CONSEQUENCES OF HUMAN GENOMICS

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ABSTRACT

The rapid development of human genomics has made the goal of “making better humans” more attainable than ever. As human genomics has dazzled people with its power to change our society, its ethical and social implications have also puzzled many critics with all kinds of backgrounds. This dissertation seeks to point out yet another aspect of the implications, which is far less noted but far more extensive than those currently identified—*i.e.*, the ability of human genomics to constitute self-identities by proffering an ideal body image that is, thanks to the advance in medical and genetic knowledge every day, thick, lucid, and meticulous rather than thin, obscure, and wishy-washy. As a result, the kind of identity that human genomics helps to produce is obdurate and fixed, which is prone to exclude and detrimental to social solidarity, because difference in such a society is to be eliminated (or fixed) but not accepted and welcomed. As a preliminary attempt to address the surging challenge that human genomics brings to the liberal democracy, this dissertation proposes that it is imperative to develop an alternative vocabulary to counter the pervasive claim of “fixing human” so as to raise our consciousness of the existence of such a danger, provide a vantage point for the public to enter and intervene, as well as liberate our political imagination regarding the subject of “making better humans.” A renewed concept of privacy rights, this dissertation argues, is an ideal candidate to translate the moral concern for identity formation into some kind of “compelling government interest” that justifies the regulation of the scientific enterprise.

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"If I have seen further, it is by standing on the shoulders of giants." Besides the above three professors whose contributions to this dissertation are material, my knowledge is accumulated and perspectives are broadened by faculty members at the University of Virginia, and earlier the University of Pennsylvania, and writers who I never have a chance to meet but learn a lot from their books and articles. They are all the giants that make this project possible and my respect to them at this time can only appear in the form of citations. My debt to Professor Richard Rorty's writings, in this sense, is even greater than the footnotes can suggest.

I am also blessed with many friends who have enriched and touched my life in so many different ways that are no less important to me. Because of the size of this group, I have to ask for their understanding for not being able to list them individually here.

Writing this dissertation has been an inexcusable act of self-indulgence. Relieving me of so many mundane duties and allowing me to spend time on thinking and writing about a topic that has no direct bearing on their welfare, my family's devotion and unqualified love provide a solid foundation that is indispensable for my study and my life. It includes my parents, two sisters, wife, the extended family and in-laws. My parents have given me everything—both tangible and intangible—in abundance, and dedicating this dissertation to them would be the best way I can think of to show my forever gratitude to them. My extended family and in-laws are also an important source of caring and supports. I would especially like to thank my wife Jeanne. She is not only a considerate companion in life but also a partner in intellectuality. Having her S.J.D. degree last year at the University of Pennsylvania, she provided most substantial help and encouragement every time I was frustrated and distressed by so many bottlenecks on the way of writing the dissertation. She is truly the best wife one can expect. As this dissertation is at its completion stage, we are expecting our first child in less than two months.

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1.1 Posing the Challenge

Ever since the seventeenth century, human beings have been seeking ways to master nature. Such a project constitutes the leitmotif of modernity. And the disenchantment of the world and human emancipation—emancipation from myths, from what Anthony Giddens called “the dogmatic imperatives of tradition and religion”—have stimulated and to some extent, promoted, the modernity project. Liberated from the status of the passive object of supernatural power, human beings have become the mastering Subjects—both spiritually and physically. Modern natural science, through the application of instrumental reason, is able to devise a plethora of powerful means to control or even manipulate the physical world of once mysterious Objects to serve the ends desired by Subjects. The jubilant announcement of the completion of a high-quality sequence of the human genome on April 14, 2003, which also coincided with the fiftieth anniversary of the discovery of the DNA double helix, certainly marked the latest accomplishment of modernity’s project for the mastery of nature; only this time, what is being mastered is human nature itself.

Another less noticed but equally—if not more—noteworthy milestone in the same year of 2003 is the thirtieth anniversary of *Roe v. Wade*. Setting aside the somewhat still publicly frenzied but legally unanswerable question of whether a fetus is a moral person, reproductive liberty now seems to be the canonical legal rhetoric in the realm of human reproduction. Indeed, the culture of autonomy and the language of choice have been so taken for granted in American society that they serve as the ultimate answer to almost everything faced by people in their everyday life. It makes Justice Holmes's language in *Buck v. Bell* some seventy years ago—"Three generations of imbeciles are enough."—look not only obsolete but also a bit impertinent. *Buck* endorsed government's engagement in the involuntary sterilization and set the stage for the passage of laws that would sanction sterilization operations on 60,000 Americans between 1927 and 1972. *Buck* remains good law today in a strict legal sense. But few would doubt that there has been a legal, social or cultural paradigm shift from reproductive responsibility of the public health model to reproductive autonomy of fundamental rights talk.

We now have, on the one hand, the exciting ability to change what is given to us as nature—such as to cure the sick, to reverse disabilities, and to pursue the dream of human perfection—and, on the other hand, a culture of autonomy that supports our taking advantage of such ability to pursue our goals. The juncture of these two seemingly irrelevant developments leads to a serious ethical challenge: whether we should leave up to individual choice the decision of making use of human genomics and the human genetic engineering (HGE) to improve or even perfect the condition of human beings. How do we evaluate substantively the value of our mastery of human nature? Should we forgo Prometheus's new contrivance? Or, should we take the same position as James Watson—the codiscoverer of the double-helical structure of DNA, the cowinner of the Nobel Prize, and also the first director of the Human Genome Project—does: "if we could make better humans, why shouldn't we?"[1]

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[1] *See* GREGORY STOCK, REDESIGNING HUMANS: OUR INEVITABLE GENETIC FUTURE 12 (Boston:

1.2 The Human Genome Project and Gene Discovery

The initial ambitious vision of the Human Genome Project (HGP), the largest biological undertaking in history, was to identify and locate all the then estimated 100,000 genes[2] in the human genome, determine their precise DNA sequences, and then learn their function and the role of various genes in health and disease.[3] To achieve the ultimate goal of identifying entire human genes and deciphering the secret of their function, several interim groundwork programs were established.[4] Among those,

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Houghton Mifflin, 2002) (quoting Watson).

[2] This estimation was based on Walter Gilbert's calculation in the 1980s. Both National Research Counsel's report of 1988 and the first five-year plan of the Human Genome Project adopted this estimation. *See* COMMITTEE ON MAPPING & SEQUENCING THE HUMAN GENOME, NATIONAL RESEARCH COUNCIL, MAPPING AND SEQUENCING THE HUMAN GENOME 13 (Washington, D.C.: National Academy Press, 1988) [hereinafter NRC HGP REPORT OF 1988]; U.S. DEP'T OF HEALTH & HUMAN SERVS. & U.S. DEP'T OF ENERGY, UNDERSTANDING OUR GENETIC INHERITANCE: THE US HUMAN GENOME PROJECT: THE FIRST FIVE YEARS: FY 1991-1995, at vii (Bethesda, MD: NIH Pub. No. 90-1590, 1990) [hereinafter THE FIRST FIVE-YEAR PLAN]. More recent estimates have varied wildly. Craig Venter and his colleagues earlier gave the estimation of 60,000~70,000 human genes. *See* Chris Fields et al., *How Many Genes in the Human Genome*, 7 NATURE GENETICS 345 (1994). Venter's Celera Genomics Sequencing Team revised the figure to 26,588 later in its working draft of the human genome sequence in 2001. *See* John Craig Venter et al., *The Sequence of the Human Genome*, 291 SCIENCE 1304, 1317, 1329 (2001). According to the International Human Genome Project Consortium's latest estimation, the number is 30,000 to 40,000. International Human Genome Sequencing Consortium, *Initial Sequencing and Analysis of the Human Genome*, 409 NATURE 860, 898-99 (2001). *See also* Jean-Michel Claverie, *What If There Are Only 30,000 Human Genes?*, 291 SCIENCE 1255 (2001).

[3] *See* THE FIRST FIVE-YEAR PLAN, *supra* note 2, at 1. Although the first five-year plan did not explicitly list gene identification as one of the specific goals (interim groundwork programs), the second five-year plan acknowledged that gene identification has always been an implicit part of the Human Genome Project. *See* Francis Collins & David Galas, *A New Five-year Plan for the US Human Genome Project*, 262 SCIENCE 43, 44 (1993) [hereinafter *The Second Five-year Plan*].

[4] *See* THE FIRST FIVE-YEAR PLAN, *supra* note 2, at 5-7.

mapping and sequencing the human genome attained most publicity. However, the completion of human genome sequencing, which is heralded to conclude the thirteen-year three-billion-dollar project, does not fully live up to its initial promise as far as the human gene identification is concerned. Up to March 2003, scientists were only able to isolate and completely spell out 15,000 of 30,000 to 35,000 human genes.[5] Not only that, the full complement of protein-coding sequences remains to be established. The function of most known genes is also poorly understood.[6] The public are galvanized by the completion of human genome sequencing only to find out that the HGP is not the end.[7] It is not even the beginning of the end. It is just the end of the beginning.[8]

But it certainly is not fair to say that the Human Genome Project contributed nothing or that human genomics does not bring about a revolution in life science researches and applications. Despite the fact that a large portion of human genes and their function have yet to be fully comprehended and that the complex interplay between

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[5] HGP claimed to identify 15,000 "full-length" human cDNAs in March 2003. *See* Francis S. Collins et al., *The Human Genome Project: Lessons from Large-scale Biology*, 300 SCIENCE 287 (2003). cDNAs are those DNA sequences that encode protein. Gene in this sense is a protein-coding DNA sequence. *See* Michael Snyder & Mark Gerstein, *Defining Genes in the Genomics Era*, 300 SCIENCE 258 (2003).

[6] *See* Francis S. Collins et al., *A Vision for the Future of Genomics Research*, 422 NATURE 835, 837 (2003).

[7] *See* RICHARD LEWONTIN, *The Dream of the Human Genome Second Epilogue*, *in* IT AIN'T NECESSARILY SO: THE DREAM OF THE HUMAN GENOME AND OTHER ILLUSION 187, 189-193 (New York: New York Review Books, 2nd ed. 2001).

