

### Journal of Law and Health

Volume 13 | Issue 2 Article

1999

# Searching for the Holy Grail: The Human Genome Project and Its Implications

Allison Morse

Follow this and additional works at: https://engagedscholarship.csuohio.edu/jlh

Part of the Consumer Protection Law Commons, and the Health Law and Policy Commons How does access to this work benefit you? Let us know!

#### **Recommended Citation**

Allison Morse, Searching for the Holy Grail: The Human Genome Project and Its Implications, 13 J.L. & Health 219 (1998-1999)

This Article is brought to you for free and open access by the Journals at EngagedScholarship@CSU. It has been accepted for inclusion in Journal of Law and Health by an authorized editor of EngagedScholarship@CSU. For more information, please contact library.es@csuohio.edu.

## SEARCHING FOR THE HOLY GRAIL: THE HUMAN GENOME PROJECT AND ITS IMPLICATIONS

#### ALLISON MORSE1

| I.   | Introduction                               | 219 |
|------|--|-----|
| II.  | THE SCIENTIFIC BACKGROUND                  | 225 |
|      | A. Reductionism v. Organicist              |     |
|      | Explanatory Models                         | 225 |
|      | B. How Genes Work                          | 228 |
| III. | WILL THE PROJECT DO WHAT IT CLAIMS?        | 230 |
|      | A. The Genome as the "Book of Man"         | 230 |
|      | B. Will it Advance Medicine?               |     |
| IV.  | THE PSYCHOLOGICAL COST OF PREDICTION       | 239 |
|      | A. Testing as Social Power                 | 239 |
|      | B. The effects of Genetic Diagnosis on the |     |
|      | Individual and the Family                  | 240 |
| V.   | SOCIOLOGICAL CONSEQUENCES OF MAP           |     |
|      | OF THE GENOME                              | 243 |
|      | A. Personal Eugenics                       | 243 |
|      | B. Eugenic Policies                        |     |
|      | C. The Reduction of Genetic Diversity      |     |
|      | and its Effects                            | 249 |
| VI.  | ACCEPTANCE OF THE POWER OF THE             |     |
|      | GENOME TO DETERMINE BEHAVIOR EFFECTS       |     |
|      | SOME OF THE BASIC IDEAS UNDERLYING OUR     |     |
|      | System of Justice                          | 251 |
| VII. | Conclusion                                 | 255 |
|      |  |     |

#### I. INTRODUCTION

The Report on the Human Genome Initiative declared that uncovering the human genome is revealing the "book of man," that by mapping and understanding the

<sup>&</sup>lt;sup>1</sup>B.A. (1991) University of California at Berkeley. M.A. (1993) in Marriage, Family and Child Therapy, Phillips Graduate Institute. J.D. (1988), University of California, Hastings College of Law. I would like to thank William Dodge, Radhika Rao, Kathryn Davis, Billie Sutherland, and Sarah Weinstein for thie inciteful comments on earlier drafts. In particular I would like to thank David Faigman and Reuel Schiller without whose encouragement and invaluable suggestions this article could not have been written.

<sup>&</sup>lt;sup>2</sup>HEALTH AND ENVIRONMENTAL RESEARCH ADVISORY COMMITTEE, U.S. DEPARTMENT OF ENERGY, REPORT ON THE HUMAN GENOME INITIATIVE 1, 5 (Apr. 1987) [hereinafter Report on THE HUMAN GENOME INITIATIVE].

human genome we will understand what it means to be human.<sup>3</sup> Many proponents of the Human Genome Project give a dominant place to an internal mechanism, the gene, as the source of human behavior.<sup>4</sup> Where we as a culture allocate responsibility has profound effects on how we construct our identity and our society.

The Human Genome Project is a scientific enterprise under the auspices of the U.S. Department of Energy and the Department of Health and Human Services. Its task is to order and sequence the human genome.<sup>5</sup> This project will require the mapping of some three billion bases from one genome that will act as the prototype of a "normal" genome.<sup>6</sup> Many of the scientists involved in the Human Genome Project believe the mapping of these three billion bases will lead to major advances

<sup>4</sup>Proponents of the Human Genome Project also acknowledge that genes do not act alone, admitting that environment is also a factor in determining traits. However, some proponents seem to merely give lip service to the importance of environment as a co-factor in behavior while at the same time allocating most of their causal explanations to the genes. For example, Walter Gilbert acknowledges that "genetic information does not dictate everything about us." WALTER GILBERT, A Vision of the Grail, in The Code Of Codes: Scientific and Social Issues in THE HUMAN GENOME PROJECT 83, 96 (Daniel J. Kevles & Leroy Hood eds., 1992). [hereinafter GILBERT] But this acknowledgment belies assertions that the genome holds the "text" of man. REPORT ON THE HUMAN GENOME INITIATIVE, supra note 2. In fact, in the paragraph just before the above quoted text, Professor Gilbert states that genes do not determine behavior. In contrast, he also says they do: "[T]o recognize that we are determined, in a certain sense, by a finite collection of information that is knowable will change our view of ourselves. It is the closing of an intellectual frontier." GILBERT, at 96. Professor Lewontin argues that these scientists cannot truly understand that the internal and external factors are equally important in how an organism functions, for if they did, they would not believe that the "sequence of the human genome is the grail that will reveal to us what it is to be human, that it will change our philosophical view of ourselves, that it will show how life works." RICHARD C. LEWONTIN, BIOLOGY AS IDEOLOGY: THE DOCTRINE OF DNA 64 (1992).

<sup>5</sup>Report on the Human Genome Initiative, *supra* note 2, at 1.

<sup>6</sup>Id. at 2. The Human Genome Project proposes to identify the entire sequence of base pairs in a prototypical DNA, from this prototype a scientist can compare other people's DNA. When they find differences consistent in people with the same behavioral or medical problem, the researchers can surmise it is the gene that controls the trait. By having a prototype, once the mutation of the "sick" person is found, the scientist has a model of what the "normal" gene should look like. LEWONTIN, supra note 4, at 49. Therefore this entire project presupposes there is such a thing as a "normal" DNA. Yet each person's genome varies from others, and these changes in the genome do not necessarily reflect changes in the protein produced. LEWONTIN, supra note 4, at 50. Professor Lewontin notes: "We do not have good estimates for humans at the moment, but if humans are anything like experimental animals, about one in every 500 nucleotide will differ in DNA taken from any two individuals chosen at random. Since there are roughly 3 billion nucleotides in human genes, any two human beings will differ on the average in about 600,000 nucleotides. And an average gene that is, say, 3,000 nucleotides long will differ between any two normal individuals by about 20 nucleotides." Id. In one study on hemophilia B, where scientists knew what the relevant gene was in a sample of 216 people with hemophilia B, they found 115 different locations for the mutation in the gene. Ruth Hubbard & Elijah Wald, Exploding the Gene Myth 55 (1997) [hereinafter HUBBARD & WALD]. That kind of variation belies the existence of a prototype with which to compare all others. Like the "Holy Grail," a map of a prototypical genome is not of this world.

 $<sup>^{3}</sup>Id.$ 

in medicine<sup>7</sup> and biotechnology,<sup>8</sup> as well as uncover the essential "text" of what it means to be human.<sup>9</sup>

Supporting scientific enterprise is an important function of government; however, science is not immune from the philosophic persuasions of its scientists. <sup>10</sup> The methods of research our government decides to endow will reflect our own culture's belief of where causal agents reside. <sup>11</sup> The assumption that genes are the carrier of our destiny is a profoundly ideological stance. It places reductionist explanations <sup>12</sup> to behavior above all others and, in doing so, allocates other causes such as environment to subsidiary roles.

Legal scholars have been quick to jump on this reductionist bandwagon and write of the legal implications resulting from the mapping of the human genome. Articles have been written on the problems of individuals obtaining insurance if a test reveals they carry the gene for a certain disease, <sup>13</sup> or on physicians becoming subject to torts for failing to disclose the presence of a genetic defect in a patient to her family members, <sup>14</sup> or on the pros and cons of genetic privacy. <sup>15</sup> These are important issues and ones that need to be addressed, but what underlies them is an assumption that the claims of the Human Genome Project are true.

Legal scholars are not alone in their enthusiasm for this reductionist explanation of human traits. The idea that a map of identifiable sequential regions in DNA can

<sup>&</sup>lt;sup>7</sup>REPORT ON THE HUMAN GENOME INITIATIVE, *supra* note 2, at 9.

<sup>&</sup>lt;sup>8</sup>*Id*. at 10.

<sup>&</sup>lt;sup>9</sup>*Id.* at 5.

<sup>&</sup>lt;sup>10</sup>Science cannot help but be effected by the bias of the researcher, for the researcher's selection of a hypothesis is "invariably infused with the researcher['s] implicit beliefs, both normative and empirical." David L. Faigman, *The Evidentiary Status of Social Science Under Daubert: Is it "Scientific," "Technical," or "Other" Knowledge?*, 1 PSYCHOL., PUB. POL'Y & L. 960, 963 (1995). In addition, selection of what is studied in science is influenced by both public and private institution's decision on what projects will get funding. John M. Conley, *The Social Science of Ideology and the Ideology of Social Science*, 72 N.C.L. REV. 1249, 1251 (1994).

<sup>&</sup>lt;sup>11</sup>See Report on the Human Genome Initiative, supra note 2, at 5.

<sup>&</sup>lt;sup>12</sup>Reductionism framework believes that by understanding the smallest component of an object, one will have the key to explaining the whole object. ERNST MAYR, THIS IS BIOLOGY 17 (1997). For a more complete explanation of reductionism see discussion *infra* Part II.

<sup>&</sup>lt;sup>13</sup>Eric Mills Holmes, Solving the Insurance/Genetic Fair/Unfair Discrimination Dilemma in Light of the Human Genome Project, 85 Ky. L.J. 503 (1996-1997).

<sup>&</sup>lt;sup>14</sup>L.J. Deftos, Genomic Torts: The Law of the Future-The Duty of Physicians to Disclose the Presence of a Genetic Disease to the Relatives of Their Patients with the Disease, 32 U.S.F. L. Rev. 105 (1997).

<sup>&</sup>lt;sup>15</sup>George P. Smith, II, Accessing Genomic Information or Safeguarding Genetic Privacy, 9 J.L. & HEALTH 121 (1994-1995). The Human Genome Project has inspired many other grist for legal scholarship mills, such as Michael J. Malinowski & Maureen A. O'Rourke, A False Start? The Impact of Federal Policy on the Genotechnology Industry, 13 YALE J. ON REG., 163 (1996). See also Julia Walsh, Reproductive Rights and the Human Genome Project, 4 S. CAL. REV. L. & WOMENS'S STUD., 145 (1994); G. Kenneth Smith & Denise M. Kettelberger, Patents and the Human Genome Project, 22 AIPLA Q.J. 27 (1994).

"control" manifested traits, from disease to personality, has been easily accepted by the public. After all, it is a highly plausible theory, to the layperson or even to someone with considerable education. Scientists have identified areas of DNA that, when mutated, affect a trait of the human host, such as the single gene for cystic fibrosis. Furthermore, a tenth-grade biology class can describe Mendelian genetics and how a gene from one's mother and another from one's father will determine the color of one's hair or eyes. 17

The wide adoption of DNA as master molecule in the scientific community is seen in the incredible explosion of trials for differing gene therapies. <sup>18</sup> "The National Institute of Health (NIH) is spending an estimated \$200 million a year to develop and test tools and techniques for gene therapy. Private companies have raised hundreds of millions of dollars to enter the field and are now sponsoring most of the clinical trials. Many academic centers have created gene-therapy programs and joined the jockeying for a piece of the action." <sup>19</sup> To date, very little concrete data on the benefits of gene therapy have resulted from all this research. <sup>20</sup> Yet, the allocation of medical research resources continues to increase in this area. <sup>21</sup>

The benefactors of the Human Genome Project will undoubtedly be the biotechnology companies. Their interests are served by fostering the "myth" of the genome; moreover, they will be the recipients of funding for new technological breakthroughs in isolating genes and will profit from the marketing of DNA tests to doctors, employers, and genetic counselors.<sup>22</sup> Universities also benefit from the continued belief in this deterministic model, gaining access to substantial funds poured into this long-term project, as well as all the subsequent research projects that hopefully will make the half-billion dollars spent on the map of the genome meaningful.<sup>23</sup> These kind of funds ensure that those individuals who choose to research microbiology over evolutionary biology will be the ones financed and thus able to produce research. This will eventually result in a substantially larger tenure track for scholars in this field as opposed to other medical or biological models and will perpetuate the stake research institutions have in this deterministic explanation for human behavior. In addition, the geneticist not only gains from this model through academic recognition, but also through financial gain.<sup>24</sup> Most established

<sup>&</sup>lt;sup>16</sup>Nelkin & Lindee's book, The DNA MYSTIQUE, examines the many ways our culture has grabbed on to the idea that DNA is the control center for behavior. DOROTHY NELKIN & M. SUSAN LINDEE, THE DNA MYSTIQUE: THE GENE AS A CULTURAL ICON 89 (1995) [hereinafter NELKIN & LINDEE].

<sup>&</sup>lt;sup>17</sup>MICHAEL C. MIX ET AL., BIOLOGY: THE NETWORK OF LIFE 207-09 (1992).

<sup>&</sup>lt;sup>18</sup>This is not to say that there are not also many critics to seeing the world through a genetic lens. *See* LEWONTIN, *supra* note 4. *See also* HUBBARD & WALD, *supra* note 6.

<sup>&</sup>lt;sup>19</sup>Eliot Marshall, Gene Therapy's Growing Pains, SCIENCE, Aug. 25, 1995, at 1050.

<sup>&</sup>lt;sup>20</sup>*Id.* Including the 1990 claimed success with the treatment of adenosine deaminase disorder with gene therapy. *Id.* 

 $<sup>^{21}</sup>$ *Id*.

<sup>&</sup>lt;sup>22</sup>See LEWONTIN, *supra* note 4, at 73-74.

<sup>&</sup>lt;sup>23</sup>*Id*. at 74.

