turn to the interests of persons with regard to genetic information to provide a check against the public health interests of the state. In the earlier discussion of informational privacy, I referred to the unique position of the family members of persons carrying diseased genes. As opposed to their relative who is already known to have a hereditary genetic disease, family members have a choice whether or not they wish to know their own genetic status. Given the psychological and social burdens that accompany such knowledge, it is reasonable to accept that implicated family members may wish not to know. Such a desire to remain in ignorance is all the more reasonable considering that often no cure or preventative treatment is available.

The issue here is not whether the implicated individual should want to know or not want to know; the issue is that it is not the state's responsibility to decide this for the individual. To reiterate Justice O' Connor's words in *Glucksberg v. Washington*, "it is the *individual's* right to make certain unusually important decisions that will affect his own, or his family's, destiny" [emphasis added] (*Glucksberg* 2307). We have already demonstrated the importance of this decision as well as the extent to which the decision will affect one's coping with their genetic destiny. The right to make this autonomous decision must remain with the individual. Relatives of a person known to carry an inherited genetic disease might unavoidably know in the abstract that there is a possibility of their expressing the same disease, but they can choose not to know in the concrete (Laurie 91). Since this right not to know finds protection under the right to privacy qua

autonomy, public health initiatives attempting to establish a duty to know must be avoided.

Both prongs of privacy thus provide strong protection for the fundamental liberties of persons in genetic contexts. We have seen that informational privacy secures persons from the unwarranted gaze of the public, which can subject them to discrimination and exploitation based upon their genomes. And we know that the right to privacy qua autonomy ensures that persons are free to make decisions involving their genomes. However, there are limits to which the concept of genetic privacy can protect persons. Legal protections have focused upon securing genotypic information, i.e. regulating the collection of samples and information in gene banks, while phenotypic information has been left unprotected. If we are to take seriously the protection of persons with regard to their genetic information, we must consider how privacy interacts with phenotypic information. We might find that it is not privacy law, but rather the spirit of privacy that acts to protect persons.

V. Understanding the Various Arrangements of Genetic Privacy

I have intentionally refrained from incorporating the distinction between genotypic and phenotypic information into our discussion of genetic privacy in order to avoid confusion in the previous sections. Simplifying the discussion in this way enabled us to consider the nuances of privacy without the complicating factor of the dichotomous nature of genetic information. But in order to proceed in this manner, it was necessary to rely heavily on one conception of genetic information. As may be seen in my analysis of genetic privacy, I have invoked the genotypic notion of genetic information to illustrate the problems and issues that arise. I have used the genotypic conception as the default

understanding largely because it more closely matches our intuitive definition of genetic information, and because current legislative efforts tend to only focus upon protecting the information gleaned from the genotype. But now that we have laid out the application of the two prongs of privacy to genetic information, we can recast our conclusions in light of this admission, and then consider the role of privacy in discussions of phenotype.

As we have seen, information that is directly derivable from a person's genome can be brought under the protection of the right to privacy in two ways. Genotypic autonomy concerns itself with decisions regarding the manipulation of one's genome. Areas in which genotypic autonomy might be exercised include the acceptance or rejection of gene therapy to correct a genetic malady, the desire to pursue cosmetic gene therapy to enhance certain genetic traits, and finally in reproductive issues such as selective abortions based upon disease, traits, or even sex. It is the *prima facie* right of persons to make decisions in these areas. As such, the issues that arise in genotypic contexts parallel those issues in traditional medicine; any infringement upon the right of genotypic autonomy must demonstrate a compelling state interest.

We also see a parallel between selective disclosure of genotypic information and disclosure of other kinds of medical information in that both are concerned with access to the information. But as I have argued, genotypic information is of a much more intimate nature, and thus exposes persons to a particularly harmful form of discrimination. For this reason, genotypic information requires special recognition and protection under the right to selective disclosure of information. Attempts have been made to regulate access to genotypic information, as well as to legislate rules for the collection and storage of

samples from which the information is derived.⁴ Bills such as the Genetic Privacy Act provide a necessary protection against unwarranted access to genotypic information, and thus, secure persons from discriminatory actions based upon their genomes.