[8] *See* Remarks by Dr. Francis Collins on the Completion of the First Survey of the Entire Human Genome Project, http://www.ornl.gov/TechResources/Human_Genome/project/clinton2.html (Jun. 26, 2000) ("Today is most certainly not the end of genomics, but perhaps it's the end of the beginning.").

multiple genetic factors (genes and their direct products) and non-genetic factors (environmental influences) still bewilders scientists' efforts to establish the links between most phenotypes and genotypes, the application of currently available results of the Human Genome Project has already sprung up vigorously.

Before the launch of full-scale sequencing of the human genome in early 1999,[9] map-based gene discovery approaches led the enterprise of elucidating the molecular basis of Mendelian genetic diseases.[10] Based on the understanding that genes which lie close together on a chromosome have a much higher chance of being inherited together than genes that lie farther apart, scientists were able to chart *genetic linkage maps* that show the relative distance between any two genes or genetic loci by determining the frequency with which they are inherited together, that is, not separated by recombination during meiosis.[11] (Distant genes recombine frequently, while nearby genes rarely

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[9] *See* Francis S. Collins, *Medical and Societal Consequences of the Human Genome Project*, 341 NEW ENG. J. MED. 28, 28 (1999).

[10] *See* Leena Peltonen & Victor A. McKusick, *Dissecting Human Disease in the Postgenomic Era*, 291 SCIENCE 1224, 1225 (2001). Inheritance pattern of mendelian disorders, including autosomal dominant, autosomal recessive, and X-linked, is relatively straightforward and have been studied and understood for nearly 100 years. *See* Alan E. Guttmacher & Francis S. Collins, *Genomic Medicine—A Primer*, 347 NEW ENG. J. MED. 1512, 1515 (2002). Map-based approach is valuable especially when knowledge about the basic biochemical defect a disease causes was not always available for scientists to identify genes from the biochemical product they produce. Map-based approach studies function of a gene after the gene is identified and mapped, while "functional cloning" approach utilizes pre-existing knowledge of gene function, such as biochemical defect a disease causes, to trace back the responsible gene. *See* Francis S. Collins, *Positional Cloning: Let's Not Call It Reverse Anymore*, 1 NATURE GENETICS 3, 3 (1992).

[11] Meiosis is a process of forming sex cells through reduction division of chromosomes. Early in meiosis, each chromosome of a pair replicates itself and pairs up again with the counterpart of the original pair. These homologous pairs may intertwine (crossover) and exchange DNA pieces before reduction

recombine and are closely linked.) All that is needed in genetic linkage analysis is a large number of families with multiply affected individuals. However, what genetic linkage map measures by family studies is a "statistical" distance between two genetic loci. Limited by the scope of pedigrees available for tracing inheritance patterns, linkage studies of two genetic loci usually allow scientists to establish a coinheritance rate no more than 99%. More often, they can only inform a rate of coinheritance around 85-90%. This means linkage studies, when converting to physical distance, at best allow a gene hunter to locate a sought-after gene in an interval containing one million and up to fifteen million DNA letters (base pairs).[12] Unless there are some other tools available to further narrow down the searching region, this still poses great difficulty for researchers to identify the precise location of a gene itself.

In order that further molecular analyses can be made on a real piece of the DNA segment containing the sought-after gene, a *physical map*, which comprises a collection of cloned pieces of contiguous DNA fragments that represent a complete chromosome or chromosomal segment, together with information about the order of these scrappy pieces, must be established. Once genetic linkage markers define the region containing the

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division. As a result, genes on each side of the homologous pairs get shuffled and recombine to form the chromosomes of the sex cells.

[12] This is the notion of centimorgan (cM). Two markers are one centimorgan apart if they are separated during meiosis 1% of the time, two centimorgans if 2% of the time, and so on and so forth. Fine mapping is often limited to genetic intervals of about 1 cM, which corresponds to approximately one million "base pairs." *See* Collins, *supra* note 10, at 3. The bases are the "letters" that spell out the genetic code. Two bases that form a "rung of the DNA ladder" are called "base pairs."

sought-after gene, these small but ordered pieces provide physical objects from which scientists can actually look into the molecular structure of the genome to ferret out the responsible culprit. With the physical piece of DNA segment that contains sought-after gene in hand, scientists are practically able to search through the segment for all protein-coding areas, compare their DNA sequence, and then look for a difference between unaffected persons and carriers of the disease gene. For instance, scientists in 1983 established that the Huntington’s Disease gene (HD) is inherited along with a DNA marker called G8 at the tip of the short arm of chromosome-4 90% of the time.[13] After sifting through around a hundred protein-coding locations in the target segment of 2.2 million base pairs looking for the responsible HD gene,[14] scientists finally isolated one by comparing normal individuals’ DNA sequence of each of those loci with that of seventy-five disease families in 1993.[15]

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[13] This estimate placed the HD gene within the range of 10 million base pairs with a G8 marker, only that scientists were not able to tell from the linkage analysis exactly which 10 million among 192 million base pairs at chromosome-4 are involved. *See* James F. Gusella et al., *A Polymorphic DNA Marker Genetically Linked to Huntington’s Disease*, 306 NATURE 234 (1983) (“[A]n estimate of the 99% confidence interval for the genetic distance separating the two loci extends to 10 cM.”). With more pedigrees in hand, scientists were able to establish only one year later that the HD gene and the G8 marker are inherited together 98% of the time and thus shortened the estimated distance separating the two to 2 million base pairs, i.e., 2 cM. *See* James F. Gusella, *DNA Markers for Nervous System Diseases*, 225 SCIENCE 1320, 1322 (1984).

[14] *See* Leslie Roberts, *The Huntington’s Gene Quest Goes on*, 258 SCIENCE 740, 740 (1992). *See also* Gillian Bates et al., *Defined Physical Limits of the Huntington Disease Gene Candidate Region*, 49 AM J. HUM. GENETICS 7 (1991); Jian Zuo et al., *Cloning of the Huntington Disease Region in Yeast Artificial Chromosomes*, 1 HUM. MOLECULAR GENETICS 149 (1992).

[15] *See* The Huntington's Disease Collaborative Research Group, *A Novel Gene Containing a Trinucleotide Repeat That Is Expanded and Unstable on Huntington's Disease Chromosomes*, 72 CELL 971

Map-based gene discovery approaches have yielded a considerable success identifying genes with simple and strong genotype-phenotype correlations, such as most of the single-gene disorders. However, map-based gene discovery faces two major difficulties when correlations between genotype and phenotype become weaker or more complex. First, *genetically heterogeneous* single-gene disorders involve multiple different mutations of the same gene. Map-based gene discovery, though an apt tool for locating the gene responsible for a single-gene disorder on the chromosome, is ineffective in identifying all disease-related mutations of that gene when the disorder is genetically heterogeneous. For example, when cystic fibrosis's CFTR gene was elucidated, as the first example of the map-based approach, in 1989,[16] scientists were still uncertain about its heterogeneous status.[17] Not until s*equence-based* approach was used were scientists able to carry out large-scale studies on genetic heterogeneity of the CFTR gene. Up to date, more than 900 disease-causing mutations have been found in the CFTR gene.[18]

Second, the utility of map-based gene discovery is limited by the *penetrance* of

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(1993).

[16] *See* Johanna M. Rommens et al., *Identification of the Cystic Fibrosis Gene: Chromosome Walking and Jumping*, 245 SCIENCE 1059 (1989); John R. Riordan et al., *Identification of the Cystic Fibrosis Gene: Cloning and Characterization of Complementary DNA*, 245 SCIENCE 1066 (1989).

[17] *See, e.g.*, E. Vitale et al., *Homogeneity of Cystic Fibrosis in Italy*, 39 AM. J. HUM. GENETICS 832 (1986); Xavier Estivill et al., *A Candidate for the Cystic Fibrosis Locus Isolated by Selection for Methylation-free Islands*, 326 NATURE 840 (1987).

[18] See Wayne W. Grody & Robert J. Desnick, *Cystic Fibrosis Population Carrier Screening: Here at Last—Are We Ready?*, 3 GENETICS MED. 87, 87-88 (2001).

gene.[19] Map-based approach works in single-gene disorders because the fully penetrant disease gene leads to a relatively straightforward inheritance pattern. But single-gene disorders account for less than two percent of the total burden of human disease.[20] If human genomics is to exert greater influence on human life, it must broaden its reach, especially when facing a managed care health system concerned with cost-effective plans for diagnosis and management of more common disorders.[21] Map-based gene discovery is of limited use in discovering genes associated with diseases that are clinically more common but genetically more complex, i.e., so-called multifactorial disorders, such as common cancers, diabetes, and coronary heart disease. The origins of multifactorial disorders involve the interplay between multiple genetic factors and between genetic factors and non-genetic environmental influences. Although multifactorial disorders are nonetheless known to aggregate in families, they are not inherited in a Mendelian fashion and thus increase the difficulty of family studies.[22] Most of the successful application of

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[19] "Penetrance" indicates the proportion of individuals with a specific genotype who will express that character in the phenotype. A disease gene is *completely penetrant* when a carrier's risk of having the disease is 100% or 1, given a normal life span. Penetrance in the population, within which the association of disease and gene is studied and established, is never below 0.5, since a greater prevalence of the disease-related gene in affected individuals than in unaffected individuals is necessary to establish that association. *See infra* note 27 and accompanying text. However, penetrance of the same gene may be below 0.5 in population other than originally studied.

[20] Single-gene disorders account for less than 2 percent of the total burden of human disease. *See* Patricia A. Baird, *Genetic Technologies and Achieving Health for Populations*, 30 INT'L J. HEALTH SERVICE 407 (1999).

[21] *Cf.* Walter J. Wadlington, *Symposium on Regulating Medical Innovation—Forward*, 82 VA. L. REV. 1403 (1996).

[22] *See* Jaakko Kaprio, *Science, Medicine, and the Future: Genetic Epidemiology*, 320 BRIT. MED. J.

map-based approach in discovering genes associated with multifactorial disorders (*susceptibility genes*) has focused on near-Mendelian subgroups, whose relatively high albeit incomplete penetrance leads to disease in a fairly large proportion of the gene(s) carriers.[23] Without such evident contributing influences, weakly penetrant susceptibility genes that contribute to common diseases are much less likely to be detected by genetic linkage studies, since a practically unachievable sample size would be needed to conduct a valid linkage analysis.[24] Unfortunately, penetrance of most susceptibility genes is incomplete and low.