 $<sup>^{24}</sup>Id$ .

molecular biologists are not only paid to map the genetic sequence, but many also have a financial stake in bio-technology enterprises, either as shareholders or as employees.<sup>25</sup>

Many media reports have also promoted the notion of biological determinism.<sup>26</sup> An illustration of how the media has promoted genetic explanations above social ones is portrayed in the *New York Times* coverage of the National Research Council's 1992 report on violence.<sup>27</sup> The Council's report gave, at best, a weak role to genes in the formation of a violent predisposition.<sup>28</sup> Out of the 464 page report, only fourteen pages dealt with any link to a biological component.<sup>29</sup> Yet the *New York Times* headlined its article on the Council's report by saying, "Study Cites Role of Biological Factors in Violence."<sup>30</sup> The news media report on a regular basis of new discoveries linking genes to behaviors, such as schizophrenia, alcoholism, and homosexuality.<sup>31</sup> Yet, the fact that virtually all these links have been denounced by further experiments do not garner the same kind of media exposure.<sup>32</sup>

Of course, there is the other extreme where people do not believe biology has anything to do with the development of traits. That is not the position of this Paper, nor of most people when they are asked to allocate the roles of nature and nurture in

 $^{29}Id.$ 

<sup>&</sup>lt;sup>25</sup>See *Id.* at 73-74. "No prominent molecular biologist of my acquaintance is without a financial stake in the biotechnology business. As a result, serious conflicts of interest have emerged in universities and in government service." *Id.* at 74. Lewontin notes that "[i]t has been clear since the first discoveries in molecular biology that 'genetic engineering,' the creation to order of genetically altered organisms, has an immense possibility for producing private profit. If the genes that allow clover plants to manufacture their own fertilizer out of the nitrogen in the air could be transferred to maize or wheat, farmers would save great sums and the producers of the engineered seed would make a great deal of money . . . . A bacterium has already been produced that will eat raw petroleum, making oil spills biodegradable." *Id.* at 73-74. To this high profit enterprise the biologist and/or the universities that do the research get an interest in the business. Thereby, "[b]iotechnology joins basketball as an important source of educational cash." *Id.* at 74.

<sup>&</sup>lt;sup>26</sup>Determinism is "the theory that all occurences in nature are determined by antecedent causes." Webster's Third New International Dictionary 616 (3d ed. 1986) [hereinafter Webster's]. Therefore, biological determinism presupposes that behavior is determined by the biology of the actor.

<sup>&</sup>lt;sup>27</sup>Nelkin & Lindee, *supra* note 16, at 89.

 $<sup>^{28}</sup>Id.$ 

 $<sup>^{30}</sup>$ *Id*.

<sup>&</sup>lt;sup>31</sup>Hubbard & Wald, *supra* note 6, at 66. "Already the confusion is enormous within the last few years, genes have been announced 'for' manic-depression, schizophrenia, alcoholism, and smoking related lung cancer. The claims about manic-depression and schizophrenia genes were withdrawn soon after their announcement and the gene for alcoholism met the same fate later, although another one has since crept into the news . . . . Although like mirages, many of these genes disappear when one tries to look at them closely a confusion of claims and counterclaims is inevitable, and there are so many stories that people are left with the impression that our genes control everything." *Id*.

 $<sup>^{32}</sup>Id.$ 

human development.<sup>33</sup> What this Paper does attempt to explore are the effects on our society when scholars, scientist and the media promote the biological explanation of behavior over environmental or individual ones.<sup>34</sup>

Legal scholars, scientists and the media continue to debate how society will deal with the seemingly preordained fact that science will one day be able to analyze each person's DNA and come up with a disease profile and perhaps a personality profile as well. For example, legal issues raised by the belief that this type of profiling is possible include matters involving privacy, 35 employment, 6 insurability, 70 eugenics, 8 and our whole notion of freewill with its implications for our entire system of justice. Yet in some sense, these "ethical issues," issues that James Watson declared to be of such importance that three percent of the money allocated to the Human Genome Project should be set aside for study, do in fact, legitimize the whole idea of the Human Genome Project itself. Certainly all of this sound and fury about the project would not exist if the project itself could not deliver this "Brave New World" in the true sense of Huxley's novel. That is, when scholars

<sup>&</sup>lt;sup>33</sup>See supra text accompanying note 4.

<sup>&</sup>lt;sup>34</sup>See Nelkin & Lindee, supra note 16, at 89. See also supra text accompanying note 4.

<sup>&</sup>lt;sup>35</sup>Worries about access to genetic information is compounded by the revolution in technology which makes it possible to store and transmit massive amounts of information via computer. *See e.g.*, Ruth Macklin, *Privacy and Control of Genetic Information*, in GENE MAPPING 165 (George J. Annas & Sherman Elias eds., 1992). The storage of DNA information has been suggested by the FBI in order to facilitate law enforcement. *Id.* If this information is accessed either permissibly or not, it could have effects on that individual's ability to gain employment or receive health care.

<sup>&</sup>lt;sup>36</sup>DOROTHY NELKIN & LAURENCE TANCREDI, DANGEROUS DIAGNOSTICS chapter 5 (1989). *See also* Hubbard & Wald, *supra* note 6, at 130-35.

<sup>&</sup>lt;sup>37</sup>Hubbard & Wald, *supra* note 6, at 140-44.

<sup>&</sup>lt;sup>38</sup>See generally Abbey Lippman, Prenatal Genetic Testing and Screening: Constructing Needs and Reinforcing Inequalities, AM. J.L. & MED. 15 (1991).

<sup>&</sup>lt;sup>39</sup>Dan W. Brock, *The Human Genome Project and Human Identity*, 29 HOUS. L. REV. 7, 13 (1992). "The second aspect of identity that the Human Genome Project is likely to deeply affect is our conception of ourselves as responsible agents and, more specifically, as morally and legally responsible for our actions, for the lives we live, and for the kinds of people that we become. The conception of ourselves as responsible agents is reflected in common moral beliefs and in important social and legal institutions and practices that place great value on individual self-determination." *Id.* 

 $<sup>^{40}</sup>$ James Watson is one of the discoverers of the structure of DNA. James D. Watson, The Double Helix (1968).

<sup>&</sup>lt;sup>41</sup>James Watson advocated and got three percent of the human genome budget to go to ethical considerations. James D. Watson, *The Human Genome Project: Past, Present, and Future*, Science, Apr. 6, 1990, at 44, 46. He said there was a need for this since the understanding of the genome will raise issues involving effects on individuals when they find out they have some genetic disease as well as the effects on that individuals' employment and insurance opportunities. *Id.* 

<sup>&</sup>lt;sup>42</sup>Brave New World is a science fiction novel where all humans are created in test tubes and genetically engineered. ALDOUS HUXLEY, BRAVE NEW WORLD (1932).

and scientists argue about the sociological ramifications of having a map that pinpoints the root of human traits, it implies this is what the map of the genome will eventually be able to do. The sociological issues ascribed to the mapping of the human genome include people losing their jobs because they have markers for certain illnesses, women aborting fetuses because a genetic marker for an unwanted trait has been found and projects such as Head Start losing their funding. These Faustian scenarios become even more obscene considering that the complete map of the human genome, and identification of the areas of the genome that correspond to certain traits, are not able to provide a deterministic model to support these types of actions.

This Paper will explore the ethical considerations of the reductionist paradigm that the Human Genome Project represents, and analyze how this paradigm affects our political institutions, our family relationships, and even our identity. Part Two will provide the scientific background for a discussion of the Human Genome Project. It will begin by defining two competing theoretical constructs scientist use when exploring biological phenomenon: reductionism and organicism. This Part will then offer a rudimentary explanation of how genes function. Yet even this rudimentary explanation illustrates the complexity involved in the functioning of genes, leaving the reductionist notions of genes as the "master molecule" wanting. Part Three analyzes the claims of what can be accomplished by the Human Genome Project and explores more productive avenues where policymakers could be allocating our financial resources. Part Four looks at how genetic testing can be a form of power which medical, insurance and government institutions can use to define what is "normal." This section also evaluates the advantages and disadvantages of predictive diagnoses on individuals and their families. Part Five looks at the subscription of our culture to the model of gene as determinant of disease and behavior, opening the door to personal and institutional eugenics. Part Six looks at the political cost of deterministic notions, and how these very concepts could undermine the theoretical foundations of our whole system of justice.

#### II. THE SCIENTIFIC BACKGROUND

#### A. Reduction v. Organicist Explanatory Models

The quest of the Human Genome Project is premised on the notion that by identifying the smallest unit involved in biological processes one will have a blueprint with which to trace human attributes. A reductionist framework presupposes that by discovering the smallest component of an object you will have found the explanatory cause for that thing.<sup>43</sup> The Human Genome Project is the quintessential reductionist endeavor.

Science has benefited from a reductionist outlook. For example, the discovery of bacteria, something unseen by the human eye, was proven to cause many diseases.<sup>44</sup>

-

<sup>&</sup>lt;sup>43</sup>MAYR, *supra* note 12, at 17. "For reductionist, the problem of explanation is in principle resolved as soon as the reduction to the smallest components has been accomplished. They claim that as soon as one has completed the inventory of these components and has determined the function of each of them, it should be an easy task to explain also everything observed at the higher levels of organization." *Id.* 

<sup>&</sup>lt;sup>44</sup>HUBBARD & WALD, *supra* note 6, at 3.

Moreover, the physical sciences were able to harness a vast amount of energy from splitting the atom. 45 The success of reductionism in science resulted in other disciplines following this paradigm as a means to gaining knowledge in their field of study. For example, in the universities, an increasing emphasis on specialization occured in order to satisfy the demand for specialized technicians in the work place.<sup>46</sup>

Although reductionism provides important insights into phenomena, it is inadequate to explain living systems. Professor of Zoology at Harvard, Ernst Mayr, wrote:

[T]he claim that every attribute of complex living systems can be explained through the study of the lowest components (molecules, genes, or whatever) struck me as absurd. Living organisms form a hierarchy of ever more complex systems, from molecules, cells, and tissues, through the whole organisms, populations and species. In each higher system, characteristics emerge that could not have been predicted from a knowledge of the components.<sup>47</sup>

Professor Mayr's point of view reflects a competing paradigm for the understanding of living organisms, called organicism. 48

Organicists believe that in order to understand an organism one must look at the organizational structure of the system, not just its disparate parts.<sup>49</sup> conceptualization of life does not negate the value of analyzing organisms at reduced levels in order to understand how the components work.<sup>50</sup> The organicist believes that it is the genetic program which functions on the parts of the organism.<sup>51</sup> To the organicist,

analysis should be continued downward only to the lowest level at which this approach yields relevant new information and new insights. Every system, every integron, loses some of its characteristics when taken apart, and many of the important interactions of components of an organism do not occur at the physicochemical level but at a higher level of integration.52

 $^{45}Id.$ 

<sup>&</sup>lt;sup>46</sup>Peter A.Y. Gunter, "Coherence Lost:" Education, Modernity, and Fractured Meaning, HUMANIST, May 1, 1995, at 25. "The progressive atomizing of knowledge into technical specialties, subspecialties, and sub-subspecialties ad infinitum, organized top-down, becomes not only the operating principle of our civilization but the common coin of education, where dogma of 'progressive specialization' rules supreme." Id.

<sup>&</sup>lt;sup>47</sup>MAYR, *supra* note 12, at xii.

<sup>&</sup>lt;sup>48</sup>*Id.* at 16-23.

<sup>&</sup>lt;sup>49</sup>*Id*. at 18.

<sup>&</sup>lt;sup>50</sup>Id. at 20.

<sup>&</sup>lt;sup>51</sup>MAYR, *supra* note 12, at 20.

<sup>&</sup>lt;sup>52</sup>*Id.* at 20.

In addition to seeing the organism as a whole, a multiplicity of viewpoints are needed to understand the complete function of the organism.<sup>53</sup> Instead of looking for one singular cause for behavior, it is important to understand the different stances from which a question is asked; whether it be at the genetic, individual, or social perspective, each reveals truths about the organism.

Multiplicity of perspective seems to go against the western world's conception of understanding; yet this understanding is not what is "natural," but is rather a product of our own culture's dogma.<sup>54</sup>

The western adherence to the illusion that the link between objects in space and events in time is a straight line is similar to the belief in religious dogma. Just as all major religions of the world begin with the assumption that beneath the flux of our sensations there lies a unifying principle, so science has discovered in Euclid's rectilinear system its corollary.<sup>55</sup>

"According to Euclidean geometry, a point cannot occupy more than one locus." Therefore, something cannot be one thing at the same time it is another. When you see different actions and reactions converge, the idea of causality looses its meaning, which can be uncomfortable for those socialized in this Euclidian world.

Our society rewards people who discover tangible things.<sup>57</sup> This perpetuates the perspective of linear cause and effect as the only paradigm in which to explain our world and to get scientific recognition.<sup>58</sup> Moreover, an easy cause-and-effect relationship fits nicely into a news sound bite.

\_

<sup>&</sup>lt;sup>53</sup>In biology, more than one theory to explain cause exists simultaneously. The acceptance of punctuated evolution does not negate the possibility of gradual evolution. MAYR, *supra* note 12, at 68. The extinction of a species could be caused by many different factors: a collision of an asteroid, human interference, or competition with another species over the same environmental niche. *Id.* These factors alone could account for extinction, or the cause could be from various combinations of these factors acting in concert. *Id.* 

<sup>&</sup>lt;sup>54</sup>An issue when advocating for a multi-layered approach is whether this type of thinking is "natural" to humans. Our mind has a difficult time grasping phenomena such as in quantum physics where a particle acts as a particle from one perspective but from another it appears as a wave. JIM BAGGOTT, THE MEANING OF QUANTUM THEORY 19 (1992). However, in art, multiplicity of view points was the norm for the painter in the middle ages. LEONARD SHLAIN, ART & PHYSICS: PARALLEL VISIONS IN SPACE, TIME, & LIGHT 43 (1991). This was done by portraying the same figure many different times in many different places within one painting, thereby representing all possible relations and identity this person had within a simultaneous description. *Id.* 

<sup>&</sup>lt;sup>55</sup>SHLAIN, *supra* note 54, at 33-34.

<sup>&</sup>lt;sup>56</sup>*Id.* at 44.

<sup>&</sup>lt;sup>57</sup>As Professor Mayr points out, there is no Nobel Prize for concepts, only for discoveries. He writes that "[e]ven if there were a Nobel Prize in biology (which there is not), Darwin could not have been awarded a prize for the development of the concept of natural selection—surely the greatest scientific achievement of the nineteenth century—because it was not a discovery." MAYR, *supra* note 12, at 26.