However, critics of efforts to pass anti-discrimination legislation argue that subsuming genotypic information under the right to privacy does not go far enough in protecting persons. Susan Wolf argues that the most serious harm to persons resulting from access to genotypic information is not discrimination per se, but the identifying of persons as their genes (346). The anti-discrimination approach assumes that genetic discrimination is deliberate, ignoring the deeper psychological dimensions like the stereotypes and prejudices that precede and fuel the drive to discriminate (345). If we are truly to protect persons from infringements of their basic liberties, we must also focus upon treating persons as persons, not as their genes. We need to expand our efforts beyond protections for genotypic information to include the roots of discrimination that are found in our daily interactions. We must apply the right of privacy to phenotypic information.

Phenotypic information poses a particular problem for privacy law. Since phenotypes are the observable expressions of the underlying genetic constitution, certain bits of information are unavoidably exposed to public scrutiny as soon as one enters the public sphere. Control of one's phenotypic information is thus extremely difficult. However, phenotypic information can be exploited just as easily as genotypic information. A genetic disease such as Huntington's disease or Down syndrome manifests itself in characteristic ways such that an observer need not have any direct

⁴ See Annas for a full description of the considerations involved in drafting the Genetic Privacy Act.

access to genotypic information in order to confirm one's genetic status. For example, insurance companies could raise premiums on account of the documentation that your father suffers from Huntington's disease.

Wolf is correct in stating that we must address these problems, but she is a bit hasty in dismissing the value of privacy in curtailing genotypic discrimination. What is necessary is a clear picture of the differing ways in which the concept of privacy can assist in protecting persons. When applied to genotypic information, the right to selective disclosure of information legally secures persons against discrimination based upon their genomes. In the case of phenotypic information, legal regulations cannot uproot the psychological prejudices that drive phenotypic discrimination. The nature of phenotypic prejudice is too complex to be captured under the auspices of the law alone. However, we can appeal to the spirit of privacy and augment attempts to eliminate phenotypic prejudice with more discerning ethical arguments. In doing so, the concept of privacy proves useful in combating both genotypic and phenotypic discrimination.

The spirit of phenotypic privacy may thus be best understood as an ethical imperative and not merely as a legal imperative. Justice Douglas seemed to have grasped this point in his majority opinion in *Griswold v. Connecticut*. In establishing privacy as the protector of our fundamental liberties, he appealed to the spirit of the Constitution, a document infused with ethical imperatives. We must carry forth the spirit of privacy to areas beyond the reach of formalized law. We must address the most subtle phenotypic discrimination that occurs in our daily interactions.

The ethical problem of genetic discrimination is not so much that we treat people differently, but that we see people as their genes. It is the reduction of persons to their

constituent genetic material that reinforces and legitimates the unequal treatment of persons. There is a belief that the biological nature of genes justifies differential treatment because it is somehow 'natural.' But differential treatment is not justified by the diversity found amongst human genomes. Since there is no one genome that can be considered 'normal' and used as a standard, differential treatment necessarily incorporates value judgments as to which genes are favorable and which genes are unfavorable. Our attack upon genetic discrimination must thus focus upon the value judgments that substantiate discriminatory actions.

The resolution of both genotypic and phenotypic discrimination is grounded in our view of persons. We must not see persons as their genes, rather we must see them as persons, complete with dignity and guaranteed the protection of their fundamental liberties. We must champion the rights of privacy, both in formal law and in spirit, that protect these liberties.