Identification of weakly penetrant genetic factors in multifactorial disorders needs to rely on a more powerful approach. *Sequence-based* gene discovery allows scientists to compare among individuals sequence variations of even a single DNA letter[25] in the

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1257, 1257 (2000). *See supra* note 10 for an explanation of Mendelian inheritance.

[23] *See* Guttmacher & Collins, *supra* note 10, at 1518.

[24] When the increased chance of having the disease conferred by a susceptibility gene is only twofold or less (relative risk □ 2), a sample size of 2,500 to 4.6 million families is needed to conduct valid linkage studies, depending on the frequency of the susceptibility gene in a population. *See* Neil Risch & Kathleen Merikangas, *The Future of Genetic Studies of Complex Human Disorders*, 273 SCIENCE 1516, 1516 (1996). Based on the algorithm provided by Risch and Merikangas, *id*. at 1517 n.6, when the increased chance of having the disease conferred by a gene is tenfold (relative risk = 10), less than 130 families are needed, and when the increased chance of having a mendelian disease conferred by a completely penetrant gene is astronomical (relative risk = ≡), *see* Neil A. Holtzman, *Putting the Search for Genes in Perspective*, 31 INT'L J. HEALTH SERVICES 445, 449 (2001), the required sample size for a valid linkage analysis is less than 10 families.

[25] Single-nucleotide polymorphisms (SNPs) are single-base-pair variations in the human genome sequence. Since any two unrelated persons share 99.9% of their three billion DNA base pairs, *see* The Int'l SNP Map Working Group, *A Map of Human Genome Sequence Variation Containing 1.42 Million Single Nucleotide Polymorphisms*, 409 NATURE 928 (2001), there are three million (0.1% x 3 x 10^9) base pairs of

entire human genome, including both protein-coding and protein-non-coding regions,[26] and to look for association of these sequence variations with specific phenotypic variations. Such association studies do not involve the analysis of large family pedigrees but only need compare the prevalence of a particular genetic variation in affected and unaffected individuals.[27] For example, the APOE locus was known to be involved in late-onset Alzheimer's disease using both traditional linkage analysis and association analysis.[28] However, the complex relationship between the APOE e-4 mutation and disease status has long baffled scientists. Association studies found that a total of 80% of familial and 64% of sporadic late-onset AD cases have at least one copy of the APOE e-4 mutation at the APOE locus compared to 31% of unaffected control subjects.[29] This

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variations between any two individuals.

[26] *See* Collins, *supra* note 9, at 32; Collins et al., *supra* note 6, at 839. Scientists have noticed that the non-coding portion of the genome is under active natural selection, suggesting that it may contain the regulatory information controlling the expression of the protein-coding genes. *See* Collins et al., *supra* note 6, at 837. The assumption that disease causing mutations would only be found in protein-coding regions may need to be modified. *See* Matthew Meyerson, *Human Genetic Variation and Disease*, 362 LANCET 259, 259 (2003).

[27] A greater prevalence of a genetic variation in affected individuals is considered evidence of association between the disease phenotype and the genetic variation. *See* Francis S. Collins et al., *Variations on a Theme: Cataloging Human DNA Sequence Variation*, 278 SCIENCE 1580, 1580 (1997).

[28] *See* M. A. Pericak-Vance et al., Genetic Linkage Studies in Alzheimer's Disease Families, 102 EXPERIMENTAL NEUROLOGY 271 (1988); A. M. Saunders et al., *Association of Apolipoprotein E Allele Epsilon 4 with Late-onset Familial and Sporadic Alzheimer's Disease*, 43 NEUROLOGY 1467 (1993); E. H. Corder et al., *Gene Dose of Apolipoprotein E Type 4Allele and the Risk of Alzheimer's Disease in Late Onset Families*, 261 SCIENCE 921 (1993).

[29] Nineteen out of ninety-five affected subjects of familial AD cases and sixty-four out of a hundred and seventy-six sporadic AD cases have no APOE-4 allele. *See* Corder et al., *supra* note 28, at 923.

finding suggests that APOE e-4 with a penetrance of around 0.7[30] is neither necessary nor sufficient for late-onset Alzheimer disease.[31] In addition to the challenge put up by the task of searching other genetic sources of risk to account for the remaining 20% of familial and 36% of sporadic late-onset AD cases, the phenotypic variation among individuals with APOE e-4 mutation, i.e., the question why some people with APOE e-4 will develop the disease while some don't, draws much of researchers' attention. To elucidate these phenotypic variations, scientists looked into the subtle sequence differences among people with APOE e-4 mutation and learned that several single base differences at the APOE locus are strongly associated with Alzheimer's disease.[32] With this precisely-gauged information, scientists expect to unravel the secret of the etiology and pathogenesis of multifactorial Alzheimer's disease someday.

To date, the accompanying efforts of the Human Genome Project to dissect the genetic basis of human diseases have produced a fruitful finding of 2,264 disease-related genes,[33] which are associated with known clinical disorders of more than this number.[34]

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[30] In familial late-onset AD, the penetrance is around 0.72 (80% / (80% + 31%)); in sporadic late-onset AD, the penetrance is around 0.67 (64% / (64% + 31%)).

[31] Indeed, evidence shows that mutations in at least four genes can cause Alzheimer's disease. *See Online Mendelian Inheritance in Man, MIM Number: #104300* (Baltimore, MD: Johns Hopkins Univ.), http://www.ncbi.nlm.nih.gov/entrez/dispomim.cgi?id=104300 (last edited Aug. 4, 2003).

[32] *See* Eden R. Martin et al., *SNPing Away at Complex Diseases: Analysis of Single-nucleotide Polymorphisms Around APOE in Alzheimer Disease*, 67 AM. J. HUM. GENETICS 383 (2000).

[33] This number is updated daily. As of September 15, 2003, the number, computed by doing a LocusLink, http://www.ncbi.nlm.nih.gov/LocusLink/, search for "disease_known," and limiting the organism search to "human," is 2,264. The number represents genes with at least one identified disease-

But to think that the gaze of human genomics will reach only two thousand or so "genetic" conditions is not only ignorant of the rapid pace of scientific progress but also conceptually mistaken. Just like the distinction between single-gene and multifactorial disorders is quantitative rather than qualitative as embodied in the concept of *penetrance* of the genotype,[35] the strict distinction between what has a genetic component and what has not may fail to hold if it is also only a matter of the magnitude of influence. It is now a banality that essentially *all* human disease is the result of interactions between our genotypes and the environment broadly defined.[36] The ubiquitous involvement of genes is based on a rather intuitive presumption: if organisms are largely the consequences of the genes that they have inherited, any similarity and difference of organisms should be the consequences of similarities and differences in their genes, even though those differences in traits may develop via quite complex pathways that remain a black box for

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related mutation. Also, 1,542 of the 2,264 genes have been either fully or partially sequenced. LocusLink search for "disease_known AND has_seq" limited to human.

[34] The reason that the number of clinical disorders exceeds the number of associated genes is because different mutations in the same gene often result in more than one distinct disorder. By the end of 2000, the number of clinical genetic disorders, excluding those caused by translation-related fusion genes, was 1,430 when the number of disease-related genes is 1,112, *see* Peltonen & McKusick, *supra* note 10, at 1225, and was reported to exceed 1,600 in late 2001 when the number of disease-related genes exceeds 1,200, *see* Victor A. McKusick, *The Anatomy of the Human Genome: A Neo-vesalian Basis for Medicine in the 21st Century*, 286 JAMA 2289, 2293 (2001). No further report of the number of associated clinical disorders based on the new finding of disease-related genes is available currently.

[35] *See* Muin J. Khoury, *Relationship Between Medical Genetics and Public Health: Changing the Paradigm of Disease Prevention*, 71 AM. J. MED. GENETICS 289, 290 (1997).

[36] *See* Fred Gifford, *Genetic Traits*, 5 BIOLOGY & PHIL. 327, 329 (1990); Muin J. Khoury, *Genetic Epidemiology*, *in* MODERN EPIDEMIOLOGY 609, 610 (Kenneth J. Rothman & Sander Greenland eds., Philadelphia: Lippincott-Raven, 2nd ed. 1998).

scientists.[37] And yet, no gene acts in a vacuum environment but always against a backdrop with non-genetic and other genetic cofactors as necessary conditions, even though very often the universality of some cofactors in the relevant environment have made us knowingly relegate them to the causal background.[38] If this is true, to attach exclusively either a genetic or an environmental label to a phenotypic trait may seem capricious since both genetic and environmental components are always present.

This insight nevertheless does not stop human genomics from extending its reach. The ubiquitous involvement of genes alone is a prima facie reason to investigate not just those 2,264 identified but the entire 30,000 to 35,000 human genes or even the non-coding regions of human genome, as genetic variations derived from all human genes are thought to underlie a full panoply of our phenotypic variations, relevant to health or not.[39] It is to this vision of the human science that the enterprise of measuring man, dated back to the emergence of anthropometry and craniometry[40] and now equipped with the newly

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[37] *See* Lisa Gannett, *What's in a Cause?: The Pragmatic Dimensions of Genetic Explanations*, 14 BIOLOGY & PHIL. 349, 353 (1999).

[38] *See id*. at 350; Fred Gifford, *Gene Concepts and Genetic Concepts*, *in* THE CONCEPT OF THE GENE IN DEVELOPMENT AND EVOLUTION: HISTORICAL AND EPISTEMOLOGICAL PERSPECTIVES 40, 42 (Peter J. Beurton et al. eds., Cambridge, UK: Cambridge Univ. Press, 2000).

[39] Through the mechanism of alternative splicing, more than 100,000 proteins can be derived from our 30,000 to 35,000 genes. *See* International Human Genome Sequencing Consortium, *supra* note 2, at 898, 902. Also, it is likely that all 30,000 to 35,000 human genes are capable of causing some kind of disease if altered substantially. *See* Guttmacher & Collins, *supra* note 10, at 1514.

[40] In the nineteenth century, anthropologist Paul Broca measured large numbers of skulls of different human in the belief that mental qualities of individuals and races could be judged from the sizes of their skulls. *See* STEPHEN JAY GOULD, THE MISMEASURE OF MAN 105-41 (New York: Norton, rev. ed. 1996).

crafted tool of human genome sequencing, is gaining unprecedented analytic power and dauntlessly claiming jurisdiction over all aspects of the human organism.