<sup>&</sup>lt;sup>58</sup>See Allison Morse, Social Science in the Courtroom: Expert Testimony and Battered Women, 21 HAMLINE L. REV. 287 (1998). This article argues scientific evidence should not be

On the other hand, if one's message is that things are complicated, uncertain, and messy, that no simple rule or force will explain the past and predict the future of human existence, there are rather fewer ways to get the message across. Measured claims about the complexity of life and our ignorance of its determinants are not show biz.<sup>59</sup>

Reductionism is "show biz" for it promises to explain all phenomena by reducing one phenomenon into its smallest particle.<sup>60</sup> In the exploration to understand human traits, that smallest particle is the gene.

#### B. How Genes Work

Genes are an important part of the functioning of an organism; yet, when you understand how they function it is clear they do not hold this sacred power as the "master molecule." The genes are merely part of a system with a complex web of feedback loops, both internal and external to the organism. It is this entire system that "controls" the behavior of an organism.

The genome is the name for one haploid set of chromosomes.<sup>61</sup> DNA is the structure inside our chromosomes that carries heredity, as illustrated in 1944 when DNA from one kind of bacteria cell was injected into a different kind of bacteria cell, and that cell subsequently began to display traits of the donor cell.<sup>62</sup> In 1953, James Watson and Francis Crick set out a model for the structure of the DNA.<sup>63</sup> The DNA's structure is like two separate strands composed of alternating sugar and phosphate molecules.<sup>64</sup> These two strands are wound into a double helix that are connected at different sections by bases.<sup>65</sup> The four kinds of bases in DNA are adeline (A), thymine (T), cytosine (C), and guanine (G). They can appear in any sequence on the DNA strand, yet, (A) must be opposite to (T) and (C) must be opposite to (G).<sup>66</sup> Three sequences of three DNA bases form the code for an amino acid.<sup>67</sup>

the only kind of expert evidence allowed in the courtroom when explicating theories of human behavior. Instead, the court should look to experts that have studied multiple methodologies. A multiplicity perspective provides a fuller picture of the issue. Additionally, different methodologies counter each methodologies inherent short-commings, thereby corroborating each others findings. *Id.* 

-

<sup>&</sup>lt;sup>59</sup>LEWONTIN, *supra* note 4, at vii.

<sup>&</sup>lt;sup>60</sup>Id. See generally MAYR, supra note 12, at 17.

<sup>&</sup>lt;sup>61</sup>Webster's, *supra* note 26, at 947.

<sup>&</sup>lt;sup>62</sup>ELAINE JOHANSEN MANGE & ARTHUR P. MANGE, BASIC HUMAN GENETICS 253 (1994) [hereinafter MANGE & MANGE].

<sup>&</sup>lt;sup>63</sup>Id. See also WATSON, supra note 40.

<sup>&</sup>lt;sup>64</sup>Mange & Mange, *supra* note 62, at 253.

<sup>&</sup>lt;sup>65</sup>*Id.* at 253-54.

<sup>&</sup>lt;sup>66</sup>Id. at 254.

<sup>&</sup>lt;sup>67</sup>HUBBARD & WALD, *supra* note 6, at 48.

1999]

Amino acids are the basic component of proteins. A protein is composed of 100 or more amino acids. Proteins are involved in all aspects of the workings of the human organism. There are no "genes" in the sense of a physical object. Genes are specific sections along the DNA molecule where inherited information from the parent is a component in the manifestation of a particular trait. The reason it is only a component, even in single gene diseases, is that a gene contains the information for a protein which is dependent on different enzymes in order for that gene to synthesize. Each enzyme is a protein. Therefore,

[t]he one-to-one correspondence between genes and proteins, commonly expressed by saying that each gene 'codes,' 'determines,' or 'mediates' the synthesis of one protein, only means that it specifies that protein's linear amino acid sequence. The whole process by which that protein is synthesized will only occur if the cell's entire metabolic apparatus functions properly. This always requires many different proteins and therefore many different genes.<sup>72</sup>

Proteins cannot be manufactured without genes, but neither can they be manufactured without completion of the metabolic process. The resulting protein's behavior is as dependent on the gene's "message" as it is to all other factors of the metabolic process. This illustrates that genes are not the determinant mechanism in biological processes, but are part of an interaction between both the genes and the organism as a whole.

Additionally, another phenomenon within an organism causes different traits, even when the organism has the same genetic code and it is nurtured in the same environment. This phenomenon is called "developmental noise." An example is the fact that identical twins have different finger prints or that we have different fingerprints on our right hand as compared to our left. This "developmental noise"

<sup>69</sup>*Id.* at 43.

 $<sup>^{68}</sup>$ *Id*.

<sup>&</sup>lt;sup>70</sup>*Id*.

<sup>&</sup>lt;sup>71</sup>HUBBARD & WALD, *supra* note 6, at 44.

<sup>&</sup>lt;sup>72</sup> *Id.* at 52.

 $<sup>^{73}</sup>Id$ .

<sup>&</sup>lt;sup>74</sup>LEWONTIN, *supra* note 4, at 48.

<sup>&</sup>lt;sup>75</sup>Developmental noise is the name for an unknown variable that contributes to variation in the outcome of the organism. DAVID T. SUZUKI ET AL., AN INTRODUCTION TO GENETIC ANALYSIS 20 (2d ed. 1981). "Like noise in a verbal communication, developmental noise adds small random variations to the predictable process of development governed by norms of reaction." *Id.* 

<sup>&</sup>lt;sup>76</sup>LEWONTIN, *supra* note 4, at 64. This variation in traits has been illustrated in experiments with fruit flies. Fruit flies have a different amount of bristles under the wings of their left side then under their right. Some fruit flies have more on one side then on the other. There is no difference in the function of the fly based on the number of bristles, but this difference in number occurs even though the fly has the same genes for both of its sides. *Id.* at 27

is attributed not to genes or environment, but to random variation that occurs in cell division.<sup>77</sup>

The idea of a gene as some kind of "master molecule" sending out orders to be completed by the rest of the body is undermined by subsequent discoveries which reveal that messages do not go in one linear pattern, but rather are interactive. DNA, in order to send a message for the production of a certain protein replicates itself onto RNA. RNA then transports this message of the DNA to another part of the cell, the ribosomes, where the production of the protein occurs. This message system, however, does not go only one way. It has been discovered that enzymes, called *reverse transcriptase*, can copy the message of the RNA and send it back to the DNA. Furthermore, this entire process can be quickened or stopped by other proteins. We need to think of DNA, RNA, and proteins as all acting upon one another, rather than assuming a neat line from DNA to protein" noted Professor Hubbard.

"Our environment is full of other living organisms, from bacteria that colonize our intestines and supply us with essential vitamins and other foodstuffs to the human beings and other animals with whom we live. Looking at all our genes, or even at all the genes of all these creatures would still not tell us very much about our interrelationships in societies and in nature."

No amount of "this gene produces X behavior" will encourage sensible legislative policies, precisely because the entire systematic structure is reduced to a single cause.

#### III. WILL THE PROJECT DO WHAT IT CLAIMS?

#### A. The Genome as the "Book of Man"

Many leading figures in the Human Genome Project extoll the power of understanding the genome as the power to understanding ourselves. He ti is clear, when one understands the place of genes in the metabolic process, the claims made by these figures go far beyond what science supports. They say the mapping of the genome will not only reveal causal connections to certain traits, but will provide answers to what causes human behavior, both on an individual as well as a group

 $^{80}Id$ 

<sup>&</sup>lt;sup>77</sup>"Differences in shape and size are partly dependent on the process of cell division that turns the zygote into the multicellular organism. Cell Division, in turn, is sensitive to molecular events within the cell, and these may have a relatively large random component." SUZUKI ET AL., *supra* note 75, at 20.

<sup>&</sup>lt;sup>78</sup>Hubbard & Wald, *supra* note 6, at 48-50.

 $<sup>^{79}</sup>Id.$ 

 $<sup>^{81}</sup>$ *Id*.

<sup>&</sup>lt;sup>82</sup>HUBBARD & WALD, *supra* note 6, at 50.

<sup>&</sup>lt;sup>83</sup>*Id.* at 9.

<sup>&</sup>lt;sup>84</sup>See supra Part I.

level. 85 Walter Gilbert equates the mapping of the Human Genome to the search for the Holy Grail. 86 He writes that mapping the genome base pairs will tell us "[w]hat makes us human," 87 and provide the key to how we are distinguished from other animals. 88 James Watson stated to Time magazine that, "[w]e used to think our fate was in our stars. Now we know, in large measure, our fate is in our genes." 89 The Report on the Human Genome Initiative to the Department of Energy on the Human Genome Project said "[t]he human genome has been called the book of man, it contains the instructions that describe each human." These assertions are justifiable only by a reductionist construct. This construct supposes that genes determine the behavior of the individual, and in turn the individual determines the form of the culture. Therefore, all human behavior can be understood through our genes. 91

<sup>&</sup>lt;sup>85</sup>GILBERT, *supra* note 4, at 92-93. "Over the last decade it has become clear that molecular techniques are a powerful way of studying almost any question in biology, ranging from questions of development to those of evolution and population biology." *Id.* 

<sup>&</sup>lt;sup>86</sup>See Id. at 83.

<sup>87</sup> Id. at 84.

<sup>&</sup>lt;sup>88</sup>Id. Not only does Gilbert tell us the genome map will provide the answer to what it is to be human, he answered the question for us, even with out the map. *See supra* note 4 and accompanying text. *Id.* at 96.

<sup>&</sup>lt;sup>89</sup>Jon Beckwith, *A Historical View of Social Responsibility in Genetics*, 43 BIOSCIENCE 327, 330 (1993). Jon Beckwith quotes Watson from a TIME MAGAZINE interview, in the interview Watson alludes to a quote from Shakespeare's JULIUS CAESAR, yet the meaning of that quote in the context of renaissance understanding, is in fact opposite to the meaning Watson implies. When Cassius says: "The fault, dear Brutus, is not in our stars, But in our selves, the implication is we are not controlled by deterministic influences as represented by the stars, in this case as an analogy to astrology, or god etc.... Shakespeare, by saying our fate is "in our selves" he means, we as humans, are self determining, that we have free will. WILLIAM SHAKESPEARE, JULIUS CAESAR, act. I, sc. 2. Watson's use of this quote as an analogy to determinism being in us, our genes and what is represented by the "stars" is now environment. Deterministic explanations have a long history of resonance to the human condition, it is but the packaging of deterministic idealogy which has changed. Before it was God's will; now it is Science's.

<sup>&</sup>lt;sup>90</sup>REPORT ON THE HUMAN GENOME INITIATIVE, supra note 2, at 5.

<sup>91&</sup>quot;Just as at one level genes determine individuals, so at another level it is individuals who determine collectivities . . . . For human beings that means that the structure of our society is nothing but a result of the collection of individual behaviors. If our country goes to war, we are told it is because we feel aggressive as individuals. If we live in a competitive entrepreneurial society, it is because, in this view, each one of us, as an individual, has a drive to be competitive and entrepreneurial." Lewontin, *supra* note 4, at 13-14. Edward Wilson and other Sociobiologists have long promulgated this belief that there is an underlying biological model to behavior. Wilson called it the human biogram. EDWARD OSBORNE WILSON, SOCIOBIOLOGY: THE NEW SYNTHESIS 548 (1975). To find this biological blueprint sociobiologist look for "universals" in human behavior and conclude that these behaviors must be "natural." From the data which they select, they conclude that certain behaviors are innate. A primary focus of the work of sociobiologist have been on the biological basis for the difference in male and females behavior. Using biology to define the parameters of appropriate behavior is a powerful tool for social control. The uncritical acceptance of

Not only do these assertions undermine their supposed nod to the complexity of the functioning of the internal operation of an organism, they negate the external interaction as well.<sup>92</sup> "Humans, or even fruit flies, are complex organisms leading complex lives, and our experiences and our biology interact in unpredictable ways. Neither genetics nor molecular biology can tell us all that much about people. They can only tell us about our genes."<sup>93</sup>

Information on how DNA functions in an organism can provide important data about the working of cells that is part of the picture of the state of our species. It is standard practice for scientists to isolate a system in order to understand "how" it functions. An example of this, offered by Giessemer, is how a doctor understands the human heart.<sup>94</sup>

'How' questions are formulated most simply if complexities are relegated to 'context.' One makes a mess of the question 'How does the heart pump blood?' by starting with the facts about human social structures critical for food production sufficient to nourish functioning human hearts. But these are nonetheless factors in a complete explanation of the pumping of blood.<sup>95</sup>

But this does not explain ultimate questions of why the heart functions that way, for ultimate questions one must also look at the context. "Biological 'systems' are simple only if their environments are not included in the description. 'Why' questions in biology are always comparative and can never avoid description of context or environment for long."

The understanding of the part, devoid of context, cannot be the beacon which will point us to a comprehensive view of ourselves.

#### B. Will it Advance Medicine

The Human Genome Project promises to be the first step toward several advances in medicine. These advances include the ability to screen for genetic disorders, to provide predictions of the onset of certain diseases or behavioral

reductionist explanations feed into the legitimization of discrimination, for the discrimination is not based on prejudice supposedly but science. But the scientific explanations of sociobiology is not science but simply stories that can be rearranged to support other explanations for the behavior. Stephen Jay Gould, The Mismeasure of Man 354-64 (1996). For an in depth criticism of the scientific proof sociobiology propounds, see Anne Fausto-Sterling, Myth of Gender (2d ed. 1985).

<sup>&</sup>lt;sup>92</sup>Evelyn Fox Keller, *Nature, Nurture, and the Human Genome Project, in* CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 281, 282 (Daniel J. Kevles & Leroy Hood eds., 1992). "Most responsible advocates are of course careful to acknowledge the role of *both* nature and nurture, but rhetorically, as well as in scientific practice, it is 'nature' that emerges as the decisive victor." *Id.* 

<sup>&</sup>lt;sup>93</sup>HUBBARD & WALD, *supra* note 6, at 10-11.

<sup>&</sup>lt;sup>94</sup>James R. Griesemer, *Tools for Talking, in ARE GENES US?* 69 (Carl F. Cranor ed., 1994)

<sup>&</sup>lt;sup>95</sup>*Id.* at 71.