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Limitations of Morality in the Context of Prenatal Genetic Testing

I. Introduction

A hallmark of contemporary life is the inordinate amount of information that is available on any subject. It seems natural that, in a deluge of morally relevant information, we react by distilling a set of principles or action guides. However, following Bernard Williams, I will argue that this tendency to search for a moral system that will provide unequivocal directives belies the inherent complexities of ethical issues. In this paper, I will attempt to explicate the thicket of moral issues that are raised by contemporary biomedical science as it inundates society with new information regarding prenatal genetic testing. This thicket can be divided into two branches: (1) issues that arise in the process of informing hopeful parents about the results of the prenatal test, and (2) issues that are implicated in the decisions of the parents in response to these results. Although attempts have been made to bring morality to bear upon prenatal testing, they have typically addressed only the former branch of the thicket. The latter branch, which largely contains the more complex and intractable issues, is left untended. I will thus argue that with respect to the issues implicit in the decisions of parents, our primary task should be to explicate the complexities of the moral dimensions of prenatal testing, not to establish a moral system to guide the decision. With a clear conception of the richness of the moral issues surrounding prenatal testing, the intractable problems will be rendered more manageable, and the deluge of information less distracting.

II. A Thicket of Moral Issues

For parents who are at risk of conceiving a child with a harmful and debilitating disease, the information that is available through genetic testing can provide

immeasurable peace of mind. If the results are negative, parents can be reassured that a particular disease that has torn at the rest of their family will not ravage the health of their child. Even if the results of the genetic test are positive, the parents can still benefit from this information. With advanced screening technologies like chorionic villus sampling, the genetic status of a fetus can often be determined within the first trimester of pregnancy, before strong emotional attachments tend to take hold. This gives the parents time to consider the import of the test results. They can discuss the quality of life that the child would have if brought to term, and they can determine how well situated they are to provide that life. This allows the parents to either choose to abort the fetus or to prepare, both emotionally and financially, for the birth of their child (McCann).

But this scenario describes prenatal testing at its best. In actuality, there are many complicating factors which make gaining genetic information about one's child not so serene and idyllic. There are many contingencies that complicate the decision. In choosing to have the tests, parents must be concerned about the welfare of the fetus. In the common prenatal test amniocentesis, a long needle is inserted into the abdomen of the mother to collect a sample of the amniotic fluid, by which cells of the fetus can be isolated and tested. There is an increased risk, however, that the fetus will spontaneously abort from the procedure (McCann). Therefore, in order to justify the risk to the fetus, there should be a significant probability that the results of the test would detect a particular disposition toward disease. A thorough family health history must thus be obtained to help determine the necessity of such testing.

The parents will not only have to consider the welfare of the fetus, but they must also consider the welfare of the mother. Although results from genetic tests can be

determined within the first trimester, as in the case of chorionic villus sampling, it is not always possible to do so. Amniocentesis delays the availability of a diagnosis by almost two months (Verp et al. 614). As the results are received later in the pregnancy, the time available for understanding and discussing the uniqueness of the situation decreases. Accordingly, there is a smaller window of time to make the decision.

This window for decision making is constrained on one side by the technology of genetic screenings. Chorionic villus sampling is performed between 7-11 weeks of pregnancy, and amniocentesis between 15-17 weeks, each needing approximately 2 weeks to receive the results. On the other side, the window is constrained by increased risk of harm to mother, increased emotional attachment to the fetus, and a recommended gestational limit of 24-28 weeks (Verp et al. 614). Because of these factors, the option of abortion becomes a less viable option as the pregnancy proceeds. If abortion is to remain an option, the parents are then left with less time to reflect upon the various implications of their decision, and, consequently, have less time to make a decision based upon their considered judgments.

This short window of time seems especially cramped when the nature of the decision is brought to light. The parents are essentially trying to determine if the harm of aborting the fetus is better than the harm of delivering a child who must live with a particular malady. Of course, the harm of some maladies is clearly extensive, such as the case of anencephaly, in which the fetus develops without a brain. But there are some maladies, for example cystic fibrosis, for which treatment is available, and improving, such that life expectancy is up into the 20's and 30's. It seems reasonable to decide that

the harm in delivering an anencephalous infant justifies the harm of abortion, but questions are raised in the case of cystic fibrosis. What sort of life is worth living?