1.3 Modernity's Subsidiary Project and the ELSI

Public attention was focused on the ethical, legal and social implications of human genomics and the HGE long before the official launch of the Human Genome Project.[41] Like any modernity's project of the mastery of nature, human genomics and the HGE kick off another new session of an ongoing process of the "colonization of nature."[42] Every time the boundary "between what is subject to human control and what is not" or "between what we are responsible for doing or deciding, individually or collectively, and what is given to us, as a background against which we act or decide, but which we are powerless to change" is moved because of a new achievement of the modernity project of mastery of nature, people are forced to take up the challenge of moral dislocation in which old settled moral convictions structured by the past boundary between choice and chance are undermined.[43]

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[41] Since the first day of the Human Genome Project, the ELSI program has been one of the project goals specifically listed in each of the Human Genome Project's five-year plans and one partaking 3-5% of the project's three billion budget. *See* THE FIRST FIVE-YEAR PLAN, *supra* note 2, at 20-21; *The Second Five Year Plan*, *supra* note 3, at 45-46; Francis Collins et al., *New Goals for the US Human Genome Project: 1998-2003*, 282 SCIENCE 682, 687-88 (1998).

[42] This term is first used in ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS & JUSTICE 82 (New York: Cambridge Univ. Press, 2000).

[43] *See, e.g., id.* at 83; RONALD M. DWORKIN, SOVEREIGN VIRTUE 443 (Cambridge, M.A.: Harvard Univ. Press, 2000).

We have witnessed how hydraulics and the construction of reservoirs transformed water usage based on natural rainfall into the problem of distributive justice among families, communities and varied industries, how the invention of smallpox vaccine made the eradication of the disease a public health responsibility, how the appearance of respirators brought about the thorny debate over death and dying, how caller ID once raised privacy issues, and how RU-486 blurs the line between contraception and abortion. This makes the restructuring of a moral system after each dislocation a subsidiary project to the modernist disenchantment of the world.

The most common case of restructuring a moral system comes from the solution suggested by traditional liberalism. The liberal program of restructuring a moral system used to ask the Subject to establish a more "rational" belief system that recognizes his/her capability to control the physical world, the Object. In addition to adding new means to the Subject's "tool kits," restructuring a moral system also redefines the baseline of possible human ends based on how new means can be used.

Before the years around 1900, no one seriously considered blood transfusion a means of medical treatment. Some physicians even thought the idea frivolous.[44] Now, the moral system of a society that prohibits blood transfusion based on an idiosyncratic belief and treats the bleeding resulting from a peptic ulcer as "the act of God" is implicitly

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[44] When the first blood transfusion experiments were conducted in the 1660s, William Harvey, the man who discovered the circulation of the blood, regarded it as frivolous. *See* Andrew Cunningham, *Blood*, *in* MEDICAL KNOWLEDGE: DOUBT AND CERTAINTY 60, 68 (Clive Seale & Stephen Pattison eds., Buckingham, UK: Open Univ. Press, 1994).

deemed irrational. Jehovah's Witness's refusal of blood transfusions is honored not because a moral system, which demonizes a rational means, is deemed equally "rational." The only reason for the coexistence of an archaic and an enlightened moral system in a modern society does not hinge so much on the question of the rationality of means as on the freedom not to choose one.[45] Individuals are, in general, not to be forced to choose a particular rational means to serve ends of others.

The liberal program of restructuring a moral system envisions a self-governing or an interest-seeking Subject providing its own ends and surrounded by rational means.[46] Since the ends are determined by Subjects, the liberal moral system holds a value-neutral attitude toward human ends and valorizes only the freedom of choice, that is, the choice of both the ends and the most rational means to those ends. In default of a substantive theory against which different ends pursued by individuals can be gauged, freedom of choice possesses no real normative content for assessing the value of means. It just celebrates the idea of the existence of more options of means and looks with suspicion at any tendency to restrict the use or even the development of them. As a result, normative analysis on the issues involving limiting the use of means is generally left with the task of carrying through the original modernity project by monitoring the instrumental rationality

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[45] "Even though we may consider [Jehovah's Witness's] beliefs unwise, foolish or ridiculous, in the absence of an overriding danger to society we may not permit [judicial] interference therewith…for the sole purpose of compelling her to accept medical treatment forbidden by her religious principles…." *In re* Brooks' Estate, 205 N.E.2d 435, 442 (Ill. 1965).

[46] Two views of Subject represent the assumption of deontological and utilitarian moral theory respectively.

of means—that is, its capability to safely and effectively control the external world. Beyond the concern of instrumental rationality lies liberalism’s promised land for individual freedom of choice. By and large, the liberalist way of managing moral dislocation constitutes the framework of conventional American bioethics in addressing the issues resulting from the introduction of biomedical technology.

Inheriting much of the tradition of mainstream American bioethics, the ELSI program surely can be seen as a liberalist task of restructuring a moral system subsidiary to the modernity project of mastery of nature. Such a task is aimed at rationalizing a moral system in ways that bring it into line with human capability of deploying human genomics and technologies of molecular biology.

It is against this backdrop that the language of freedom of choice becomes the shibboleth in the answer in the ELSI literature to any moral dislocation that human genomics has and will cause. In this context, the concerns of informational privacy (confidentiality), safeguards against discrimination, safety and effectiveness of technologies all become auxiliary devices that assist Subjects in getting used to the new moral milieu.

1.4 The Dominant Rhetoric of Choice

When human capability to crack the secret of human genomics was first presented to the public in the form of genetic testing, excitement about the dream of human perfection was always mixed with a worry that can trace its origin to the repulsion for state-sponsored mandatory eugenic programs. Decades after the first report regarding genetic testing that proposes the principle of voluntariness and the concomitant rule of informed consent,[47] it seems to be settled now that freedom of choice, autonomy, or decisional privacy in the language of constitutional law[48] should take the reins over not only the initiation of therapeutic-diagnostic and experimental procedures but also how one will use the information so generated in making one's other life plans. But what is even more significant is that the rhetoric of choice virtually sets the tone for the reckoning of the possible ethical and social implications of human genomics.

1.4.1 Freedom of Choice as the Panacea

All the main ELSI-era literatures on the topic, including the Institute of Medicine's Assessing Genetic Risks in 1994,[49] Final Report of the NIH-DOE Task Force on Genetic Testing in 1997,[50] and the recommendations of the Secretary's Advisory Committee on Genetic Testing (SACGT) in 2000,[51] claim freedom of choice as the overarching

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[47] *See* COMMITTEE FOR THE STUDY OF INBORN ERRORS OF METABOLISM, NATIONAL ACADEMY OF SCIENCES, GENETIC SCREENING: PROGRAMS, PRINCIPLES, AND RESEARCH 251 (Washington, D.C.: National Academy of Sciences, 1975).

[48] *See*, Anita L. Allen, *Genetic Privacy: Emerging Concepts and Values*, *in* GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 31, 35, 47-49 (Mark A. Rothstein ed., New Haven: Yale Univ. Press, 1997).

[49] COMMITTEE ON ASSESSING GENETIC RISKS, INSTITUTE OF MED., ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 21-22, 248, 259-64 (Lori B. Andrews et al. eds., Washington, D.C.: National Academy Press, 1994).

[50] TASK FORCE ON GENETIC TESTING, NATIONAL INST. OF HEALTH, PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES 12 (Neil A. Holtzman & Michael S. Watson eds., Baltimore, MD: Johns Hopkins Univ. Press, 1998) [hereinafter TASK FORCE FINAL REPORT].

[51] SECRETARY'S ADVISORY COMM. ON GENETIC TESTING, ENHANCING THE OVERSIGHT OF GENETIC

principle governing the issues of genetic testing.

Legal paradigms have also since the 1940s and 1950s witnessed a shift from reproductive responsibility of a public health model to reproductive autonomy of fundamental rights talk. American society now would allow only a few genetic tests to be state-sponsored and mandatory. Most of such tests occur in the setting of newborn screening, whose extent varies state by state. Virginia's current programs of mandatory newborn screening cover eight genetic disorders or conditions.[52] Other states have lists of several different genetic conditions.[53]

Twenty states provide exemptions for parents who object for religious or other reasons.[54] But more often than not, testing is de facto mandatory even though the exemption is statutorily provided. The justifying premise of the exception to the principle of voluntariness lies in the belief that early detection contributes to preventing imminent

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TESTS: RECOMMENDATIONS OF THE SACGT vii (Bethesda, MD: National Institutes of Health, 2000) [hereinafter SACGT RECOMMENDATION], *available at* http://www4.od.nih.gov/oba/sacgt/reports/oversight_report.pdf.

[52] They are phenylketonuria (PKU), congenital hypothyroidism, galactosemia, Maple Syrup Urine Disease, homocystinuria, biotinidase, sickle cell disease (SCD), congenital adrenal hyperplasia, and medium-chain acyl-CoA dehydrogenase. Among them, Congenital Hypothyroidism only has a proportion of cases with a genetic etiology. *See* National Newborn Screening & Genetics Resource Ctr., *U.S. National Screening Status Report*, http://genes-r-us.uthscsa.edu/resources/newborn/screenstatus.htm (last modified Aug. 15, 2003).

[53] The only two conditions that are screened for by all states and the District of Columbia are PKU and congenital hypothyroidism. *See id.*

[54] They are AL, CA, CT, GA, IL, IN, KY, LA, MA, NY, ND, OH, RI, SC, TX, UT, VA, WA, WI, and WY. *See* National Conference of State Legislatures, *Newborn Genetic and Metabolic Disease Screening*, http://www.ncsl.org/programs/health/screen.htm (last modified Jan. 2003).

and substantial harms to individuals.[55] The NIH-DOE Task Force on Genetic Testing further takes the stand that mandatory newborn screening can be justified only when the available therapeutic interventions have been proved to be safe and effective.[56] By confining the exception to voluntariness to a very limited area, it is generally believed that people hold control over the initiation of the production of genetic information.