 $<sup>^{96}</sup>Id$ 

disorders, and eventually to eradicate unwanted genetic disorders by gene therapies.<sup>97</sup> The Human Genome Project itself just calls for the mapping of the genome, that is, identifying the pattern of base pairs, the adeline, thymine, cytosine, and guanine, a task that will take many years and many millions of dollars to complete.<sup>98</sup> For this information to have meaning, research must identify each sequence or gene that sends the signal to make certain proteins that result in certain functions or malfunctions in the organism.<sup>99</sup> When and if these areas are identified, a statistical analysis will need to be done to provide an estimate of the chance of variation in the gene that will cause the undesired effect, and if a causal connection can be found, the probability of the severity and the possible onset of the trait.<sup>100</sup> The completion of all of these tasks will be well worth the effort if the promise of the project is true: that cancer, cardiovascular disease, and mental disorders can best be cured through the mapping of the human genome.<sup>101</sup> Some understanding of the function of the human body will come from this project, but whether this is the best recourse for the cure of disease is questionable.<sup>102</sup>

100 Id. Kitcher points out that even if a study shows that each person with a particular trait has the same altered gene, this does not mean, that science can then conclude that each person who carries that particular gene sequence will have the trait. Id. at 68. Kitcher cites the experience, which occurred approximately two decades ago, where a study revealed that a large percentage of men in prison had an extra Y chromosome. Id. at 69. Experts claimed that the presence of the extra Y chromosome predisposed those men to anti-social behavior. Id. Future studies revealed that 96% of men with the extra Y chromosome lead normal lives. Id. Therefore, before DNA testing can even come close to being of value to an individual, an analysis of the statistical probability between the gene sequence and the specific trait must be formulated. Id. at 72. This type of analysis can be particularly arduous when dealing with diseases like colon cancer which can strike at any time, thus requiring studies that can last as long as a lifetime. Id. at 70. What is also essential in making DNA information relevant is providing not only the probability that the person will have the trait, but also the different probability for the onset of that trait. Id. at 71. Even in a single gene disease such as cystic fibrosis the range of mortality from this disease goes from childhood to middle age. Id.

<sup>101</sup>Gilbert, *supra* note 4, at 94. Walter Gilbert, one of the first scientists to sequence DNA, argues that scientists armed with the map of the human genome will be able to pinpoint the location for unitary based genetic diseases and they "will find sets of genes for such conditions as heart disease, susceptibility to cancer, or high blood pressure. Along with many other common afflictions, these will turn out to have multiple genetic origins in populations, as will such mental conditions as schizophrenia, manic-depressive illness, and susceptibility to Alzheimer's disease." *Id.* Of course, proponents of the genome project are quick to point out that there will be a gap between the ability to diagnose a genetically caused illness and the ability to treat it. Leroy Hood, *Biology and Medicine in the Twenty-First Century, in* CODE OF CODES 136, 159 (Daniel J. Kevles & Leroy Hood, eds., 1992).

<sup>102</sup>Beckwith, *supra* note 89, at 331. Beckwith questions the utility of looking at only genes in the cause of cancer relying only on correlation. This ignores the "systematic analysis" of environmental and other influences that may cause cancer. "[I]n those cases where there is a susceptibility, it is usually only a susceptibility." *Id.* In addition, Professor

<sup>&</sup>lt;sup>97</sup>Dena Davis, Genetic Dilemmas and the Child's Right to an Open Future, 28 RUTGERS L.J. 549, 552-53 (1997).

 $<sup>^{98}</sup>$ See Report on the Human Genome Initiative, supra note 2.

 $<sup>\</sup>rm ^{99}Philip$  Kitcher, The Lives To Come: Genetic Revolution and Human Possibilities 68-72 (1996).

It is true that locating certain abnormal genes can be used as prediction for some diseases, and that gene therapy has been used in some situations. 103 It is not inevitable that a cure can come from manipulating our genes, even when a common mutation exists for a particular disease. Unitary genetic diseases such as Tay Sachs or cystic fibrosis have been known and located for many years with no resulting cure. 104 Huntington's disease is attributed to a flaw in a gene; yet, "[s]cientists have been unable to detect how the flawed gene switches on dementia and palsy." 105 Furthermore, discovering the flaw will predict the eventual onset of this disease, but not when. 106 One theory for the difference in onset might be related to which parent the child inherited the flawed disease from, meaning the exact same sequential flaw in the genome would result in different outcomes depending on who gave the flaw to the child. 107

Cystic fibrosis is another single gene disease that has been known for many years. <sup>108</sup> It has been located and sequenced. <sup>109</sup> The protein made at this location has been discovered, yet a cure is not in evidence. <sup>110</sup> The reason that no cure is known is that the protein produced "looks like a lot of other proteins that are part of the cell structure, so it is hard to know what to do next." <sup>111</sup>

Hubbard suggests a more fruitful inquiry would be to look at "the composition of the DNA sequence of one or more specific genes in many different individuals. This would make it possible to figure out which correlations between base sequences and traits are significant and which ones are purely coincidental." HUBBARD & WALD, *supra* note 6, at 54-55. Learning about the power of certain proteins for application in and outside our body is a worthy enterprise. Of course there already are successes in hormonal replacement, (Hood, *supra* note 89, at 159), and with some actual gene replacement therapies. KITCHNER, *supra*, note 99, at 46. But because the immense variation in between genes suggests mapping a prototype of a gene is not the most effective means to discovering medical treatments. See also footnote five for a discussion of the how the mandate of the Human Genome Project to map a gene sets up a social construction that implies that science mapping of the genome will provide us with a genetic map of what is "normal."

 $^{110}Id$ .

-1-1

<sup>&</sup>lt;sup>103</sup>This paper does not propose that genes are not a fruitful avenue to be explore toward the curing of some diseases, yet this paper does question whether the mapping of one entire prototype of the human genome is the way to get there. See discussion *supra* Part I.

<sup>&</sup>lt;sup>104</sup>LEWONTIN, *supra* note 4, at 66.

<sup>&</sup>lt;sup>105</sup>Stanton Peele & Richard DeGrandpre, *My Genes Made Me Do It*, PSYCHOL. TODAY, July 1, 1995, at 50 [hereinafter Peele & DeGrandpre].

<sup>&</sup>lt;sup>106</sup>The time of onset of Huntington's disease can be early in life or in one's middle age. Hubbard & Wald, *supra* note 6, at 53. Likewise, cystic fibrosis onset can be in childhood to middle age. Kitcher, *supra* note 99, at 71.

<sup>&</sup>lt;sup>107</sup>HUBBARD & WALD, *supra* note 6, at 53.

<sup>&</sup>lt;sup>108</sup>LEWONTIN, *supra* note 4, at 66.

 $<sup>^{109}</sup>Id.$ 

 $<sup>^{111}</sup>Id$ 

Even if there is a direct causal link, it has already been proved that functional areas are not confined to one place but are in many different sites. <sup>112</sup> The reason for this is DNA was not manufactured but it evolved, meaning layers of information were transcribed at different times and for different purposes. <sup>113</sup> Some of the purposes are no longer part of what it is to be human, but relate to what it was to be Homo habilis, or our simian ancestor, or a tree shrew. <sup>114</sup> The mapping of all the loci on the DNA controlling a single trait is itself more complex than the project presents.

As mentioned earlier, the causal chain from gene to trait, is not linear but a "complex chain" in which the interaction of environment and genes does not result in a formulistic outcome, but triggers "chains of events split into further possible paths." Examples abound of diseases supposed to have genetic origin but result in different outcomes. Type 1 diabetes, the kind that typically manifests in childhood, is thought to have a genetic basis. This hypothesis is based on studies which show that if one child has type 1 diabetes, there is a six percent chance her sibling will also have type 1 diabetes, a likelihood twenty times higher than the average. If an identical twin has type 1 diabetes, there is a thirty-six percent chance the other twin will also have diabetes. A strong argument can be made for a genetic basis for this result, but since more than half of the identical twins 119 did not develop the disease,

<sup>&</sup>lt;sup>112</sup>Horace Freeland Judson, *A History of the Science and Technology Behind Gene Mapping and Sequencing*, in CODE OF CODES 37, 79 (Daniel J. Kevles & Leroy Hood eds., 1992).

<sup>&</sup>lt;sup>113</sup>Morris Goodman, *Molecular Evolution '99: The Genomic Record of Humankind's Evolutionary Roots*, 64 Am. J. Hum. Genetics 31 (1999). "Forty to 30 million years ago (Ma) neocorital portions of the brain increased in the two emerging branches of anthropoid primates - the platyrrhines (or New World monkeys) and the catarrhines. Within the catarrhines branch, additional marked enlargements occurred by 18-6 Ma in the lineage to the ancestors of modern hominids." *Id.* 

 $<sup>^{114}</sup>$ Id. "We share with our most distant livingape relatives (the gibbons and the siamangs) >95% identity in genomic DNA, and with our closest relatives (the chimpanzees and bonobos, or pygmy chimpanzees) > 98.3% identity in typical noncoding DNA and probably ~99.5% identity in the active coding sequesnees of functional nuclear genes." *Id.* 

<sup>&</sup>lt;sup>115</sup>Peele & DeGrandpre, *supra* note 105. *See also* MAYR, *supra* note 12, at 66. Mayr writes that cause can be ascertained in simple chemical reactions. *Id.* 

But in biology this approach is usually not successful; in fact, it is often misleading. It may be difficult, if not impossible, to pinpoint *the* cause in an interaction of complex systems, with the final effect being the last step in a long chain reaction. Here we may have to adopt a different way of thinking. An interaction between two individuals, prior to its conclusion, goes through a whole series of stages, during most of which each of the acting individuals has several options available. Which of these [we] will choose is not strictly determined at the beginning of the stage but depends on a number of factors and contingencies. Strict causality can usually be construed only when the chosen option at each step of the chain of actions is looked retrospectively. *Id.* 

<sup>&</sup>lt;sup>116</sup>HUBBARD & WALD, *supra* note 6, at 77.

<sup>&</sup>lt;sup>117</sup>*Id*.

<sup>&</sup>lt;sup>118</sup>*Id*.

<sup>&</sup>lt;sup>119</sup>Identical: meaning having the same DNA.

more than the genetic component is determining the realization of this disease. <sup>120</sup> Another possibility is that environmental factors alone contributed to the disease. The high instances of the disease in a family can be explained by the fact that family members are more likely to be exposed to the same environmental influences. <sup>121</sup> In fact, viral infections or toxins have long been suspected to be what causes type 1 diabetes. <sup>122</sup>

The considerable variation in behaviors for a genetic disease raises several doubts about what a map of the genome will really tells us. If scientists do find correlations to an abnormal site in the DNA of many people with type 1 diabetes, that does not mean it is the best place to look for a "cure." By promoting the DNA as the "master molecule," this type of reductionist belief that the smallest essence explains the whole can result in the public and scientists spending their time looking for the part, when the best way to combat some diseases would be at a higher level of interaction. Sometimes it will be the manufacture of the protein, at other times the affected organ, or the nutritional balance of the host, or the psychological well being of the person. The idea that the human genome can be the Rosetta Stone for disease ignores physical, chemical, and environmental factors. If a person's genome is absent markers for disease according to the "map," that does not mean the person will not have disease.

When so many financial and intellectual resources are allocated to the one modality of Human Genome Project, other fruitful avenues of research, such as, different methods of identifying genetic components to disease<sup>127</sup> or the exploring

<sup>121</sup>Peele & DeGrandpre, *supra* note 105. They write: "Most claims linking emotional disorders and behaviors to genes are statistical in nature. For example, differences in the correlations in traits between identical twins (who inherit identical genes) and fraternal twins (who have half their genes in common) are examined with the goal of separating the role of the environment from that of genes. But this goal is elusive. Research finds that identical twins are treated more alike than fraternal twins. These calculations are therefore insufficient for deciding that alcoholism or manic-depression is inherited, let alone television viewing, conservatism, and other basic, everyday traits for which such claims have been made." *Id.* 

122HUBBARD & WALD, *supra* note 6, at 76. "Type 1 diabetes results from the destruction of cells in the pancreas that normally produces insulin, a hormone involved in sugar metabolism. Type 1 diabetes is thought to involve the immune system and be the result of an allergic response to toxic chemicals in the environment, a viral infection, or some other unidentified stimulus." *Id.* Another disease that has been proclaimed to have a genetic basis is schizophrenia. Yet, in a famous case where four monozygotic quadruplet daughters all developed schizophrenia, the severity of the symptoms were markedly different. One daughter lived her entire life outside institutions, marrying and raising a family, while another daughter was continuously hospitalized in a condition of severe psychosis for her entire life. ROBERT C. CARSON ET AL., ABNORMAL PSYCHOLOGY AND MODERN LIFE 323-26 (8th ed., 1988).

<sup>&</sup>lt;sup>120</sup>HUBBARD & WALD, *supra* note 6, at 77.

<sup>&</sup>lt;sup>123</sup>Beckwith, *supra* note 89, at 331.

<sup>&</sup>lt;sup>124</sup>MAYR, supra note 12, at xii.

<sup>&</sup>lt;sup>125</sup>Evelyn Fox Keller, *Master Molecules*, in ARE GENES US? 90 (Carl F. Cranor ed., 1994).

<sup>&</sup>lt;sup>126</sup>See Hubbard & Wald, supra note 6, at 73.

<sup>&</sup>lt;sup>127</sup>See supra note 102 for a discussion of alternative medical research designs.

cause via environmental agents, can become subsidary. An alternative way to cure many diseases is to analyze and improve environmental factors.

The proponents of the Human Genome Project say they do not negate the environmental factors; yet, raising the inheritable aspect of disease to the forefront allows individuals, businesses and policy makers to ignore the part they play in creating of environments that cause disease. In terms of medical issues, even a susceptibility to a particular disease does not necessarily mean that one will get it, and not having a propensity does not mean one will never develop the problem. Por instance there is considerable evidence that people metabolize food at different rates, but that anyone who eats enough without exercising will gain weight. Phe considerable increase in the United States over the last ten years of people who are overweight is addressed more effectively through a program of diet and exercise than waiting for some genetic cure. After all, the time it would take a gene to mutate and spread through an entire species is a considerably slower process in comparison to change that can occur through culture. Thus what explains such rapid change in weight gain in the U.S. is environment and culture, not genetics.