There are two sets of information that must be addressed if parents are ever to make a decision that does not rest upon ignorance, bias, or pure chance. The first set is the factual considerations that go into making the decision, and the second set is the particularly moral considerations and consequences of their decision. I will briefly address the first set of factual information in prenatal decision-making, but will spend most of my analysis on the more intractable issues of the second set.

III. Role of Genetic Counselors

The primary role of genetic counselors is to provide clients with accurate, up-to-date information about the facts pertinent to their situation. In a case where a fetus has been positively linked to the cystic fibrosis gene marker, the genetic counselor would explain various aspects of the disease to the parents. These might include the probability that the child would actually suffer from the disease, the range of severity of the disease, and the available treatment options for a child with cystic fibrosis. To the average lay person, the language of genetics and genetic screens may seem foreign. To speak in terms of probability is to speak in a language that humans are notoriously inept at comprehending. It is because the results of genetic tests are largely undecipherable to the untrained person that the need for a skilled translator has arisen. Genetic counselors are persons trained in genetics, in the mechanics of laboratory testing, and in counseling. Their duty is to translate genetic information into terms that the client can understand. Thus, genetic counselors ensure that parents have all of the facts regarding the results, which gives them a basis from which they can begin to make a decision.

Thus, with regard to the two sets of pertinent information, genetic counselors address the first set, the factual considerations. Any moral decision must reflect the facts of the situation. Without its attending facts, a moral decision is blind in its prescription. The factual information that is supplied by genetic counselors provides the necessary conditions that will help the parents determine which options are real options. Thus, genetic counselors have a role-related duty to provide their clients with the basic factual information.

It does not follow, however, that the presentation of facts is the counselor's only duty. As a profession, genetic counseling prides itself upon respect for the client's autonomy. It aspires to be value-neutral in its presentation of the facts, and allows the client the freedom to evaluate the situation according to his or her own values. Given the past practices of sterilization campaigns and extreme paternalism by physicians,¹ this separation between facts and values has valid historical reasons for its justification. However, strong arguments have recently been raised that this separation is no longer tenable,² and that genetic counselors should take a more active role in providing moral guidance.³ If indeed it is true that genetic counselors must involve themselves in the evaluation of the facts as part of their presentation to their clients, then it would seem that genetic counselors also have a role-related responsibility to facilitate an understanding of the ethical dimensions of the situation.

¹ For a more in depth discussion of the values and practices in the history of genetic counseling, see James Sorenson.

² See Dan Brock.

³ See Karen Grandstrand Gervais. It should be noted that she does not call for a return to a paternalistic approach to genetic counseling. Rather, Gervais is directive in that she calls upon genetic counselors to encourage clients to consider the full range of issues.

There have been two notable attempts to bring morality to bear upon the issues raised by genetic testing,⁴ both originating in the autonomy of persons. Thus, the focus of these moral systems is upon the duties of the genetic counselor to respect the beliefs and decisions of the client regardless of their content. They focus their attention upon resolving quandaries involving confidentiality or whether or not to inform clients about false paternity. In these limited respects, both moral systems do an adequate job of resolving the dilemmas.⁵ But to the extent that they attempt to capture the ethical dimensions of prenatal testing, they simply ignore the more intractable issues that arise.

IV. Overzealous Pruning

In his book, Ethics and the Limits of Philosophy, Bernard Williams chastises a modern conception of morality that attempts to distill the ethical life into a simple principle or system. Williams's "morality" is characterized by a relentless search for an "Archimedean Point," a foundation from which all moral issues might be uniquely resolved. But past attempts to find such a point either in well-being (Aristotle) or practical reason (Kant) have both failed. Since such a foundation cannot be found, at least in any powerful way, attempts to do so are not mere folly. They actually harm the ethical enterprise by diverting its attention away from the richness of the ethical life and restricting its scope. We should, then, commit ourselves to the messiness of ethical life, and work to explicate and understand the issues that face us.