In addition to the initiation of information flow, the rhetoric of choice also applies to varied other life plans one must face because of the existence of new information generated by genetic tests one took. Admittedly, more ethical and social considerations need to be addressed in the stage after genetic information of an individual has been produced. If one finds out he or she has been tested positive for a treatable condition, one may need to decide whether to undergo a particular treatment. The decision would be less troublesome, if the genotype identified has high penetrance, and the condition involved is life threatening. Difficult problems arise when the penetrance of the genotype is incomplete, or when the condition involved neither threatens life nor serious physical pain and suffering. Incomplete penetrance of the genotype forces life-planning choices to be made in uncertainty. Even high penetrance may bring in thorny questions about the concept of normal human species functioning and the boundary between disability and

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[55] *See* LORI B. ANDREWS, FUTURE PERFECT: CONFRONTING DECISIONS ABOUT GENETICS 26 (New York: Columbia Univ. Press, 2001). *But see id.* at 155-56 (questioning the wisdom of mandatory newborn screening).

[56] TASK FORCE FINAL REPORT, *supra* note 50, at 12.

difference.[57] When should we treat a condition as an impairment that needs to be medically fixed? When should we not?

The questions become equally complicated when it comes parallel to the issue of human reproduction either in the context of prenatal testing or in a couple's carrier testing for purposes of reproductive planning. The technology of preimplantation genetic diagnosis (PGD)[58] further poses the challenges of germinal choices.[59] Should we, as suggested by Watson, take advantage of the power of human genomics to "make better humans"?

Familiar risks associated with the use of genetic testing are identified and oftentimes advanced by many as the reasons to oppose the introduction of genetic testing, such as risks of psychological and emotional harm or survival guilt,[60] risks of losing informational privacy in a society where both the interest and the ability to collect and store personal genetic information is briskly increasing, risks of being adversely treated

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[57] *See, e.g.*, Tom Koch, *Disability and Difference: Balancing Social and Physical Constructions*, 27 J. Med. Ethics 370 (2001).

[58] PGD was first introduced at the beginning of the 1990s as an alternative to prenatal diagnosis, to prevent termination of pregnancy in couples with a high risk for offspring affected by a sex-linked genetic disease. For a brief introduction of the technology, see Karen Sermon et al., *Preimplantation Genetic Diagnosis*, 363 LANCET 1633 (2004).

[59] *See* STOCK, *supra* note 1, at 135, 137.

[60] *See, e.g.*, Barton Childs et al., *Tay-Sachs Screening: Social and Psychological Impact*, 28 AM. J. HUMAN GENETICS 550 (1976); Theresa M. Marteau et al., *Effects of Genetic Screening on Perceptions of Health: A Pilot Study*, 29 J. MED. GENETICS 24 (1992); Janet K. Williams & Debra L. Schutte, *Benefits and Burdens of Genetic Carrier Identification*, 19 W.J. NURSING RES. 71 (1997).

because of an undesirable genetic profile, risks of unsafe technologies, and risks of uncertainty inherent in many multifactorial conditions.

They are, however, under the scheme of conventional American bioethics trustingly regarded as external obstacles standing in the way to the smooth execution of one's freedom of choice: They affect Subject's interest and willingness to take up genetic testing, but they do not of its own force justify the deprivation of Subject's freedom to employ genetic testing as means to his or her own life plans, let alone the proscription of the making of this means; they need to be harnessed, but they do not need to be prohibiting. It is in that sense—to smoothen the process of voluntary decisionmaking—that the task of "regulating genetic testing" is now conceived and implemented.

1.4.2 A Complimentary Technical Solution

The current framework for oversight of genetic tests in the federal level is not specifically designed for the task. It gradually takes shape while the FDA's original reluctance succumbed to the pressure of public concerns about genetic testing.[61] The collaged framework now consists of the FDA's traditional purview over medical devices and the Centers for Medicare and Medicaid Services' regulation of non-research laboratory testing performed on humans through the Clinical Laboratory Improvement

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[61] *See* Anny Huang, *FDA Regulation of Genetic Testing: Institutional Reluctance and Public Guardianship*, 53 FOOD DRUG L.J. 555, 556 & 556 n.5 (1998).

Amendments of 1988 (CLIA).[62] As a result, genetic tests marketed as kits and those marketed as a service offered in a laboratory may receive different oversight. Much debate now centers on what role the FDA should play in making the current hodgepodge an integrated and consistent regulatory scheme.[63]

There are certainly reasons why the FDA feels so reluctant to assume the responsibility of regulating genetic tests in general. The political climate demanding more regulation to protect sufficiently the public health and meet the FDA's statutory obligation has given way in recent years to criticisms on excessive bureaucracy and oversight that prevents medical benefits from reaching the public with adequate speed.[64] Serious questions of legal jurisdiction also stand in the way to extending the FDA's power to regulate those intrastate genetic testing services provided by laboratories that do not apparently fall within the constitutional boundaries of federal power.[65]

But when it comes to the case in which the FDA is willing to assert jurisdiction over genetic testing so that genetic test kits and testing services are equally regulated,

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[62] Clinical Laboratory Improvement Amendment of 1988, Pub. L. 100-578, 102 Stat. 2903 (1988) (codified as amended at 42 U.S.C.A. §§ 201, 263(a) (2004)). *See also* 42 C.F.R. pt. 493 (2003). The agency in charge of CLIA was the Health Care Financing Administration before June 14, 2001.

[63] *See, e.g.*, Neil A. Holtzman, *FDA and the Regulation of Genetic Tests*, 41 JURIMETRICS J. 53 (2000); Richard A. Merrill, *Genetic Testing: A Role for FDA?*, 41 JURIMETRICS J. 63, 63-64 (2000).

[64] *See* Huang, *supra* note at 61, 570-71.

[65] *See* PETER BARTON HUTT & RICAHRD A. MERRILL, FOOD AND DRUG LAW 1066 (Westbury, NY: Foundation Press, 2nd ed. 1991). *See* also Huang, *supra note* 64, at 574-85 (for a discussion of the boundaries of FDA jurisdiction on regulating genetic testing).

ethical and social considerations identified by ELSI scholars are nonetheless left out of regulators' purview. The erasure of ethics and social considerations from proposed regulatory schemes can be attributed to several grounds.

First, the FDA is historically structured to focus on technical issues of safety and effectiveness rather than on the riddles of social or ethical implications.[66] As Professor Richard A. Merrill points out, the FDA's statutory mandate, which centers on evaluating product performance, a priori circumscribes its role in tackling difficult issues of autonomy, consent and privacy,[67] issues that most ELSI scholars believe to be the social and ethical implications of genetic testing that need to be attended to and properly regulated beforehand. Without expanding current statutory authority and boosting its resources, the FDA simply lacks expertise and capacity to provide a forum for serious ethical deliberations.

Second, the FDA's rigid adherence to reviewing only product performance in terms of safety and effectiveness has effects spilling over to matters that are not on its face ethical or social. For instance, the criteria of "clinical utility," recommended both by the NIH-DOE Task Force and the SACGT primarily to minimize the potential harms caused by the *therapeutic gap*,[68] is not transformed successfully into FDA's review guidance.

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[66] For another example of social and ethical concerns marginalized in FDA's regulatory scheme, see Emily Marden & Dorothy Nelkin, *Displaced Agendas: Current Regulatory Strategies for Germline Gene Therapy*, 45 MCGILL L.J. 461, 464 (2000).

[67] Merrill, *supra* note 63, at 63-64.

[68] TASK FORCE FINAL REPORT, *supra* note 50, at 28; SACGT RECOMMENDATION, *supra* note 51, at

The alleged rationale for this disparity is a long embraced position that the FDA is not empowered to regulate medical practice.[69] If the safety and effectiveness of a medical device has been established and confirmed by the FDA, it is a doctor's prerogative to assess and communicate with the patient about the utility of the medical device within the setting of the doctor-patient relationship. This is true when a genetic test is approved as a device for use only through the prescription of a doctor.[70]

Currently, none of the genetic test kits cleared for marketing is approved for over-the-counter use because the FDA determines that the safety and effectiveness of the genetic test cannot be assured except under the supervision of a practitioner licensed by law to direct the use of the test.[71] Some of the test kits need special training and experience for safe and effective specimen preparation. For example, PathVysion's HER-

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[69] *See, e.g.*, Linder v. United States, 268 U.S. 5,18 (1925) ("[D]irect control of medical practice in the States is beyond the power of the federal government."); Food and Drug Administration Modernization Act of 1997 § 214, 21 U.S.C. 396 (1997) ("Nothing in this chapter shall be construed to limit or interfere with the authority of a health care practitioner to prescribe or administer any legally marketed device to a patient for any condition or disease within a legitimate health care practitioner-patient relationship.").

[70] *See* Federal Food, Drug, and Cosmetic Act of 1938 § 520(e), 21 U.S.C. § 360j(e) (2004); 21 C.F.R. § 801.109 (2003). It is a manufacturer's responsibility to demonstrate to FDA that untrained users can perform the genetic test and get results if the manufacturer intends to sell the test kit over-the-counter.

[71] Britain currently has no mandatory regulation covering over-the-counter genetic test kits sold through shops and over the internet. An over-the-counter genetic test for cystic fibrosis was first introduced in the United Kingdom in 1997. *See* Mairi Levitt, *Let the Consumer Decide? The Regulation of Commercial Genetic Testing*, 27 J. MED. ETHICS 398, 399 (2001). *But see* News In Brief, *Shops Reject Company's Human Genetic Testing Kits*, 324 BRIT. MED. J. 1412 (2002) (reporting that thirteen major retailers in the UK decided not to sell an over-the-counter genetic test kit, which tests for polymorphisms in nine genes using cells collected from inside the mouth).

2 DNA Probe Kit requires the test to be done on formalin-fixed, paraffin-embedded human breast cancer tissue specimens.[72] Some others have procedures so complicated that the same reliable results cannot always be produced in the hands of laypersons as in the hands of skilled users. Whether information produced can be clearly communicated to lay users is equally of importance. Counseling needed for correct interpretation of complex information generated from genetic testing usually cannot be substituted with simple directions under which the layman can use the test kit safely and effectively as intended.[73]

However, if the FDA's only interest is whether safe and effective product performance, and not the ethical and social concerns, of a genetic test can be assured, it is not impossible that someday over-the-counter genetic test kits could become available to the public, for example, those testing for autosomal dominant single-gene diseases with highly penetrant disease-related genes and low genetic heterogeneity[74] and those

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[72] *See* U.S. FOOD & DRUG ADM', SUMMARY OF SAFETY AND EFFECTIVENESS DATA FOR PATHVYSION; HER-2 DNA PROBE KIT (2001), *available at* http://www.fda.gov/cdrh/pdf/P980024S001b.pdf.