The obvious main difference between Darwinian evolution and cultural change clearly lies in the enormous capacity that culture holds — and nature lacks — for explosive rapidity and cumulative directionality. In an unmeasurable blink of a geological eyelash, human cultural change has transformed the surface of our planet as no event of natural evolution could ever accomplish at Darwinian scales of myriad generations. <sup>132</sup>

Researchers and the media show considerable excitement in the search for a genetic cause of mental illness.<sup>133</sup> What we know about depression suggests that a purely genetic solution is too narrow. The data suggests environment is a crucial factor in the manifestation of depression.<sup>134</sup> Epidemiological study has shown that

133HUBBARD & WALD, *supra* note 6, at 5. "Witness the next piece in the "Medical Notebook." It begins, 'A series of attempts to confirm the existence of a gene for schizophrenia have failed, three years after the announcement of an apparent gene link caused a stir among mental health researchers.' If a link cannot be confirmed after repeated attempts, that would seem to suggest that the condition is not genetic. However, the column quotes a psychologist named Irving Gottesman as saying that 'studies continue to indicate that a gene or genes creates 'risk enhancing factors for schizophrenia. The studies he refers to show that people who have schizophrenic siblings are somewhat more likely to be schizophrenic then people who don't. Since many psychiatrists think that schizophrenia is caused by family problems, this result is not surprising." *Id.* 

<sup>134</sup>Peele & DeGrandpre, *supra* note 105. "[F]or example, according to epidemiologist Myrna Weissman, Ph.D., Americans born before 1905 had a 1 percent rate of depression by age 75. Among Americans born a half century later, 6 percent became depressed by age 24! Similarly, while the average age at which manic-depression first appears was 32 in the mid

<sup>&</sup>lt;sup>128</sup>HUBBARD & WALD, *supra* note 6, at 73.

<sup>&</sup>lt;sup>129</sup>Peele & DeGrandpre, *supra* note 105.

<sup>&</sup>lt;sup>130</sup>STEPHEN JAY GOULD, FULL HOUSE 220 (1996).

 $<sup>^{131}</sup>Id.$ 

 $<sup>^{132}</sup>Id.$ 

the rate of depression has increased considerably over the last hundred years. 135 Furthermore, the onset of manic depression in the last thirty years has gone from age thirty-two to age nineteen. 136 This does not mean that depression does not have a biological factor, but it does suggest that ignoring the societal ones can be detrimental. What is so seductive about reductionist explanations is that we can blame the individual with the disease instead of spending our resources on wider sociological solutions, solutions that never come in such neat packages as a reductionist one.137

By raising the genome as the control center of all disease, the issue of environmental toxins becomes the problem of the individual's genetic susceptibility, and not the conditions of different environments that are health hazards. 138 Excluding whole classes of people such as women of child bearing years or men with propensity to lung cancer from the work place may be more convenient and cheaper for the employer than creating safer work conditions, but is it from a societal standpoint the solution that we should tolerate? Furthermore, safety precautions by excluding certain types of people add to the employer's justification to gain access to their employees' DNA information in order that they can have a "safe" work environment. Privacy may be a protected right, but it is one that is circumvented when the government's reason for the intrusion is protective of some governmental interest. 140

The lure that genes hold the key for behaviors, as well as diseases, can absolve policy makers from funding social programs. Programs for the poor and minorities are unpopular, <sup>141</sup> (since the poor rarely vote, or contribute to legislators' campaigns.)

1960's, its average onset today is 19. Only social factors can produce such large shifts in the incidence and age of onset of mental disorders in a few decades." Id.

 $<sup>^{135}</sup>Id$ 

 $<sup>^{136}</sup>Id$ 

<sup>&</sup>lt;sup>137</sup>LEWONTIN, *supra* note 4, at vii.

<sup>&</sup>lt;sup>138</sup>HUBBARD & WALD, *supra* note 6, at 62-63.

<sup>&</sup>lt;sup>139</sup>In International Union UAW v. Johnson Controls, 111 S. Ct. 1196 (1991), the Supreme Court held that fertile women could not be excluded from working around high exposures to lead in a battery factory. Yet, this case illustrates the desire on the part of some employers to exclude "susceptible workers" instead of providing the expense of further safety precautions which can only benefit the entire work force.

<sup>&</sup>lt;sup>140</sup>Laws against attempted suicide are legal. Planned Parenthood v. Casey, 505 U.S. 833 (1992), said a minor asking for parental permission or permission of the court for abortion was not an undue burden. In Jefferson v. Griffin Spalding County Hosp. Authority, 274 S.E.2d 457, 458 (1981), Georgia's supreme court ordered a caesarian c-section on a pregnant woman who refused the treatment on religious grounds. The doctors had determined that the fetus had a 99% chance of being still-born and the mother had only a 50% chance of surviving a vaginal delivery. Id. at 458. The court overrode the woman's objection to surgery on the grounds of protecting the fetus and the mother. Id. at 460.

<sup>&</sup>lt;sup>141</sup>See generally Thomas Ross, The Rhetoric of Poverty: Their Immorality, Our Helplessness, 79 GEO. L.J. 1499 (1990). Professor Ross discusses societal attitudes toward the poor that depict them as separate from normal society. Id. at 1500. That there is some deficiency in the poor that places them in that position, that they are "morally weak." Id. at 1500-01.

The supposed discovering of genes that can control intelligence, strength, perhaps even moral turpitude could legitimize the lack of access to higher education and the continual glass ceiling in corporate jobs for women and minorities.

#### IV. THE PSYCHOLOGICAL COST OF PREDICTION

#### A. Testing as Social Power

Testing categorizes people. Either you have a disease or you do not. You are a potential carrier of a disease or you are not. You are more susceptible to certain toxins or you are not. Of course, whether you manifest the symptoms of a disease, or to what severity, is not ascertained from genetic tests. In most cases genetic testing provides mere categorization of potentiality. Yet, a positive result on potentiality, itself, becomes a social construct of a disease regardless of whether symptoms are ever manifested. 143

Categorization of people opens the door to scrutiny by society as a whole on what choices should be made available to individuals. For example, an individual who carries a gene that could cause a birth defect is faced with an ethical choice of whether or not to bear children. This choice is not merely a personal one, but is formed by the options and the stigma the society she lives in creates. <sup>144</sup> Does she have resources to pay for extra medical expenses if her child is not "normal?" Will insurance cover her child if she could have aborted the fetus? Will laws be created that can subject the mother or the doctor to "wrongful life" claims by the child? <sup>145</sup>

In addition, tests can pigeonhole an individual to confine themselves to certain life paths. For example, if your IQ is not quite high enough, a career counselor may lead you away from entertaining a career as a doctor, engineer, or even a lawyer.<sup>146</sup>

<sup>&</sup>lt;sup>142</sup>HUBBARD & WALD, supra note 6, at 36-38.

<sup>&</sup>lt;sup>143</sup>See Larry Gostin, Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests By Employers and Insurers, 17 Am. J.L. & MED. 109, 118 (1991). Gostin in his article on the use of genetic discrimination by employers and insurance companies points out how genetic discrimination has already occurred based on a person's genetic status regardless whether that person has manifest any symptoms of a disability. Id. He writes, "Genetic discrimination affects not only heterzygotes (unaffected carriers) and "at risk" individuals (those with a predisposition to disease), but also persons who are asymptomatic or have a minor form of the disease. For example, several cases of discrimination were reported involving heterozygote of sickle cell or Gaucher Disease. These genetic traits may affect a future offspring, but not the carrier herself." Id.

<sup>&</sup>lt;sup>144</sup>See infra Part III.B.

<sup>145</sup> See generally Deftos, supra note 14. Although there are currently no sustained tort claims for wrongful life against the parents, there have been cases against physicians for failure to warn parents of possible genetic disease as well as failure to warn third parties. Id. Furthermore, Professor Shaw argues that because of the availability of contraception and abortion, the parents have a choice on whether to carry on their genetic legacy and have a child. If they choose to have a child, then they should be accountable to any pain and suffering the child experiences that could have been avoided. Margery W. Shaw, Conditional Prospective Rights of the Fetus, 5 J. LEGAL MED. 63, 93 (1984). "If parents know the genetic risk in advance, then failure to employ artificial insemination or in vitro fertilization could be considered a tort at the moment of conception." Id.

<sup>&</sup>lt;sup>146</sup>See generally Nelkin & Tancredi, supra note 36, at 73.

If you have a biological susceptibility to certain toxins, trying to gain employment at a factory producing those toxins is seen as unreasonable, when in fact what is probably unreasonable is exposing all individuals to those toxins. Nelkin and Tancredi in their work *Dangerous Diagnosis* argue that the very act of categorizing people through socially sanctioned tests provides the justification for "institutions" to discriminate. The implementation of discrimination is seen in our education system, which separates the achievers from the students with learning problems, 149 or through psychological tests that determine whether an individual is competent to take care of herself, 150 or biological tests that define the type of life the person can expect for herself and her off-spring. 151 Genetic testing offers to categorize people before any symptoms are manifest.

#### B. The Effects of Genetic Diagnosis on the Individual and the Family

The danger of relying on genetic testing goes beyond vulnerability to disease. It can also affect us psychologically. Criticism of genetic testing has focused on the problems that can occur if the results of the test are made public. Genetic testing that purports to predict the onset of certain diseases or traits has psychological consequences as well, even when the predictions never come to fruition.

The first decision an individual must make is whether to be tested or not. Much of the discussion in this area has centered around the ethics of doctors testing children for diseases at the request of their parents. Most commentators agree that if the testing can provide a direct medical benefit, then the parents' decisions to have their child tested should be upheld, <sup>153</sup> thereby limiting genetic testing of minors to situations in which a medical protocol has been established for treatment of that disease or when early detection improves the prognosis of the patient. <sup>154</sup> The mere fact that genetic tests are available does not mean they should be administered. Studies on early diagnosis of cystic fibrosis have revealed increased medical costs

<sup>151</sup>See infra Part III.B.

\_

<sup>&</sup>lt;sup>147</sup>HUBBARD & WALD, *supra* note 6, at 61. "[I]t makes no sense to identify the susceptibilities of individual factory workers to industrial dusts or other toxic substances without reducing the hazards under which they work. Yet, the drumroll of publicity that touts genes as 'causes' of an ever-expanding range of traits, diseases, and disabilities draws our attention to the affected individuals and away from the conditions that provoke their problem. *Id.* at 61-62. Professor Hubbard goes on to site examples of social, economic and environmental influences on a persons health. *Id.* at 62-63. Yet, policy makers description of how to prevent disease is defined as in the individuals' control, through measures such as diet and exercise, thereby avoiding the more complicated sociological issues. *Id.* at 63.

<sup>&</sup>lt;sup>148</sup>NELKIN & TANCREDI, *supra* note 36, at 110-31.

<sup>&</sup>lt;sup>149</sup>See generally Id. at 108.

 $<sup>^{150}</sup>Id$ 

<sup>&</sup>lt;sup>152</sup>See Smith, supra note 15. See also Macklin, supra note 35.

<sup>&</sup>lt;sup>153</sup>Davis, *supra* note 97, at 577. Professor Davis reports that in Great Britain the consensus is only to allow testing of minors if medical interventions are available. The opinion in the United States seems to be following this logic. *Id*.

 $<sup>^{154}</sup>Id$ 

and unnecessary treatments for the pre-symtomatic child, with no discernable medical benefit.  $^{155}$ 

The impact of genetic tests on children and the family can have profound emotional consequences on the family dynamics. Many people want testing for their children or themselves in the hopes of relieving their anxiety about their status of having a genetic disease. They reason that if it turns out that they do have the disease, they can prepare themselves for the consequences. But this is not the only consequence to pre-symptomatic testing; studies have shown that parents alter the way they interact with a child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease, including a pattern of over-protecting the child diagnosed with a serious disease,

In examining behavior toward the diagnosed child, in particular when the diagnosis portends a limited future, parents tend to censor from their language any future-oriented comments. This change not only affects the socialization of the child, but it also affects the socialization of the non-diagnosed siblings. "Parents are less likely to say 'when you grow up...' or 'when you have children of your own...' to any of their children, because they cannot say these words to the ill child." Yet, genes in very limited situations determine outcomes. The manifestation of diseases and behavioral traits occur within the organism system from multi-level interactions at the cell level, as well as between the cell and its

<sup>&</sup>lt;sup>155</sup>ASHG/ACMG Report, *Points to Consider: Ethical, Legal, and Psychosocial Implications of Genetic Testing in Children and Adolescents*, 57 Am. J. Hum. Gent. 1233, 1234 (1995). Therefore, if the person has a propensity to a disease that can benefit from early warning, then a test that can pinpoint that propensity is an important tool in promoting health. A map of the human genome may identify some of these inherited tendencies, that could be valuable in prevention. However, as mentioned in Part Two of this Paper there are other strategies for identifying genetic components to disease that seem to be more productive at targeting particular diseases.

 $<sup>^{156}</sup>$ See Davis, supra note 97, at 577-78 (regarding parents reasons for testing their children).

<sup>&</sup>lt;sup>157</sup>*Id*.

<sup>&</sup>lt;sup>158</sup>Dorothy C. Wertz et al., *Genetic Testing for Children and Adolescents: Who Decides?*, 272 JAMA 875, 876 (1994).

<sup>&</sup>lt;sup>159</sup>*Id*.

 $<sup>^{160}</sup>Id.$ 

<sup>&</sup>lt;sup>161</sup>Davis, *supra* note 97, at 576-77.

<sup>&</sup>lt;sup>162</sup>Wertz et al., *supra* note 158, at 878.

 $<sup>^{163}</sup>$ *Id*.

<sup>&</sup>lt;sup>164</sup>See supra Part II.B.

environment.<sup>165</sup> Presymptomatic testing can, therefore, create a self-fulfilling prophecy.

Self-fulfilling prophecies have been a major area of research in social psychology since Rosenthal and Jacobson's study illustrated a correlation with teacher expectation and student performance. Another example of self-fulfilling prophecy is illustrated by the behavior of a person who believes she is an alcoholic. Alcoholism is a behavior that researchers have declared at one time or another as having genetic origins. A person who believes she is an alcoholic, when informed a particular drink contains alcohol, will consume more of the drink then the average person, even if there is no alcohol in the drink.

Studies show that people's behavior changes when they think a person has a physical or emotional disability. They will physically distance themselves from the one who is perceived as having a disability, act patronizing, and the exchange will be marked by increased tension. This change occurs because the "normal" person perceives the other as stigmatized. In addition, the individual with the unwanted trait also triggers tension. "[T]he stigmatized individual, believing that he or she is disliked or thought inferior, consequently may behave in ways that bring about such feelings on the part of the others." Part of the reason for this change of behavior is that the stigmatized person assimilates the view of her culture, thereby viewing himself as abnormal.