In order to bring prenatal testing under a principled morality, it was necessary to consider one aspect of the ethical milieu – that of genetic counseling. But by confining

⁴ See Bernard Gert et al. and Beauchamp and Childress.

⁵ However, I do concede that with respect to resolving bioethical dilemmas, Gert's system of moral analysis presents a more reasonable and consistent method than the checklist of principles of Beauchamp and Childress.

the ethical scope of genetic testing to the responsibilities of genetic counselors, principled moral systems ultimately fail to grasp the rich complexity of ethical issues that attend prenatal testing. To illustrate how the search for universal principles restricts ethical inquiry, let us take a closer look at Bernard Gert's method of moral analysis.

In analyzing the moral issues surrounding genetic testing, Gert ultimately finds his foundation in the Kantian idea of a rational and impartial agent. Gert then distills from the ethical life a primary motivation--the avoidance of harm. Given the rational and impartial nature of humans and their motivation to avoid harm, a set of moral rules can be established. According to Gert, all rational and impartial agents would agree to this set of moral rules for the foundation of a moral system. An appeal for the legitimacy of the system is grounded in the universal consensus of the moral rules. Once he has established the moral rules as a public product, Gert has a code of conduct to which all rational and impartial agents could agree.⁶

At its foundation, Gert's moral system appeals to impartial principles to determine which actions are prohibited, given the universal motivation to avoid harm. Although there may be some question as to whether or not the avoidance of harm is our primary motivation, a more damning criticism of Gert's system is that which Williams raises against all systems based upon a Kantian notion of impartiality. Williams contests the idea that when we are deliberating a moral dilemma, we can extract ourselves from the situation and arrive at impartial principles. While it may be possible to distance ourselves from the situation through reflection, it does not explain how the impartial

⁶ Although Gert's system is more complex than my cursory sketch portrays, complete with justifications for violations of the moral rules and an additional analysis of moral ideals, it ultimately relies upon the basic foundation that I have described.

principles are achieved. When we extract ourselves from our particular situations, we do not become detached selves, merging into an impartial, communal self. We remain the selves that are doing the extracting. Therefore, although we can say that it is reasonable to accept the moral rules for oneself, we cannot say that it is reasonable for others to accept them (Williams 61), which is essential for Gert's moral system. The only way we can arrive at these impartial principles together is if we are already committed to them. The foundation of Gert's moral system, like all moral foundations, is thus an illusion.

However, according to Williams, the folly of pursuing philosophical mirages is not without its costs. It is a harmful distraction from the more important process of coming to understand the issues that attend the ethical life. By focusing upon the responsibilities of genetic counselors to the exclusion of the clients, Gert and other moral systematists oversimplify the problems that face us and underestimate the complexity of the moral decisions that must be made. The ethical issues that attend prenatal testing cannot be restricted to those that surround the translation of facts and probabilities. The moral issues extend beyond the conveyance of factual information.

V. A Thickening of the Thicket

A full exploration into the ethical issues surrounding prenatal testing must address the decisions that are being made by the parents, and consider the various parties who are implicated in the decision-making process. I will address three such parties: the biomedical community, society, and the parents. With the addition of each interested party, the complexity of the ethical dimensions of prenatal testing multiplies, until the decision of whether to abort or not challenges the limits of traditional morality.

The first group that is implicated in the decision of the parents is the biomedical community. We have seen that in order for parents to be able to make a decision that is not based upon ignorance, bias, or chance, they need to be aware of the facts of the situation. However, the parents must also be able to evaluate these facts. In order to do this, parents need to make judgments concerning the definition of terms like 'disease' and 'severe.' Although all parents have some thin idea of what these terms mean, the decisions that they will make depend upon thorough conceptions of these terms. Parents must be able to determine that anencephaly is a 'severe disease,' and that this severe disease would cause more harm if the pregnancy was continued than if it were to be terminated.