[73] *See* SACGT RECOMMENDATION, *supra* note 51, at 16 ("The complexity of the interpretation of a test result is a critical determinant of risk…. The more complex the interpretation, the greater the possibility that the clinical utility may not be well-understood.").

[74] Genetic heterogeneity or allelic heterogeneity refers to the situation in which the same genetic disease may be associated with mutations of different alleles or with different mutations of the same *allele*. *See* Gannett, *supra* note 37, at 349. An *allele* is one of the variant forms of a gene at a particular locus, or location, on a chromosome. Single-gene disorders do not necessarily have only one disease-related *allele*. High genetic heterogeneity increases the difficulty of result interpretation and very often leads to reduced sensitivity of tests. For instance, currently available tests for cystic fibrosis screen for only 25 most common mutations and identify around 85 percent of carriers in the U.S. population. *See* Wayne W. Grody,

requiring only easy procedures such as collecting a cheek swab to perform the test.[75] In either scenario of prescription or over-the-counter devices, the nature of the FDA's concerns about genetic testing is technical rather than ethical or social.

Interestingly, an issue so hotly debated because of its ethical and social implications actually ends up with a pure technical solution. The remaining hassles seem to be merely about "who" should be in charge of the task.[76] It certainly is not fair to suggest that the FDA is to be blamed for marginalizing ethical and social issues. After all, if the underlying rationale is that, as a guardian of consumers, the FDA assists but not replaces individual consumers' decisions based on each consumer's values and preferences, what the FDA has to do, no more or less, is to ensure that the options available are safe and the information needed for decision-making is accurate and sufficient. Anything else would

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Cystic Fibrosis: Molecular Diagnosis, Population Screening, and Public Policy, 123 ARCHIVES PATHOLOGY & LABORATORY MED. 1041 (1999).

[75] Some believe that the success of home-use test kits in recent years suggests that the market would probably be receptive to over-the-counter genetic tests. *See, e.g.*, Huang, *supra* note 64, at 581 n.183 (citing Al Heller, *Do-it-yourself Health Care Boosts Sales in Home Diagnostics Category*, DRUG STORE NEWS, Oct. 6, 1997, at 21). But note that the concept of the over-the-counter device is still different from that of the home-use device. Some devices may be available for home use by prescription only. FDA currently only issues review guidance for home-use in vitro diagnostic devices. *See* OFFICE OF IN VITRO DIAGNOSTIC DEVICE EVALUATION & SAFETY, U.S. FOOD & DRUG ADM', ASSESSING THE SAFETY AND EFFECTIVENESS OF HOME-USE IN VITRO DIAGNOSTIC DEVICES (IVDS): DRAFT POINTS TO CONSIDER REGARDING LABELING AND PREMARKET SUBMISSIONS (1988), *available at* http://www.fda.gov/cdrh/ode/odecl272.html. But logically, over-the-counter devices must conform at least the safety and effectiveness requirements FDA set for home-use devices.

[76] Many ELSI research energies have been devoted to the issue of "who should decide" the validity and utility of any given genetic test. *See Technological Advances in Genetics Testing: Implications for the Future: Hearing Before the Subcomm. on Tech. of House Comm. on Science*, 104th Cong. 33-35 (1996) (statement of Mary Pendergast, Deputy Commissioner and Senior Advisor to the Commissioner, FDA).

be infringement upon consumers' freedom of choice.[77]

We then are given the promise that once the safety and effectiveness of genetic tests are assured, any great ethical challenge associated with genetic testing is to be resolved within the domain of individual moral deliberation and decision-making. A simple rhetoric of choice covers the entire consideration of the ethical landscape. All other mechanisms, such as confidentiality, data protection and anti-discrimination laws, are merely the side-effects controls that complement the panacea.

1.5 Discontent and Possible Alternative

But does the rhetoric of choice really address the complete listing of ethical and social implications of genetic testing and the powers it makes available? Could it not be the case that the limited solutions we have in hand determine and hence constrain how we identify the problems, and not the other way around?

Once the familiar problems of involuntary eugenics, encroachment of informational privacy, employment and insurance discrimination, safety, and false and inaccurate genetic information are taken care of, we are basically deprived of means, reason, or disposition to be hostile to the great success of man's mastery of nature. Yet, unarticulated disquiet and uneasiness still remain lurking behind our Promethean confidence. They come not only at the age of overt foolishness, or during the season of

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[77] Professor Merrill contends that "FDCA's product-focused requirements provide an odd-fitting framework for regulating what is basically an information service." Merrill, *supra* note 67, at 65.

total Darkness. They come even when it is the best of time, when Prometheus's fire can be freely, safely and justly used.

But what are the sources of this disquiet and uneasiness? Why should anyone be worried about modifying one's behavior or life style to prevent a susceptibility gene from developing into a disease? What could be wrong with efforts to spare our children the burden of having a genetic susceptibility to an undesirable condition? Or, to paraphrase James Watson's query, why shouldn't we make better humans if we've mastered the technique to do so? What exactly are the real ethical problems with human genomics and the HGE? How do we evaluate their value substantively?

It is not easy to answer those questions especially when we indeed lack vocabulary or conceptual apparatuses to formulate an alternative to the dominant moral system. Unsuccessful efforts have been made. We have sometimes heard people invoking the objections to "playing God." As suggested by the President's Council on Bioethics, the charge is meant to reprimand as much "usurping God-like powers" as "doing so in the absence of God-like knowledge." [78] While the latter concern can somehow be incorporated into the analysis of the instrumental rationality of means, playing God, especially in the first sense, is thought wrong in itself independent of the moral system that American bioethics used to evaluate genomic technologies.

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[78] LEON R. KASS ET AL., THE PRESIDENT'S COUNCIL ON BIOETHICS, BEYOND THERAPY: BIOTECHNOLOGY AND THE PURSUIT OF HAPPINESS 287 (Washington, D.C.: Pre-Publication Version, 2003) [hereinafter BEYOND THERAPY].

It fails, however, to recognize that since the first day of modernity's project for the mastery of nature, human beings have literally been "playing God" and trying to alter the natural conditions in a way most beneficial to us.[79] We invent penicillin and use it to avert natural catastrophes. We eradicate smallpox. We wear eyeglasses. We save premature birth. If God's given is very often "red in tooth and claw,"[80] why shouldn't human beings change it? In an era when people in general do not seek to found their moral convictions on God's instruction, the fact that an argument against playing God could receive much currency now merely attests to the widespread sentiment of disquiet and uneasiness. It offers no substantive reason that is attractive enough in a modern secular society.[81]

There are also some secular variations of the playing God argument. The assertion of "a human right to unaltered genetic constitution," "the sanctity of human genome" figures eminently in European countries,[82] as well as the lament of the "eventual

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[79] *See, e.g.*, STOCK, *supra* note 1, at 131; DWORKIN, *supra* note 43, at 443.

[80] This is Alfred Tennyson's memorable phrase: "Who trusted God was love indeed. And love Creation's final law—Tho' Nature, red in tooth and claw. With ravine, shriek'd against his creed." ALFRED TENNYSON, IN MEMORIAM: AUTHORITATIVE TEXT: CRITICISM 41 (Erik Gray ed., New York: W.W. Norton, 2nd ed. 2004).

[81] *See, e.g.*, Peter G. Woolcock, *The Case Against Evolutionary Ethics Today*, *in* BIOLOGY AND THE FOUNDATION OF ETHICS 276, 277 (Jane Maienschein & Michael Ruse eds., Cambridge, UK: Cambridge Univ. Press, 1999).

[82] *See, e.g.*, Convention on Human Rights and Biomedicine, April 4, 1997, Council of Europe ("An intervention seeking to modify the human genome may only be undertaken for preventive, diagnostic or therapeutic purposes and only if its aim is not to introduce any modification in the genome of any descendants.").

disappearance of the human."[83] They share a common fatal flaw with the playing God argument if they mean only that what is given to an *individual* is what should be kept intact. Professor John Fletcher ridiculed the idea of halting an effective treatment because of a patient's right to an untampered genetic patrimony to be plain wrong.[84] The current constitution of the human genome, after all, is a contingent historical product of past evolution and is constantly subject to change in the ongoing process.[85] It seems extremely arbitrary to have any random snapshot of a continuous changing state to be the model of eternal. If the laws of nature do not keep human from evolving, the advent of posthuman is doomed to realize even without human hubris. It is not a question of whether, but a question of when and how.

Apart from a pure biological view, both assertions of "a right to unaltered genetic constitution" and "the sanctity of the human genome" may also be viewed as some metaphysical notion of a *common* "human nature" in disguise. After man no longer sought God's instruction for guidance as to what human values should be, foundationalist moral philosophers have hoped to ground our moral intuitions on some premises which

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[83] *See* Gregg Easterbrook, *Will Homo Sapiens Become Obsolete?: Medical Evolution*, NEW REPUBLIC, Mar. 1, 1999, at 20 (human cloning).

[84] STOCK, *supra* note 1, at 132 (quoting a comment of John Fletcher: "Suppose we really knew how to treat cystic fibrosis…and didn't do it because of the belief that people had a right to an untampered genetic patrimony…. It doesn't take a highfalutin ethicist to realize that's just plain wrong. You violate one of the basic principles of morality…."

[85] *See* David L. Hull, *A Matter of Individuality*, 45 PHIL. SCI. 335, 358 (1978); David L. Hull, *On Human Nature*, *in* THE PHILOSOPHY OF BIOLOGY 383, 385-89 (David L. Hull & Michael Ruse eds., New York: Oxford Univ. Press, 1998).

are capable of being known to be true independent of the truth of our moral intuitions. They find a universal “human nature” to be such a premise.[86] Differences among moral theories often can be understood in terms of their different approaches to comprehend what is “human nature.”[87] Unlike the assertion of a right to unaltered *individual* genetic constitution, the notion of a preexisting *common* “human nature” seems to avoid the difficulty Professor Fletcher pointed out, even though life science has made that metaphysical notion of a common “human nature” increasingly questionable.