In addition, when the labeled individual believes the cause for her disease will affect her psychological well being.<sup>172</sup> Individuals who perceive a bad event as something internal to them are more likely to experience loss of self-esteem.<sup>173</sup> If the causal agent is perceived as something over which the individual has no control, then depressive reactions will in all probability be more severe, resulting in feelings of helplessness.<sup>174</sup>

The case of obesity—along with schizophrenia, depression and alcoholism—raises a striking paradox. At the same time that we should be treated medically, their prevalence is growing precipitously. The very

<sup>166</sup>Stephanie Madon et al., *In Search of the Powerful Self-Fulfilling Prophecy*, 72 J. Personality & Soc. Psychol. 791 (1997).

<sup>&</sup>lt;sup>165</sup>*Id*.

<sup>&</sup>lt;sup>167</sup>Peele & DeGrandpre, *supra* note 105.

<sup>&</sup>lt;sup>168</sup>See generally HUBBARD & WALD, supra note 6, at 98-104 (on the controversy surrounding the interpretations of the studies who hold a genetic component to alcoholism).

<sup>&</sup>lt;sup>169</sup>Peele & DeGrandpre, *supra* note 105.

<sup>&</sup>lt;sup>170</sup>Russell A. Jones, Self-Fulfilling Prophecies: Social, Psychological, and Physiological Effects of Expectancies 113-14 (1977).

<sup>&</sup>lt;sup>171</sup>Id. at 115.

<sup>&</sup>lt;sup>172</sup>Christopher Peterson & Martin Seligman, *Causal Explanations as a Risk Factor for Depression: Theory and Evidence*, 91 PSYCHOL. REV. 347, 348 (1984).

 $<sup>^{173}</sup>Id$ 

<sup>&</sup>lt;sup>174</sup> Peele & DeGrandpre, *supra* note 105.

reliance on drugs and other medical treatments has created a cultural milieu that seeks external solutions for these problems. Relying on external solutions may itself be exacerbating matters; it may be teaching us helplessness that is at the root of many of our problems. Instead of reducing the incidence of these problems, this seems to have fueled their growth.<sup>175</sup>

Defining the cause of a medical condition by one's genetic inheritance creates an environment in which individuals will give up trying to fight their disease. This despair can have a profound impact on the person's prognosis, for there is strong evidence that the patient's attitude toward recovery affects the speed of that recovery. Hence, the environment of social interaction attached to a diagnosis of abnormality, rather than the underlying genetic mutation, may cause the manifestation of symptoms.

#### V. SOCIOLOGICAL CONSEQUENCES OF A MAP OF THE GENOME

Regardless of whether genes can really provide us with substantive predictions of the onset of disease or of personality types, the increasing availability of scientific forecasts of these things and the medias acceptance of them, can result in sociological shifts. Mapping the genome can have a profound effect on personal choices such as abortion. This result, coupled with the way our institutions respond to what is perceived to be "abnormal," creates the danger of entrenching policies of eugenics on both a personal and an institutional level.

#### A. Personal Eugenics

At their best, genetic tests provide potential parents with information about the health of their fetus, allowing couples to have more power to make a choice about whether to have children. The tests for certain early onset genetic diseases, like cystic fibrosis and Tay Sachs, provide the parents with information necessary to decide whether or not to bring their fetus to term. Ideally, the choice is based on the parents' ethics, and it is within their judgment to make the difficult choice of whether to abort the fetus.

Genetic tests that can predict susceptibilities can offer advantages even if there is not yet a cure. A susceptibility for a certain disease established though genetic testing can be monitored for early onset of the disease, and in the case of certain illnesses, the prognosis is improved if the disease is discovered early. DNA testing may also assist doctors in confirming diagnoses. For example diseases such as

<sup>176</sup>*Id*.

<sup>&</sup>lt;sup>175</sup>*Id*.

<sup>&</sup>lt;sup>177</sup>See Keith J. Perie et al., *Role of Patients' View of Their Illness in Predicting Return to Work and Functioning After Myocardial Infarction: Longitudial Study*, 312 BRIT. MED. J. 1191 (1996). For example, a study on patients positive attitude toward their recovery from myocardial infaction resulted in shorter rehabilitation time before they resumed their normal lifestyle. *Id.* 

<sup>&</sup>lt;sup>178</sup>ASHG/ACMG Report, *supra* note 155, at 1234-35.

<sup>&</sup>lt;sup>179</sup>*Id.* at 1235.

neurofibromatosis  $^{180}$  and fragile  $X^{181}$  can be difficult to diagnose, and genetic tests offer substantiation of diagnoses if conventional tests are inconclusive.  $^{182}$ 

Genetic tests do offer information to parents, but the parents' choice is derived from the meaning they place on the information. How we as a society view and define disease affects the meaning placed on genetic tests. How experts, scientists, or doctors communicate the validity of this information also affects the meaning placed on genetic tests, have as a does the availability of economic resources for people diagnosed with genetic abnormality. How these concepts are defined creates a real danger that the choice parents make about their off-spring will be guided by strong social values of what constitutes normal. The technology promised by the Human Genome Project, whether that technology is valid or not, he means these social values will not only affect a person's psychological conceptions of self-worth but can be actualized in the entire production of future human off-spring.

The idea that the Human Genome Project will usher in a time when each family can participate in personalized eugenics ignores the way personal choice is affected by the zeitgeist<sup>187</sup> of the greater society, leading to homogeneity in the choices the parents make. This homogeneity will be dictated by our culture's definition of normal because what is considered an undesirable trait has always been dictated by

<sup>183</sup>Jerome Bruner, Professor of Psychology at NYU, has written that the human brain which is confronted numerous stimuli, provides coherence to that stimuli by selecting out the stimuli that have meaning while ignoring what does not. Jerome Bruner, Actual Mind, Possible Worlds 109-10 (1986). He writes: "The limits of our processing system, whatever mode of organizing is operative, impose still further selectivity on input as well as on interpretation of input. As Robert Woodworth put it a century ago, there is no seeing without looking, no hearing without listening, and both looking and seeing are shaped by expectancy, stance, and intention." *Id.* at 110.

<sup>&</sup>lt;sup>180</sup>Neurofibromatosis is a genetically transmmited disease which causes may cause fleshy growths of abnormal nerve tissue. THE MERCK MANUAL OF MEDICAL INFORMATION 384 (Robert Berkow, Mark H. Beers & Andrew J. Fletcher eds., 1997) [hereinafter MERCK MANUAL]. Some people diagnosed with Neurofibromatosis exhibit no symptoms. Depending on where and how numerous, the growths occurrence will affect the severity of symptoms a patient will experience. *Id.* Symptoms can be as varied from no symptoms, cosmetic problems, bone deformity to blindness. *Id.* 

<sup>&</sup>lt;sup>181</sup>Fragile X syndrome is caused by recessive gene on the X chromosome. MERCK MANUAL, *supra* note 180, at 1240. This syndrome usually results in mental retardation and some deformities, although some persons with the disease vary in the degree that these symptoms will manifest, including being asymptomatic. *Id*.

<sup>&</sup>lt;sup>182</sup>Id.

<sup>&</sup>lt;sup>184</sup>See Dorothy Nelkin, *The Social Power of Genetic Information, in* CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 177, 186-87 (Daniel J. Kevles & Leroy Hood eds., 1992).

<sup>&</sup>lt;sup>185</sup>See Id.

<sup>&</sup>lt;sup>186</sup>See supra Part I discussion on how perceiving genes as derministic is misleading.

<sup>&</sup>lt;sup>187</sup>Zeitgeist is defined as "the spirit of the time: the general intellectual and moral state or the trend of culture and taste or characteristic of an era." WEBSTER'S, *supra* note 26, at 2657.

the culture. 188 Additionally, Professor Hubbard points out that the search for a homosexual gene occurs only because that trait is stigmatized. 189 If it were an accepted lifestyle, time and money would not be involved in finding its origin. 190

Many of the problems associated with being disabled result not from physical impairment but from lack of access to the mainstream of society. Proponents of the Human Genome Project expect that fetal genetic testing expanded by the mapping of the human genome will offer a list of probable traits the fetus will carry. These tests will give parents the choice of what type of child they are willing to bring to term. If a fetus has an unwanted characteristic, the parents can choose to abort the fetus. Parents In the future, gene therapy may be used on the fetus to replace the "bad" gene with a superior one, thereby providing an alternative to abortion in order to eradicate unwanted traits.

According to Thomas Szasz, we are already defining certain symptoms as a "disease" or as "normal", depending on cultural acceptance. Thomas Szasz explored how the definitions of mental disease are culture specific. Szasz believes that there is such a thing as a disease that is independent of the diagnosis. People have cancer, malaria, or infections. Yet the ways human traits, including disease, are categorized is socially constructed. Categories for disease can differ across cultures, reflecting positive or negative perceptions which each culture holds for different traits. For example, "[f]ocal infections, masturbatory insanity, and homosexuality were diagnoses in the past; now they are considered to be diagnostic errors of normal behaviors. In France, physicians diagnose 'liver crisis'; in Germany 'low blood pressure'; in the United States, 'nicotine dependence.' How the culture defines

<sup>&</sup>lt;sup>188</sup>See generally Thomas Szasz, Mental Illness Is Still a Myth, 31 Soc'y 34 (1994).

<sup>&</sup>lt;sup>189</sup>See Hubbard & Wald, supra note 6, at 95.

<sup>&</sup>lt;sup>190</sup>See Id.

<sup>&</sup>lt;sup>191</sup>See Id. at 28.

<sup>&</sup>lt;sup>192</sup>See April L. Cherry, A Feminist Understanding of Sex-Selective Abortion: Solely a Matter of Choice, 10 Wis. Women's L.J. 161. "Although the number of sex-selective abortions is almost impossible to determine because women are not required to disclose why they are choosing abortion, one 1988 survey of obstetricians/gynecologists suggests that approximately 100 abortions for sex-selection are performed each year in the United States." *Id.* at 163.

<sup>&</sup>lt;sup>193</sup>Scientist have conducted animal experiments with different kinds of gene therapies. Most of the research on gene therapies involves inserting a normal gene into an individual's diseased somatic cell. DAVID SUZUKI & PETER KNUDTSON, GENETHICS 183-84. (1989). Yet, there has also been experiments where a rat's growth hormone gene is inserted into a mouse's fertilized egg resulting in changing the DNA of the mouse to include the rat's gene. *Id.* One of the consequences of altering germ cells is the alterations made to the DNA does not only affect the individuals whose cell was altered genetic properties, but will alter that persons offspring as well. *Id.* at 203.

<sup>&</sup>lt;sup>194</sup>See SZASZ, supra note 188, at 34.

<sup>&</sup>lt;sup>195</sup>See Id. at 36.

<sup>&</sup>lt;sup>196</sup>See Id.

wanted or unwanted traits will be reflected in the ways individuals perceive those traits and make their choice of which traits should come to fruition.

How a culture perceives disease can be dictated by certain elites within that culture. In our society the medical profession and the courts hold strong influence on how certain traits are perceived. The medical profession classifies or diagnoses disease based on several motives, <sup>198</sup> including categorizing traits to make them easier to identify and then to treat. <sup>199</sup> Other motives that influence medical categorizations involve the insurance industry. <sup>200</sup> For example, in order to cut costs, some insurance companies categorize certain physical illnesses, like arthritis, as not purely physical and, therefore, not fully covered by the insurance. <sup>201</sup> Whether a disease has easy access to treatment will affect how detrimental it is to have that disease and, in turn, how much stigma may be associated with that disease.

Scientists also influence how disease is defined. Looking at a problem from a reductionist perspective, the scientist intends to define the cause of traits by the smallest unit that is part of the manifestations of traits, the gene. Some biologists believe the view from which to understand a trait is not looking at a specific part of the organism, but viewing the entire system of the organism as the creation of the trait. They believe this concept will define the origin of traits, which is quite different from the reductionist model. The viewpoint embraced by legislatures, universities, and the media will be the perspective the greater culture will ultimately embrace. Their perception, in turn, will affect the weight the layperson will give to genetic tests, and what the dominant culture defines as unwanted traits could be taken out of the gene pool. The country of the gene pool.

Scientists and the medical profession hold persuasive positions over an expectant couple's choice on the status of their fetus.<sup>206</sup> Data obtained from the mapping of the human genome will be cloaked in the attributes of scientific discovery, and as such, will have a compelling effect on a couple's decision about the health of their fetus.

<sup>202</sup>MAYR, supra note 12, at 17. See also supra Part I.A.

1

Diverse Individuals, in REVIEW OF PSYCHIATRY (J. Oldham & M. Riba eds., 1995). This article explores how a psychiatrist should evaluate a person's symptoms when that person comes from a different culture. *Id.* The article points out that what is defined as pathological in our culture might be seen as normal in another culture. *Id.* at 490. Likewise, there are certain diseases that are culture-bound. *Id.* at 491. "An example of a culture-bound syndrome is *taijin kyofusho*, a Japanese syndrome that refers to an individual's intense fear that his or her body or its functions are offensive to other people. Of note is that this syndrome is listed as a diagnosis in the Japanese clinical modification of ICD-10." *Id.* 

<sup>&</sup>lt;sup>198</sup>See SZASZ, supra note 188, at 37.

<sup>&</sup>lt;sup>199</sup>Id. at 36.

<sup>&</sup>lt;sup>200</sup>Id. at 37.

 $<sup>^{201}</sup>Id$ 

<sup>&</sup>lt;sup>203</sup>See supra Part II.A.

<sup>&</sup>lt;sup>204</sup>MAYR, *supra* note 12, at 18.

<sup>&</sup>lt;sup>205</sup>See infra Part IV.C.

<sup>&</sup>lt;sup>206</sup>Nelkin, *supra* note 184, at 179.

The language of science itself is a convincing agent, even if scientific data is highly speculative.<sup>207</sup> Unfortunately, genetic testing presents findings to the parents in the language of science. "Images on a screen convey precision. Statistical findings processed by computers appear, at least to nonscientists, to be objective, neutral, beyond refutation, somehow equivalent to truth."<sup>208</sup> In our scientifically specialized society, where we blindly rely every day on science's miracle inventions, a certain amount of trustworthiness and prestige follows from scientific discovery. Therefore even when the scientist relates the probabilities associated with the presumed abnormalities in the fetus, the image of scientific data fortelling the outcome for the genetic abnormality holds a persuasive force on the parent's choice.<sup>209</sup>

#### B. Eugenics Policies

Eugenic thinking is not only transmitted to a parent through discourse, but it has the very real possibility of being institutionalized. This change would not necessarily be through baby factories as described by Aldous Huxley in *Brave New World*, <sup>210</sup> but through the courts, social services, and access to health insurance.