Since one of the problems parents must overcome is this lack of clear conceptions of 'disease' and 'severe,' they will often look to the biomedical professionals to fill out these terms. But the biomedical community is hardly more prepared to substantively define these terms than parents. In medicine, disease is sometimes defined as any condition that threatens the health of an individual, or deviates from a healthy individual's normal functioning.⁷ But 'health' is no more explicit a term than 'disease'; in fact, it is the key concept that needs clarification in order to determine the right course of action in prenatal testing situations. In order to know what terms like 'disease' and 'severe' are, we must first have some idea of the core concept of 'health.' If the professionals of the biomedical community, like genetic counselors, either cannot provide these substantive definitions or will not provide them because of the evaluative content of such definitions, then parents are left isolated and must resort to ad hoc reasoning.

⁷ For a discussion of the definition of 'health' based upon organ function, see Boorse 1987.

Here, we must at least consider the possibility of parents having questionable intentions for aborting a fetus. It is reasonable to assume that all parents desire a perfectly healthy child. But a cultural tendency to expect nothing less than a perfect child may result when the vagueness of what constitutes a 'healthy child' is combined with the power to know if one has a 'diseased child.' Consider the example of chromosomal trisomy 47, XXY. The fetus carries an extra sex chromosome, which might legitimately be considered a disease in that it causes a deviation from normal functioning. Although the infant will most likely be phenotypically normal and perhaps taller as an adult, the child will likely have a low IQ, characteristically leading to difficulty in school and in psychosocial development. Parents are additionally informed that this difficulty in psychosocial development correlates with ten times the chances of the child being incarcerated as an adult (Verp et al. 615). Why should parents accept these circumstances when there are other opportunities for creating a more perfect child? When the evaluative terms used by the biomedical community are left to be applied by parents, some eugenic trends might begin to creep into the decision to abort, even in cases where the genetic anomalies are not generally considered 'severe,' as we will soon see.

It may be argued that even if these eugenic trends were being established, it is for the parents to determine whether the affected fetus is brought to term. But this argument belies an assumption which implicates the society's interests in the parents' decision-making process. This argument assumes that the decision is uniquely the parents' concern, i.e. the choice to abort a fetus rests solely in the hands of the parents, specifically in the hands of the woman in the legal tradition. Yet, as the example of

parental decision making in the case of sex chromosome anomalies suggests, there is a peculiar, yet compelling, societal concern which arises in the context of genetic testing. If such a societal concern can be legitimized, the richness of the issues pertinent to the decision reaches a further level of complexity, one that challenges the sovereignty of individual autonomy.

To say that the right of parents to choose an abortion extends to the decisions regarding genetic testing is to confuse the abortion of a fetus with the abortion of a particular fetus because of certain characteristics. By aborting a particular fetus with trait X, one is saying that trait X is negative enough to overshadow other considerations that might require our respect, i.e. the parents would want the fetus to continue development if it did not have trait X. Although it might be argued that this judgment is strictly a private decision that has no effect upon anyone other than the family, it might also be argued that the effects of this judgment may very well extend beyond the parents in at least two important ways.

In part of a study by Verp et al. in 1988, parents chose to abort fetuses with autosomal aneuploidies (more or less than 2 copies of a chromosome) in 87.5% of cases recorded. The study followed parents' decisions for three types of aneuploidies: trisomies 13, 18, and 21. Although each disease has its unique manifestations, all three diseases share similar prognoses of severe mental retardation and shortened life spans. In these cases, there is no clear directive concerning the decision to abort. Persuasive arguments can be made both in favor of and in opposition to abortion, depending upon the way in which the substantive concept of 'severe' is understood. Because of this indeterminacy, the moral consequences for society are hard to discern, except the

utilitarian concerns, which I reject, of the economic burden such individuals place upon society.

We can escape this indeterminacy and make the interests of society more easily visible if we consider the results of the second part of the same study. In the case of sex chromosome anomalies, parents chose to abort affected fetuses 41.2% of the time (Verp et al. 616). Although this study looked at four different aneuploidy arrangements in the sex chromosomes, they all share much less severe disease symptoms. Each arrangement in sex chromosomes expresses itself differently, but in general, these individuals look normal, have slight drops in average IQ, slight increases in psychosocial difficulties, may be infertile, and perhaps need hormonal treatments in adolescence. There is no decrease in life expectancy or clear indications of a painful life.