Such a notion of human nature is problematic, however, less because the modern empirical approach has rendered it a pseudoscientific construct than because its preexisting character has deprived us of the ability to discern any identity-forming force. A moral system presuming the notion of a preexisting human nature is only able to identify external repressive forces as the potential danger to the completeness of Subject and leaves out the possibility that Subject is indeed constantly and positively constituted by various non-repressive forces. Given its belief of the inviolability of the preexisting nature of Subject, the liberalist agenda would consider the most serious crisis of modernity to be the paradox that what the modernist project aims to control and manipulate is human nature itself. This presumption of a preexisting human nature also prompts the President’s Council on Bioethics to make a distinction between a doctor standing as nature’s servant to restore a preexisting “natural human whole” and a

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[86] *See* BUCHANAN ET AL., *supra* note 42, at 89.

[87] *See* FRANCIS FUKUYAMA, OUR POSTHUMAN FUTURE 112-24 (New York: Farrar, Straus & Giroux, 2002).

bioengineer using genomic technologies for purposes beyond therapy, and to regard the latter as more problematic because only the latter poses the danger of wrecking that "natural human whole."[88]

Different from the problems identified by mainstream discourse, I assert that the consequence of failing to discern the identity forming forces of human genomics is that the ethical and social implications of human genomics cannot be fully appreciated and that the disquiet and uneasiness regarding human genomics can never be articulated and put to rest. Voluntariness, autonomy and privacy surely are ethical issues occasioned by human genomics that need to concern us. But they are the subjects of micro-ethics. Despite its wide appeal in a pluralistic society, micro-ethics is very often confined by the notion of a preexisting human nature in exchange for a neat solution of neutrality toward substantive values. Its neatness nevertheless is purchased at the price of ignoring the identity formation effects of means on Subjects and forgoing the moral evaluation of such effects.

Without seeking to metaethically ground morality on our knowledge about a preexisting nature of human beings, macro-ethics, instead, asks the pragmatical questions of whether the effects of human activities can achieve solidarity and social cooperation more readily in a liberal democracy and whether human suffering can hence be reduced in a more tolerant society. The call to address the substantive values embraced in macro-

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[88] *See* BEYOND THERAPY, *supra* note 78, at 6, 7, 17, 287.

ethics does not deny the existence of a pluralistic society, in which people often hold different moral convictions toward things. If a pluralistic society is to sustain itself, however, defending the minimum substantive values of macro-ethics as the very basis of a liberal democracy becomes imperative. Such an understanding sets apart the inquiries of micro-ethics and concerns of macro-ethics. Only on the scale of macro-ethics could the value of a means with its identity forming force be adequately weighed. A technology or knowledge can be perfectly innocent from the perspective of micro-ethics even as it does great damage to solidarity and social cooperation.

With that knowledge in mind, I will argue in this dissertation that the most serious danger of human genomics lies not in the familiar risks that have been identified by current ELSI researches, nor on our possible eventual disappearance. Rather, what is at stake is the ability of human genomics and the HGE, accompanied by a culture of self-control constituted by current reproductive rights discourse, to form a fixed and callous selfhood that is less willing to extend its boundary to encompass “others” into the “we” category.

Human genomics and the HGE does render the material *body* more and more malleable. But genetic *malleability* does not make the notion of a flexible *selfhood* more agreeable to people. And people are even much less willing to imagine a better society as a possible alternative to the current social scheme. In all likelihood, the body image provided by human genomics almost monopolizes the source of human understanding of human beings. Such a “fixed and callous selfhood” would make the true human solidarity and social cooperation extremely difficult and damage the very foundation of a liberal democracy. This is the exact concern that forms the basis of a response to Watson's original query "If we could make better humans, why shouldn't we?"—the question now is not so much why we should not make better humans if we could, but what "better humans" really means.

We surely have the chance to make physically stronger, cosmetically prettier, mentally brighter and intellectually wiser humans with a fixed and callous selfhood. And yet we are equally given a chance to make ordinary humans whose sensitivity and responsiveness to the needs of a larger and larger variety of people and things make the imagination of a more tolerant and better society possible.

In view of the growing popularity of the empirical instrumentalist approach of law that holds a simple "interest-seeking" assumption about human nature and asks only which social policy is the most efficient and effective way to serve this end without touching any harder moral questions,[89] it is understandable if such macro-ethics talk would at the first glance be less appealing to the legal academy than a traditional micro-ethics talk that embraces the principle of value neutrality toward the ends and gives its full attention to developing more rational means. Identity forming forces of human

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[89] The most famous champion of such instrumentalist approach is Chief Judge Richard Posner. *See, e.g.*, Richard A. Posner, *The Problematics of Moral and Legal Theory*, 111 HARV. L. REV. 1637 (1998). *But cf.* Ronald Dworkin, *Darwin's New Bulldog*, 111 HARV. L. REV. 1718 (1998) (criticizing Posner's instrumentalist approach). Posner agrees that the instrumentalist approach works well only where there is at least "moderate agreement on ends." Richard A. Posner, *What Has Pragmatism to Offer Law?*, 63 S. CAL. L. REV. 1653, 1668 (1990). Posner's "moderate agreement on ends" is arguably his "interest-seeking" assumption about human behavior. *See* Steven D. Smith, *Expressivist Jurisprudence and the Depletion of Meaning*, 60 MD. L. REV. 506, 525-27 (2001).

genomics and genomic technologies are seemly less tangible than what the "harm principle" usually would take into account.

Logics and frameworks of the current regulatory scheme are also at odds with the idea of assessing identity formation effects of genomic technologies (since they are merely the product of the conventional wisdom). The only candidate that seems plausible to have an interest in addressing the identity formation effects of human genomics is anti-discrimination law. Its usefulness, however, is limited. This is not only because the operation of anti-discrimination law always needs to negotiate with and sometimes is contained by the logic of the market economy, but also because anti-discrimination law fails to address the fount of identity formation effects directly.

To accomplish this end and to engage in a deeper and sounder moral evaluation of human genomics portrayed by macro-ethics, we need to devise a new regulatory scheme. In sum, we should not passively wait until human genomics has developed new classifying categories and take those categories as a given to work on our own identity formation. We should, instead, call into question the direction of its gaze at the very beginning. On the one hand, we should understand that the concepts of illness and disease can never be settled by a pure biomedical model. On the other hand, there is also a moral dimension to the questions of etiology of any given medical condition. Genetics is only one of the many pragmatic handles available for tackling diseases. Choosing which handle to manipulate is not merely a question of empirical science, although obviously it is relevant. Rather, it involves the issue of allocating social resources. We should be able to debate our willingness to extend our selfhood as early as at this stage. This is a domain of moral thinking, questioning our sense of solidarity. In other words, in addition to requiring that people be granted the freedom to choose which genetic test to take, macro-ethics requires that we contest whether social resources should be spent on searching for genes associated with *X* and whether we can overcome *X* by simply extending our selfhood. Engaging in such a moral deliberation not only breaks the monopoly of human genomics in our identity formation but also provides us more vocabulary to imagine and describe an alternative view of *better humans*.

1.6 The Organization of this Study

The dissertation moves through two phases: Part I focuses mainly on devising an approach to provide a better *description* that takes into account the identity formative effects of human genomics and the HGE on the ethical and social landscape. Part II covers both a critique of the current solutions that are used to address the ethical and social impacts of human genomics and the HGE as well as a *normative* proposal that aims to induce a public deliberation of bioethics that best responds to the descriptive impacts identified.

By tracing the paradigm shift of eugenic jurisprudence from the public health model of reproductive responsibility to the fundamental rights talk of reproductive autonomy, Chapter 2, as the opening of Part I, engages in a critical examination of the binary of rights discourse and freedom of choice, which is thought to be the settled principle in deciphering and handling the ethical, legal, and social implications of human genomics. Instead of understanding the legal paradigm shift simply as another achievement of emancipatory politics, I suggest in Chapter 2 that the emergence of reproductive autonomy should be viewed as a new form of governmentality in the post-eugenics era.

Following the lead of Chapter 2, Chapter 3 aims to develop an alternative account of the implications of the rights paradigm and specify how the rights discourse of negative liberty positively constitutes self-identity. Rejecting the traditional concept of liberal neutrality, which on the one hand demands state neutrality and discredits the undertaking of any formative project and on the other hand denounces and renounces the interplay between law and self-identity, I argue for a more realistic stance that recognizes the inevitable constitutive effects of legal discourses on identity. Such a descriptive investigation illuminates the function of negative liberty rights in building and securing the conduit of identity formation, through which the formative projects undertaken by the state to mold its citizens and steer their lifestyle are implemented, and through which the *mirror images* of self-identity provided by symbolic Other are delivered.

Chapter 4 proceeds to explicate how the development of human genomics exerts its formative influence on self-identity. After investigating the relationship between discourses about the body and identity, I suggest that, by means of the risk management paradigm and the individualized approach of genomic medicine, the formative influences of human genomics penetrate virtually all aspects of human life. Such influences have made the body image envisaged by human genomics an imperative and domineering source of identity formation.

Chapter 5 sets off the second part of the dissertation by outlining the dominant thinking and strategies as to how to mitigate the adverse consequences that human genomics would have for the ethical and social landscape. The survey of current or proposed regulatory schemes identifies three approaches embodied: (1) regulating genetic information flows, (2) banning decisionmaking based on genetic information, and (3) combating prejudice as a matter of increasing rationality, making apparent the commonly-perceived adverse consequences of human genomics. The familiar fear is that genetic information will be used in ways that could harm people—for example, to deny them access to health insurance, employment, education, and even loans. Such a fear is very often translated into the worry about inequality as the unjust distribution of goods and services.

However, as will be demonstrated in Chapter 6, such a grasp of the harms that human genomics would pose on the ethical and social landscape does not adequately reflect the concern of inequality as exclusionary politics. Indeed, comprehending the harms of human genomics as implicating merely the issue of distributive justice often ends up in false assurance that disarms the charge of inequality entirely. Yet, the emerging nature of exclusionary politics engendered by human genomics proves to be difficult to tame in any case under the current equal protection jurisprudence.

Chapter 7 takes on the incapacity of equal protection approach and formulates an alternative strategy to tackle the problem at its inception. To achieve this goal, it takes more than conceding that the moral value of the formative influence of scientific knowledge—both its production and its application—should concern a society as a whole. It also requires that we come up with an evaluating standard both sympathetic to the apprehension of exclusionary politics and compatible with the idea of liberal pluralism. Unlike the familiar approach that depends on the concept of “what it means to be a human being” as the bulwark against the development of human genomics, I suggest that replacing the concept of “human nature” with the open-ended imagination of “what sort of people we want to become” better equips ourselves to confront the real harm posed by human genomics, that is, its potential to form inflexible identities and its threats to social solidarity. I identify privacy right, after rehabilitating its capacity to protect a “freer” interior domain, as the best legal doctrine that shores up the proposed science regulatory scheme.