When the Supreme Court decided that a woman's reproductive choice was not an affirmative right, but a neutral one as in the abortion financing cases,<sup>211</sup> the Court ignored the coercive effect a "neutral" stance can have.<sup>212</sup> Professor Dorothy Roberts articulates this predicament,

[T]he court's reasoning ignores the real-life effect of the government's funding choices on poor women. An indigent woman who is unable to pay for either childbirth or abortion has no choice but to accept the government's determination. By funding only one option, the government has really made the women's choice for her.<sup>213</sup>

The financial options available to a woman carrying a child restrict the woman's choice of the continued gestation of her fetus.<sup>214</sup> Insurance companies, by deciding

<sup>214</sup>See Tribe, supra note 211, at 336-37.

<sup>&</sup>lt;sup>207</sup>See supra Part I.

<sup>&</sup>lt;sup>208</sup>Nelkin, *supra* note 184, at 186.

<sup>&</sup>lt;sup>209</sup>Id. at 179.

<sup>&</sup>lt;sup>210</sup>See HUXLEY, supra note 42.

<sup>&</sup>lt;sup>211</sup>See Harris v. McRae, 448 U.S. 297, 314 (1980); See also Maher v. Roe, 432 U.S. 464, 474 (1977). See Lawrence H. Tribe, The Abortion Funding Conundrum: Inalienable Rights, Affirmative Duties and the Dilemma of Dependence, 99 Harv. L. Rev. 330 (1985). Professor Tribe writes that although most of our constitutional rights are negative ones, meaning the government cannot intrude upon them, certain rights are affirmative, where the government has a responsibility to ensure that individuals are able to exercise these rights. Examples of affirmative rights include the right to counsel, right to speedy trial. Id. at 332. Affirmative rights can also be inferred in the Fourteenth Amendment. Id. Professor Tribes analyzes the reasons underlying why some rights implicate an affirmative duty and concludes that a woman's right to reproductive choice is one of those rights. Id. at 330-43.

<sup>&</sup>lt;sup>212</sup>See Dorothy E. Roberts, Punishing Drug Addicts Who Have Babies: Women of Color, Equality, and the Right of Privacy, 104 HARV. L. REV. 1419, 1478 n.295 (1991).

 $<sup>^{213}</sup>Id$ 

not to cover a fetus whose genetic test has determined it to have a high probability of contracting a disease, give only the very wealthy the choice to carry that child to term. Increased access to genetic information may also subject the woman to wrongful life suits, <sup>215</sup> if the child is born and does contract the predicted disease. <sup>216</sup> Although such wrongful life suits have yet to be held against the mother, <sup>217</sup> advocates for the elimination of the abnormal fetus like Dr. Margery W. Shaw, call for the active implementation of these suits against the mother. <sup>218</sup>

State sanctioned eugenics have already occurred in our country, encouraging sterilization of the mentally handicapped.<sup>219</sup> In *In re Sterilization of Moore*, the court stated, "[t]he people of North Carolina also have the right to prevent the procreation of children who will become a burden on the State."<sup>220</sup> This rationale opens the door

<sup>&</sup>lt;sup>215</sup>"Wrongful life" is distinguished from "wrongful birth" suits. Wrongful birth suits are brought against a party whose negligent action caused the defect, while wrongful life is typically brought by the child claiming she should never have been allowed to be born. Shaw, supra note 145, at 104. Wrongful life suits in a majority of states are disfavored. Id. at 105. "Widespread among the opinions and discussions in wrongful life opinions is the declaration that there can be no legal remedy because it is logically impossible to compare life with defects against no life at all." Id. California has upheld some wrongful life suits as in Curlender v. BioScience Labs., 106 Cal. App. 3d 811 (1980). This case was brought against a medical labrotory who tested if the parents were carriers of Tay Sachs gene and falsely told them they were not. Id. When their child was born with Tay Sachs a suit was brought on his behalf against the labortory. Id.

<sup>&</sup>lt;sup>216</sup>See Shaw, *supra* note 145. Professor Shaw provides an overview of the state of the law on "wrongful life" claims. *Id.* at 104-11. Few courts have upheld wrongful life suits, although both California and Washington allow it. *Id.* at 106.

<sup>&</sup>lt;sup>217</sup>See Id.

<sup>&</sup>lt;sup>218</sup>*Id.* Professor Shaw's article advocates that "wrongful life" actions should be brought against mothers who fail to abort fetuses they know have a chance of having severe genetic diseases. *Id.* at 110. She argues that genes are like infectious agents, both are transferrable and both can have severe effects on the host, and like infectious agents the government should have the right to control the spread of genes, to impose a "genetic quarantine." *Id.* at 94.

<sup>&</sup>lt;sup>219</sup>See Buck v. Bell, 274 U.S. 200 (1927); Strump v. Sparkman, 435 U.S. 349 (1978) (involving a lawsuit by girl who was sterilized by parent, courts at age 15); In re Sterilization of Moore, 221 S.E.2d 307, 312 (N.C. 1976). More recent cases have found that they did have the authority under parens patriae to decide if incompetent person should be sterilized. But see In the Matter of Grady, 85 N.J. 235 (1981). See also In the Matter of Hayes, 93 Wash. 2d 228 (1980). See contra Skinner v. Oklahoma, 316 U.S. 535 (1942). The U.S. Supreme Court held it was unlawful for Oklahoma to sterilize Skinner, a convicted criminal. Id. Although, the Court reaffirmed the importance of the individual's right to procreation, they did not overrule Buck v. Bell, finding instead that the Oklahoma statute violated the equal protection clause of the Fourteenth Amendment. Id. See also Barbara L. Bernier, Class, Race, and Poverty: Medical Technologies and Sociopolitical Choices. 11 HARV. BLACKLETTER J. 115 (1994). Professor Bernier provides an overview of the historical movements that have pressured the poor and woman of color to be sterilized. Id. at 128-42. She focuses on the language of the eugenics movement of the progressives to the present who target these women. Id. These ideas infiltrated the medical profession. Id. Professor Bernier provides examples of uniformed or coerced sterilization that occurred to many women with little response by the society at large. Id.

<sup>&</sup>lt;sup>220</sup>In re Sterilization of Moore, 221 S.E.2d 307, 312 (N.C. 1976).

very wide for state intervention as to who should and should not have children. Genetic information can add a sense of scientific certainty to these decisions. A presumed burden to the state would be the birth of a child with amyotrophic lateral sclerosis, but that child could be another Stephen Hawking;<sup>221</sup> or that carriers with Huntington's Disease should not be allowed to procreate, but lost would be the chronicles of American life through Woody Guthrie's songs; or a fetus with the predisposition for mental illness, but gone too would be the art of Vincent Van Gogh.<sup>222</sup>

Biology and environment make us who we are. It is difficult to determine what factors make some people great. Perhaps part of the answer comes from the struggles these individuals have had to overcome. I do not argue that the limitations and the pain people suffer should be seen as good for them, and that therefore we should ignore any medical technology to ease their suffering. Most parents whose child suffers a disease, either because of the limitations the disease imposes on the child's body or because society at large creates obstacles by limiting access, would want treatment to reduce the child's pain or the choice not to bring the fetus to term. Yet it is important to remember that genetic mutations are not abnormal.<sup>223</sup> Genetic diversity is normal, which is one of the reasons the idea of mapping a prototype genome sets up a false reality.<sup>224</sup>

#### C. The Reduction of Genetic Diversity and its Effects

Eugenic choices affect the pool of diversity on which a healthy species depends. Excluding certain traits from the human population not only raises ethical issues for the individual, but also can affect a baseline of genetic diversity in the human species. 226

The definition of a "good" or a "bad" trait is constructed by the culture, and culture is a product of its environment. Selection can occur in one environment leaving the species ill-equipped to adapt to changes when necessary. <sup>227</sup> It is biological diversity that helps a species to adapt when the environment changes, <sup>228</sup> as

<sup>&</sup>lt;sup>221</sup>HUBBARD & WALD, *supra* note 6, at 28.

<sup>&</sup>lt;sup>222</sup>Russell R. Monroe, *Creative Brainstorms: A Story of Madness and Genius*, 19 J. AM. ACAD. PSYCHOANALYSIS 462 (1991). Dr. Monroe's work examines the connection of mental illness to some artist's work. Besides Vincent van Gogh, he also looked at Mary Lamb, Virginia Woolf, Auguste Strinberg and Edward Munch, all who had experienced psychotic episodes. *Id.* He writes: "Noteworthy in these individuals was the intensity of their feelings. These were painful - depressing, frightening, and/or rageful - but sometimes ecstatic, and it is this wide spectrum of emotions that characterizes their creative endeavors whether with words or paint." *Id.* at 463.

<sup>&</sup>lt;sup>223</sup>LEWONTIN, *supra* note 4, at 49.

<sup>&</sup>lt;sup>224</sup>See supra Part II.C.

<sup>&</sup>lt;sup>225</sup>SUZUKI & KNUDTSON, *supra* note 193.

<sup>&</sup>lt;sup>226</sup>Id. at 290-315. Suzuki and Knudtson write on the dangers of gene therapies that effect germ cell. Meaning, the manipulation of genes that not only effect the host but also subsequent generations. *Id.* at 181-207.

<sup>&</sup>lt;sup>227</sup>SUZUKI & KNUDTSON, *supra* note 199, at 204-05.

<sup>&</sup>lt;sup>228</sup>Id. at 205.

is illustrated by examining the sickle cell mutation in humans. If the sickle cell trait is inherited from both parents, it will result in disease.<sup>229</sup> If inherited from only one parent, this mutation turns out to be an advantage for people who live in areas exposed to malaria, for it offers an immunity to the disease.<sup>230</sup> This resulted in a high percentage of people with sickle cell genes in areas of west and central Africa where there was malaria.<sup>231</sup> The threat of malaria in these regions was a relatively recent occurrence in evolutionary time. The rise of malaria occurred with a dramatic change in environment, when humans turned to slash-and-burn agriculture.<sup>232</sup> The deforestation that occurred with this practice in tropical areas resulted in stagnant pools of water; these pools provided a breeding ground for mosquitoes carrying the malaria parasite.<sup>233</sup> Loss of genetic diversity could have been a loss of this mutation, which turned out to be an advantage in a malaria ridden environment. Of course, this same mutation in a malaria free environment is detrimental, since in its homologous form, it can cause disease and even death.<sup>234</sup> The story of the sickle cell mutation illustrates that it is impossible to foresee into the future and know which traits will be advantageous and which ones harmful.

In one environment, or in one culture, certain traits may be prized, but if the environment changes it may be the genes that are now eradicated that would have offered the most advantage.<sup>235</sup> Professor David Suzuki and Professor Peter Knudtson point to the perils of reducing genetic diversity through an analysis of genetic engineering that humans have waged on maize.<sup>236</sup> While the domestication of maize resulted in higher yield crop,<sup>237</sup> it also resulted in less genetic diversity within the crop,<sup>238</sup> as seen by the reduction in the variety of maize that exists today. At the time of Columbus' arrival in America, there were hundreds of different type of maize plants,<sup>239</sup> now primarily only six types of maize remain.<sup>240</sup>

Genetic diversity is also lost within each category of maize.<sup>241</sup> Examination of the chromosomes in these plants shows that a number of the genes are identical in

\_

 $<sup>^{229}\</sup>mathrm{Harry}$  Nelson & Robert Jurmain, Introduction to Physical Anthropology 131 (3d ed., 1985).

 $<sup>^{230}</sup>Id$ .

 $<sup>^{231}</sup>Id$ 

<sup>&</sup>lt;sup>232</sup>Id. at 132.

 $<sup>^{233}</sup>Id.$ 

<sup>&</sup>lt;sup>234</sup>MERCK MANUAL, *supra* note 180, at 749-51.

<sup>&</sup>lt;sup>235</sup>See Suzuki & Knudtson, supra note 193, at 204-05.

<sup>&</sup>lt;sup>236</sup>Id. at 290-315.

<sup>&</sup>lt;sup>237</sup>*Id.* at 291.

<sup>&</sup>lt;sup>238</sup>Id. at 290.

<sup>&</sup>lt;sup>239</sup>Id. at 299.

<sup>&</sup>lt;sup>240</sup>SUZUKI & KNUDTSON, *supra* note 193, at 292-93.

<sup>&</sup>lt;sup>241</sup>*Id.* at 290-91.

every single plant, <sup>242</sup> leaving the entire species vulnerable to a disease that attacks that single site.<sup>243</sup> According to Suzuki and Knudtson, this loss is what happened to the corn crop in the United States during an outbreak of Southern leaf blight fungus.<sup>244</sup> The significance of this incident was not that this disease could destroy corn crops,<sup>245</sup> but how quickly the disease spread throughout the South and into the Midwest, killing over twelve percent of the annual harvest of the United States. 246 The reason for this quick contagion was the fact that the gene for male sterility was bred by geneticists into the corn crops. It turned out this site on the genome was also the locus for another trait, one that was susceptible to the fungi causing Southern leaf blight in corn. 247 This example shows the vulnerability of disease of an entire species when there is limited genetic diversity. It also points out how limited our knowledge of the function of genes is, even after we have mapped a particular location on the genome as corresponding to a particular trait. When geneticists match certain genes to certain traits, this does not mean that is the only function of that gene. We may eradicate or manipulate a gene site to promote or discourage a certain trait, but at the same time we may be affecting other traits as well that could be advantageous to our species.248

## VI. ACCEPTANCE OF THE POWER OF THE GENOME TO DETERMINE BEHAVIOR EFFECTS SOME OF THE BASIC IDEAS UNDERLYING OUR SYSTEM OF JUSTICE

Propounding the gene as the key to ourselves is to define ourselves not as morally autonomous agents with our own free will, but rather as our actions as subject to our genetic blueprint.<sup>249</sup> This conception runs counter to our construction of legal institutions that base our notions of justice on the individual's capacity to choose certain behaviors over others.<sup>250</sup> For, "[t]he conception of ourselves as responsible agents is reflected in common moral beliefs and in important social and legal institutions and practices that place great value on individual self-determination."<sup>251</sup> This conception is derived from enlightenment philosophers such as John Locke who described human beings real essence as that of autonomous

<sup>245</sup>*Id.* at 310. This disease had been known for a while but affected less than one percent of the corn crop prior to this epidemic. *Id.* 

\_\_

<sup>&</sup>lt;sup>242</sup>Id. at 290. An example of how genetic sequences that result in the same trait can vary substantially is seen in experimental animals where it has been found that every one in 500 nucleotide will differ in DNA between two animals. LEWONTIN, *supra* note 4, at 50. Billions of nucleotide can make up genes. *Id.* Therefore, finding so many identical genes within the maize crop speaks to the loss of genetic variation within the crop.