By aborting these fetuses in 41.2% of the cases, these parents have, in effect, stated that a slight decrease in IQ and psychosocial adjustment, infertility, and hormonal treatments cumulatively make a life unworthy of the trouble. Here, the societal concern is apparent when you consider those individuals in society who have these chromosomal arrangements, and who are living fulfilling and worthwhile lives. Is the abortion of an otherwise desired fetus because of 'minor' genetic anomalies an attack upon the lives of persons in society who have these same genetic anomalies? Is the decision to abort a fetus because it has the female arrangement of sex chromosomes (XX) an attack upon women in society? I do not intend to address these highly charged questions in this paper. I will leave these questions open for further exploration. These are used only to point out that the decision of the parents may extend to the concerns of others in society,

and to demonstrate the level of complexity which ethical issues in genetic testing achieves.

Society has a real interest in protecting the dignity of its individual members from discrimination. It may be concluded that selective abortion violates a person's dignity, and thus extends beyond the interests of the parents in two ways. First, society may have an interest in extending its protection to include the protection of future persons against discrimination. Thus, society would have an interest in prohibiting abortion only in cases of selective abortion in which the act is discriminating against future persons based upon genetic criteria. Second, it could be determined that discriminating actions against fetuses based upon certain genes also discriminates against persons who share those genes. If either of these societal interests can be substantiated, then the autonomy of parents to abort a fetus for particular reasons raises a host of issues to consider. But the more important point for this paper is that these are questions that cannot go unanswered.

Ultimately, the decision to abort remains with the parents. Although they must consider the impact of their decision upon others, it is largely the psychological and financial burden of the parents to bear and raise the child. Therefore, the final decision rests with the parents and relies upon their judgment. We have seen that the decisions parents must make are complicated both by the vagueness of concepts like 'disease' and 'severe', and by societal considerations. But there is another consideration that parents must face, which will further add richness to this issue: parents must wrestle with their fear of contingency.

The contingency aspect of moral decision making in the context of prenatal testing can perhaps best be illuminated through an understanding of the conflicting

desires of the concerned parents. On one side, the parents want a child, often any child. They would embrace the birth of a little girl or little boy. They would equally embrace a baby with curly locks of hair or silky tufts of fuzz, sparkling blue eyes or deep brown ones. All of these genetic traits would be equally endearing, and in some senses, the surprise following the awareness of these traits is the beauty of contingency in childbirth. But on the other side, parents want a 'healthy' child. There are some contingencies that parents fear, such as their child inheriting a debilitating disease. The contingencies of childbirth thus strike both awe and fear into the hearts of parents.

However, with the availability of prenatal genetic information through testing, parents can now separate these conflicting aspects of contingency and prevent their child from expressing a particular genetic disease. Although any life is full of things that occur randomly and out of one's control, prenatal genetic testing can offer a small, yet powerful, respite from some of the fearful contingencies of childbirth. With a few genetically identifiable diseases, parents can circumvent the contingency of inheriting a genetic malady, and determine the relative health of their child in this respect.

Although in some ways, this can be a wonderful new means to prevent the suffering of both parents and children, there are two points that must be kept in mind with regard to the power to overcome contingency. First, we must remember that some contingencies in genetics will always remain. We may be able to control certain aspects of genetics, but other aspects will remain indeterminate. Only the most straightforward of genetic diseases are detectable, or have any hope of being detectable with precision. At one level, the interactions between genes responsible for complex diseases are hard to discern. And at another level, the interactions between genes and the environment

exacerbate the complexities of multiple gene interactions, ensuring some large areas of indeterminacy. If we quixotically attempt to overextend our limited mastery over the contingencies of childbirth, we are surely to be disappointed. And it will not be us, but rather our children, who embody some of the inevitable contingencies of procreation, who will bear the brunt of our disillusionment.

The second consideration with regard to contingency is its inverse relationship with responsibility. We tend to judge a person's moral decisions more generously if the person is acting in response to contingencies, as opposed to situations in which they have helped determine the circumstances. Consider the example of a boy who helped a kitten down from a high tree branch. If the boy merely noticed the kitten on the branch, and acted to bring the kitten down, we would morally applaud the boy. Had he not acted to save the kitten, we would refrain from applauding him, but would tend not to make a moral judgment against him. However, if the circumstances were different such that the kitten in the tree is not a contingent fact for the boy, let us say that he chased the kitten up the tree, then an absence of action to help get the kitten down would be morally deplorable. From this simple example, it is evident that the more we determine the circumstances of a situation, the more moral responsibility we have over the outcome of the situation. As we consider the possibility of determining certain aspects of childbirth, we must remember this relationship with responsibility.

We thus seemingly arrive at a paradox. Fetal genetic information made available by prenatal testing seems to demand more from the parents who receive a positive diagnosis than can reasonably be expected from them. Within a small window of time, parents must not only come to understand the factual considerations of their situation,

they must also come to appreciate the moral considerations I have described above. And while the ability to comprehend these moral dimensions reach heroic proportions at the level of the individual, we have seen that the parents are increasingly more responsible for the outcome of their decision.

Consider a set of parents who learns that there is an 80% chance that their child will not express the disease cystic fibrosis. They figure that the chances are pretty good that their child will not express this disease. However, soon after the birth, it is determined that the child does have a particularly severe form of cystic fibrosis. The 20% chance of the child expressing the disease actually occurred. The child spends the next 6 years of her life in and out of the hospital, suffering from the complications of cystic fibrosis before death finally ends her suffering. Did the parents make a mistake? Are they responsible for the suffering of their daughter?

The answer to this paradox lies in its dissolution. To place the blame squarely on the shoulders of the parents is to mistakenly believe that the decision is uniquely the decision of the parents. As I have attempted to demonstrate, although the ultimate decision rests with the parents, the parents are not moral actors independent of society. The biomedical community gives the parents their concepts of probability and 'disease' upon which the parents must make their decision. And society in general can promote an over-confidence in mastering the contingencies of childbirth. Just as society shares an interest in the decisions of parents, so does society share responsibility for their results. The paradox dissolves as we reintegrate society into the picture. Although the complications that parents must consider are too much for isolated individuals, they are not too much for a collective body of individuals.

VI. A Call to Landscape Thickets into Trimmed Hedges

Throughout this paper, I have attempted to present a picture of the complexities that arise with increased genetic information in the context of prenatal testing. I have largely raised more questions than I have answered, but at this stage, we must be concerned with the scope of the problem before we move too quickly for solutions. Following Williams, I have resisted the temptation of bringing these issues immediately under a moral system of principles. Instead, I have attempted to explicate some of the more intractable problems that undergird the issues surrounding prenatal genetic testing. At some point, we must turn our attention to the resolution of these complex problems, but this deserves the attention of separate papers. Thus, I will end by merely proposing a starting point for a sustained discussion of how these issues might be resolved.

We have seen how both individual parents and society at large have interests in the issues that arise in the context of prenatal genetic testing. We should begin our discussion with this core understanding. Once we admit this, we can address the various complications that make these issues so difficult. As individuals always in relation to society, we must define substantive concepts like 'severe disease' and 'quality of life.' We must fill out these concepts with our collective experiences. Likewise, the proper role of contingency in our lives must also be fully explored. How much contingency do we want in our lives? Answering these questions up front as a collective group will mitigate against the pressures placed upon the individual when he or she must decide as an individual.

The most pressing concern that we face in contemporary life is the organization of the influx of information of all kinds. As individuals, we have little hope of sorting

through this mountain of information and making responsible decisions based upon careful consideration of the issues involved. But as a collective whole, there is hope: hope to organize the information about the world, hope to understand our world, and hope to guide the world by the common values that we hold.

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