<sup>&</sup>lt;sup>243</sup>SUZUKI & KNUDTSON, *supra* note 193, at 311.

 $<sup>^{244}</sup>Id.$ 

<sup>&</sup>lt;sup>246</sup>Id., at 310.

<sup>&</sup>lt;sup>247</sup>*Id*. at 311.

<sup>&</sup>lt;sup>248</sup>See Id. at 205.

<sup>&</sup>lt;sup>249</sup>See supra Part I.

<sup>&</sup>lt;sup>250</sup>Brock, *supra* note 39, at 13.

 $<sup>^{251}</sup>$ *Id*.

beings. This autonomy is derived from human beings ability to reason, and if man accepts reason as its guiding principle human beings are free to obtain happiness.<sup>252</sup>

Thomas Jefferson incorporated many of the enlightenment ideals into the Declaration of Independence when he expressed that all men had certain rights that must have the opportunity to be expressed unfettered by government. These rights belonged to the individual. The proposition that only the individual can express these rights means that these rights are "naturally" pursued in many different ways. The government would be seen as external to the individual's self-determination, then government would not be an antithesis to the expression of these rights, government would just need to discover the right answer to enable the natural expression. But the founders called for these rights to be free from government intrusion. This assumes each individual would express these rights differently, and if not the problem would not be government intrusion, but ensuring the right kind of government policy.

James Madison believed that human beings will naturally splinter into many factions.<sup>257</sup> He reasoned that a federal system would be the best form of government for it would protect minorities from large factions, while at the same time allowing

In the *Essay* Locke stresses repeatedly that knowledge cannot be immediately communicated, that one must think for oneself if one is to attain knowledge. Just note again the statement, 'we may as rationally hope to see with other Mens Eyes, as to know by other Mens Understandings. So much as we our selves consider and comprehend of Truth and Reason, so much we possess of real and true Knowledge. The floating of other Mens Opinions in our brains makes us not one jot the more knowing, though they happen to be true.' To this doctrine of epistemic autonomy there corresponds that of moral autonomy. *Id.* at 68-69.

-

<sup>&</sup>lt;sup>252</sup>Peter A. Schouls, Reasoned Freedom: John Locke and Enlightenment 63 (1992).

<sup>&</sup>lt;sup>253</sup>THOMAS JEFFERSON, DECLARATION OF INDEPENDENCE (1776).

<sup>&</sup>lt;sup>254</sup>Id. "We hold these truths to be self evident, that all men are created equal, that they are endowed by their Creator with certain unalienable Rights, that among these are Life, Liberty and the pursuit of Happiness." Id.

<sup>&</sup>lt;sup>255</sup>Enlightenment philosopher John Locke wrote that what was natural to human beings was his use of reason which enables human beings to be morally responsible for his actions. SCHOULS, *supra* note 252, at 41. Reason must be understood autonmously if it is to have meaning.

<sup>&</sup>lt;sup>256</sup>The ideas of the American Revolution were the ideas of the enlightenment. Enlightenment ideals saw the function of government was to ensure that individuals liberty interest be protected from the tyranny. Bruce J. Winick, *On Autonomy: Legal and Psychological Perspectives* 37 VILL. L. REV. 1705, 1708 (1992). *But see* Philosopher Thomas Hobbes, who postulated that political philosophy should begin by understanding man's nature and this understanding "serves primarily to determine the reasons, the purposes, or the ends for the sake of which men form political societies. These ends being known, the political problem becomes one of how to organize man and society in order to realize the ends most effectively." Laurence Berns, *Thomas Hobbes*, *in* HISTORY OF POLITICAL PHILOSOPHY 373 (Leo Straus ed., 1972) In addition, Hobbes, unlike the Enlightenment philosophers, thought man's nature was reveled by his passions not his reason. *Id.* 

<sup>&</sup>lt;sup>257</sup>THE FEDERALIST No. 10, at 44 (James Madison) (Garry Wills ed., 1982). "The latent causes of faction are thus sown in the nature of man; and we see them every where brought into different degrees of activity, according to the different circumstances of civil society." *Id.* 

for the multiplicity of expression these factions represented.<sup>258</sup> The First Amendment of the Bill of Rights codified that a multiplicity of view points is fundamental to our liberty interest.<sup>259</sup>

A strand of western philosophy later picked up on these ideas and solidified them in the view of individuals as autonomous and the creators of their own destiny. John Stuart Mill in his essay *On Liberty* wrote that the individual is the most competent to make choices regarding his welfare.<sup>260</sup> Immanuel Kant saw each individual as autonomous, free to make his own decisions.<sup>261</sup> Society was obligated to respect this personal autonomy,<sup>262</sup> and in turn, society could hold the individual accountable for his actions.<sup>263</sup>

This theory is clearly demonstrated in our definitions of crime. "[E]xcept in rare circumstances, a person is not guilty of an offense unless he performs a voluntary act (or omits an act that is his legal duty to perform) that causes social harm (the *actus reus*), with a *mens rea* (literally, a 'guilty mind.)"<sup>264</sup> The *mens rea* requirement, asking that the state prove that the defendant had the requisite state of mind, is based on retributive notions of punishment.<sup>265</sup>

Crimes are public wrongs; a finding of guilt implies that the convicted party wronged the community as a whole. By convicting a criminal defendant, society denounces the actor; it condemns and stigmatizes him as a wrongdoer. Respect for human dignity suggests, if it does not dictate, that stigma should not attach and liberty should not be denied to one who has acted without a culpable state of mind.<sup>266</sup>

<sup>&</sup>lt;sup>258</sup>*Id.* at 48. "The smaller the society, the fewer probably will be the distinct parties and interests composing it; the fewer the distinct parties and interests, the more frequently will a majority be found of the same party; and the smaller the number of individuals composing a majority, and the smaller the compass within which they are placed, the more easily will they concert and execute their plans of oppression." *Id.* 

<sup>&</sup>lt;sup>259</sup>U.S. CONST. amend. I.

<sup>&</sup>lt;sup>260</sup>JOHN STUART MILL, ON LIBERTY 101 (Norton Critical & David Spitz eds., 1975). *See also* Winick, *supra* note 256, at 1714.

<sup>&</sup>lt;sup>261</sup>KANT, FOUNDATIONS OF THE METAPHYSICS OF MORALS 59-67 (J. Beck trans., 1959).

 $<sup>^{262}</sup>Id.$ 

 $<sup>^{263}</sup>$ Id. at 197. See also Joshua Dressler, Understanding Criminal Law 11 (2d ed. 1995).

<sup>&</sup>lt;sup>264</sup>Dressler, *supra* note 230, at 101.

<sup>&</sup>lt;sup>265</sup>*Id.* at 103. There are different schools of thought on the justification for punishment. Retributivism begins with the idea that each individual has a free will. When the individual chooses to violate the laws of society, society is justified in punishing the wrongdoer, regardless if it will have a deterrent effect. *Id.* at 11. This is in contrast to Utilitarian rationale for punishment, that sees the only purpose of punishment as a deterrent. *Id.* at 9.

<sup>&</sup>lt;sup>266</sup>Id. at 104. See also Morissette v. United States, 342 U.S. 246 (1952). "A relation between some mental element and punishment for a harmful act is almost as instinctive as the child's familiar exculpatory [sic], 'But I didn't mean to.'" Id. at 250-51. See also H.L.A. HART, PUNISHMENT AND REPONSIBILITY 114 (1968). "All Civilized penal systems make liability to punishment for any rate serious crime dependent not merely on the fact that the

State of mind requirement is not only a part of criminal law, but also applies in tort law where proof of negligent intent is required.<sup>267</sup>

The current thirst to grab onto genetic causes for behavior<sup>268</sup> could undermine the conception that individual choice can be held as the cause of behavior. This article has argued that it may be irrelevant that the medical data points to a dialogue between biological, psychological and sociological components as well as randomness in constructing an individual's choices, a change in paradigmatic understanding can occur when a majority of people accept one factor as controlling. Therefore, if society accepts that genes cause behavior, this undermines the current legal distinction that certain acts are more culpable than others, such as acts with a requisite state of mind versus acts done in the heat of passion; no longer are these two acts divided by the idea of choice on the part of the actor.<sup>269</sup> Some schalors have argued that the acceptance of determinism<sup>270</sup> need not undermine the idea of legal reponsibility.<sup>271</sup>

One theory, the 'as if' view of legal responsibility, accepts the truth of the determinist doctrine but holds that the law should treat individuals as if they were free.... When reponsibility is viewed from a backward-looking perspective, the 'as if' view is easily refuted. If determinism negates freedom and if lack of freedom precludes the ascription of responsibility, then it is fundamentaly unjust to treat persons as if they were responsible when all behavior is causally determined. With the traditional, backward-looking conception, ascription of responsibility results from a determiniation that the agent understood his action, that he intended it, and that he could have done otherwise. But by admitting that

person to be punished has done the outward act of a crime, but on his having done it in a certain state of frame of mind or will." *Id.* 

\_

<sup>&</sup>lt;sup>267</sup>See John Lawrence Hill, *Law and the Concept of the Core Self*, 80 Marq. L. Rev. 289, 296 n.11 (1997). Professor Lawrence writes, "the *mens rea* requirement in criminal law, and the various state of mind requirements in contemporary tort law are evidence of the law's recognition of the mind/body distinction and of the general moral proposition that the person should only be held morally and legally responsible for the acts of the self, rather than those of the body. The most striking example of this commitment is embodied in the defense of automatism or unconsciousness. *Id.* at 296.

<sup>&</sup>lt;sup>268</sup>See supra Part I.

<sup>&</sup>lt;sup>269</sup>Of course the questioning of free will and therefore moral reponsibility under the law is not new. There is a large amount of philosophical inquiry as well as legal scholarship on the issue of determinism versus free will. *See* HART, *supra* note 266. *See also* REASON & RESPONSIBILITY (Joel Feinberg ed., 4th ed. 1978).

<sup>&</sup>lt;sup>270</sup> Determinism, adhered to mostly in the fields of science and medicine, is the theory that all events are caused by something else and therefore, are predictable." Rachel J. Littman, *Adequate Provocation, Individual Responsibility, and the Deconstruction of Free Will*, 60 ALB. L. REV. 1127, 1132 (1997).

<sup>&</sup>lt;sup>271</sup>John L. Hill, Freedom, Determinism, and the Externalization of Responsibility in the Law: A Philosophical Analysis, 76 GEO. L.J. 2045, 2056-57 (1988).

the agent could not have done otherwise, the 'as if' view repudiates this traditional view of responsibility.<sup>272</sup>

The type of mental gymnastics involved in the "as if" approach does not solve the problem of the incompatability between a system that holds the individual responsible for his choices and an ideology that finds all choices are in fact predetermined, in fact this approach highlights the incompatability. As like the problem of seeing components of behavior as an either nature or nurture instead of as a reciprocaple interaction, so is the problem defining behavior as free or determined.<sup>273</sup>

#### VII. CONCLUSION

What makes an individual the particular person he is, is not his genes, but the aggregation of all the elements of his life, and how the individual constructs these elements in a way that has meaning.<sup>274</sup> Professor Hill explains that "[w]e come to see ourselves in our work, our love, our families the things to which we are attached, and with which we identify. On this theory, to alienate these objects is to do harm to our inner most selves."275

Geneticists could argue that the psychological and the sociological consequences of mapping the genome is out of their control. If they find the causal agent for a disease in the gene, this information should not be censored simply because it does not fit into the conception of humans as the self- determining agents of their own destiny. Yet it is not the facts that are discovered by science that are the problem, but the interpretation of these facts, the meaning our culture places on them. There is no doubt that genes play a role in behavior and in disease. To elevate the role genes

 $<sup>^{272}</sup>Id.$ 

<sup>&</sup>lt;sup>273</sup>There are different varients of the Determinist school of thought some which do not see the behavior in such either or terms. Littman, supra note 270, at 1134.

Soft determinist posit that determinism and freedom are not incompatible. Compatibilists believe that freedom exists even if determinism is true. Thus, even if the individual is caused by some external or past event, the individuals actions need not necessarily be caused by the same events. The actions are still 'free' to the extent that they are not compelled, but are still committed according to the individual's desires and wishes. Social or environmental factors may influence a persons character, but that does not prevent an individual from being free, i.e., responsible for his actions that may nonetheless have some causal link to the character formed by factors beyond the individual's control. Id.

The compatibilist theory comes close to integrating individual responsibility with determinism; however, it works on reconciling behavior that was caused by environmental factors, it is not clear if this integration would work if behavior was caused by one's biological make-up, by ones genes.

<sup>&</sup>lt;sup>274</sup>See Gerald Dworkin, The Theory and Practice of Autonomy 31 (1988). Professor Dworkin writes, "[w]hat makes an individual the particular person he is his life plan, his projects. In pursuing autonomy, one shapes ones life, one constructs its meaning. The autonomous person gives meaning to his life." Id. See also MICHAEL WHITE, NARRATIVE MEANS TO THERAPEUTIC ENDS (1988). White discusses a new method of therapy, where the client's psychological well being is improved by reconstructing the meanings the client has placed upon their predicament. Id.

<sup>&</sup>lt;sup>275</sup>Hill, *supra* note 267, at 368.

play in the manifestation of traits to the position of a "blueprint" - a predetermined design where environment, internal and external to the organism, are merely supporting players that provide the necessary elements in order that the predetermined design can be actualized, is a conceptualization that places the essential understanding of who we are as in our genes, even though it acknowledges that environment plays a role.

A more satisfying conceptualization of the role genes play in manifestation of traits is as merely a part of a complex process in which genes affect the organism, the organism affects the gene, the external environment affects the organism, which in turn, affects the gene's message to manufacture proteins, and so on. Reductionist explanations may satisfy our culture's need to explain through sound bites, <sup>276</sup> but these explanations do not even come close to the complexity involved in defining "what it means to be human."

<sup>276</sup>LEWONTIN, *supra* note 4, at vii.