PART I RIGHTS, LIFE SCIENCE, AND IDENTITY FORMATION

> *Every epoch in the history of human evolution, by which Man transforms nature by technology, is also a period in which the nature of Man is transformed. Each period then gives rise to a (physical) ideal of Man, a special characterology which is also and simultaneously a new body.*
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> ~ Bryan S. Turner[†]

[†] Bryan S. Turner, *Recent Developments in the Theory of the Body, in* THE BODY: SOCIAL PROCESS AND CULTURAL THEORY 1, 9 (Mike Featherstone et al. eds., London: Sage Publications, 1991).

2/ EMANCIPATORY POLITICS AND REPRODUCTIVE RIGHTS

There are historical reasons why the analysis of the ethical and social impact of human genomics is always tethered to the country's eugenics past. Eugenics was once the large-scale experiment of human genetics when the science was still in its infancy. Links between the early development of human genetics and the enterprise of controlling and improving population quality through a governmentally mandated reproductive scheme are now well recognized and explored. Through the 1960s, most of the leading figures in medical genetics bluntly proclaimed their work as a form of eugenics. During the first ten years of the American Society of Human Genetics (ASHG) founded in 1948, eight of its presidents were also members of the Board of the American Eugenics Society.[1]

The public excitement about the promising new scientific discipline of human genetics in the early decades of the twentieth century proved to be one of the propelling forces behind the eugenics movement. Against this backdrop, three categories of population were identified as the popular subjects of the study of human genetics and the urgent targets of the eugenics movement in the first three decades of the twentieth century: the feebleminded, the criminal, and the "non-white" race. The eugenics movement eventually led to the upsurge of state eugenics legislation aiming to regulate human reproduction of these three populations with the familiar measures of eugenic segregation, coercive sterilization, and marriage control. Between 1900 and 1970, ninety-

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[1] *See* DIANE B. PAUL, *Eugenic Origins of Medical Genetics*, *in* THE POLITICS OF HEREDITY: ESSAYS ON EUGENICS, BIOMEDICINE, AND THE NATURE-NURTURE DEBATE 133, 138 (Albany: State Univ. of New York Press, 1998).

two statutes drafted under the eugenics rationale were enacted in state legislatures.[2]

In addition to the historical factors that linked old eugenics and the predecessor of new human genomics, there is another reason to engage in a eugenics talk. The rise and the demise of the eugenics movement itself provide ample clues for tracing the development of body politics in the post-eugenics era. As will be gradually made clear, comprehending the form of governmentality in this post-eugenics era through the analysis of the eugenics legal paradigm shift from a public health law model to a rights model is crucial to our task of understanding the ethical and social implications of human genomics. To produce a fuller understanding of the presently constituted rights model, the analysis of eugenic jurisprudence and the legal paradigm shift it entailed will not be undertaken in an ahistorical Whiggish manner. It will instead be approached so that process of discursive formation can be traced. Thus, a new form of governmentality that necessarily incorporates reproductive rights as well as the language of choice will surface. Reproductive rights as a form of governmentality becomes the apparatus through which the new human genomics operates on individuals and the population as a whole.

In what follows, I will first detail eugenic jurisprudence and explicate the legal paradigm shift it entailed. Second, I will show that to understand this paradigm shift simply as another achievement of emancipatory politics will miss the implication of reproductive autonomy as a new form of governmentality. The concept of and the

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[2] *See* MARK H. HALLER, EUGENICS: HEREDITARIAN ATTITUDES IN AMERICAN THOUGHT 142 (New Brunswick, NJ: Rutgers Univ. Press, 1963).

distinction between negative and positive liberty under emancipatory politics prove to be unsuitable for grasping the meaning of reproductive rights in the post-eugenics era. The problem of emancipatory politics' rights talk lies in its entire indifference to or the extreme voluntarism toward the relation between one's freedom of choice and one's self-identity. Unless a more realistic account of the effect of rights discourse on identity formation can be obtained, the form of governmentality in the post-eugenics era would not be properly comprehended and the ethical and social implication of the new human genomics would therefore not be adequately assessed.

2.1 Eugenic Jurisprudence and the Legal Paradigm Shift

Notwithstanding the rapid increase in number during the eugenics era, eugenic laws were only challenged thrice in the Supreme Court. Each of the three cases dealt with reproductive controls on one of the three targeted populations: *Buck v. Bell* endorsed coercive sterilization of the feebleminded in 1927,[3] *Skinner v. Oklahoma* tackled coercive sterilization of habitual criminals in 1942,[4] and finally *Loving v. Virginia* struck down the prohibitions on interracial marriage between white and non-white in 1967.[5]

During the forty years between *Buck* and *Loving*, eugenic jurisprudence witnessed a paradigm shift from the public health model of reproductive responsibility to the

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[3] 274 U.S. 200 (1927).

[4] 316 U.S. 535 (1942).

[5] 388 U.S. 1 (1967).

fundamental rights talk of reproductive autonomy.[6] As January 2003 marked the thirtieth anniversary of *Roe v. Wade*,[7] reproductive liberty has seemed to be the canonical legal rhetoric in the realm of human reproduction. As noted in Chapter 1, this makes the language of Justice Holmes in *Buck* look not only obsolete but also a bit impertinent. But, this paradigm shift is more a change of ethos than a clear overruling of specific precedent. Indeed, as argued by Professor Paul Lombardo, the three eugenics cases today still provide points of reference whenever reproductive issues reach the courts.[8] Thus, the appearance of this legal paradigm shift may look somewhat different from two more familiar examples: the New Deal Court's abandonment of the laissez-faire jurisprudence of the *Lochner*[9] era by overruling a progeny[10] of *Lochner* in *West Coast Hotel Co. v. Parrish*,[11] and the rejection of *Plessy v. Ferguson*'s separate-but-equal principle[12] by

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[6] *See*, *e.g.*, DIANE B. PAUL, CONTROLLING HUMAN HEREDITY: 1865 TO THE PRESENT at 129 (Atlantic Highlands, NJ: Humanities Press International, 1995).

[7] 410 U.S. 113 (1973).

[8] *See* Paul A. Lombardo, *Medicine, Eugenics, and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL'Y 1, 23 (1996) [hereinafter Lombardo, *From Coercive Sterilization to Reproductive Freedom*].

[9] Lochner v. New York, 198 U.S. 45 (1905) (finding unconstitutional a state maximum work hour regulation as an infringement of the economic autonomy of employers).

[10] Adkins v. Children's Hosp. of District of Columbia, 261 U.S. 525 (1923) (striking down a law prescribing minimum wages for women).

[11] 300 U.S. 379 (1937) (upholding a state law authorizing the fixing of minimum wages for women). For a more detailed discussion of this paradigm shift, see 2 BRUCE ACKERMAN, WE THE PEOPLE: TRANSFORMATIONS 279-311 (Cambridge, MA: Harvard Univ. Press, 1998).

[12] 163 U.S. 537 (1896).

Brown v. Board of Education.[13] The ambiguous status of the eugenic cases, especially *Buck*, makes it a little bit more difficult to decipher the true implication of the eugenics paradigm shift.

2.1.1 *Buck v. Bell*: The Launch of State Imposed Reproductive Controls

Buck was about the constitutionality of the coercive sterilization of the institutionalized mentally retarded, a measure of reproductive control springing up in the early twentieth century. Reproductive control was a relatively new concept to the business of regulating the population of the mentally disordered. It represented the most contemporary thinking and technique of the governance of the deviant, a still evolving enterprise of governmentality dated almost three hundred years back before the term eugenics was coined in 1883 by Sir Francis Galton—a time when regulation of human reproduction had yet to be enlisted as the technique of governance.

Confinement of mentally disordered persons began in the mid-seventeenth-century Europe when the condition and the quality of population emerged as the theme of modern states. Along with the mentally disordered, including both the insane and the feebleminded, various other deviant populations—such as, the unemployed, the poor, the idle, and the criminal—deemed threats to social order and morality, however, were also

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[13] 347 U.S. 483 (1954). However, the court opinion of *Brown* did not overrule *Plessy* directly. It merely rejected *Plessy* as applied to public education. It was not until 1970 that the first clear statement in the Supreme Court to the effect of *Plessy*'s being overruled appear in *Oregon v. Mitchell*, 400 U.S. 112, 133 (1970) (Black, J., dictum). *See also* JACK M. BALKIN, WHAT *BROWN V. BOARD OF EDUCATION* SHOULD HAVE SAID 48 (New York: New York Univ. Press, 2001).

committed undifferentiatedly in the same institutions. The purpose of such confinement was to protect the public from the menace of the "socially useless" and to instill into the inmates the virtuous conduct and the work ethic of a burgeoning industrial society through forced labor in houses of confinement, a kind of establishment functioning between a workhouse and a prison.

The system of undifferentiated and passive confinement faced vehement criticism as the idea of positively administering the deviant, an advanced form of governance often couched in the languages of humanitarianism and scientism, initiated the classification of the previously undifferentiated populations in the late eighteenth century. The sick were to be separated from the criminal,[14] and the idiots be distinguished from the insane.[15] With the asserted purpose of training and rehabilitation, the first residential facility exclusively for persons with mental retardation, Abendberg, was founded in Berne, Switzerland in 1841.[16] Seven years later, Harvey Backus Wilbur's Institute for the Education of Idiots, Imbeciles and Children of Retarded Mental Development of Mind was privately established across the Atlantic in Massachusetts. With fifteen pupils, Wilbur's experiment was a success after only three years.[17] He had proved that idiots

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[14] *See* MICHEL FOUCAULT, MADNESS AND CIVILIZATION: A HISTORY OF INSANITY IN THE AGE OF REASON 221-40 (Richard Howard trans., Vintage Books, 1988) (1965).

[15] *See* NICOLE HAHN RAFTER, CREATING BORN CRIMINALS 23-24 (Chicago: Univ. of Illinois Press, 1997).

[16] *See* R. C. SCHEERENBERGER, A HISTORY OF MENTAL RETARDATION 71-73 (Baltimore: Paul H. Brookes, 1983).

[17] *See* RAFTER, *supra* note 15, at 17-18.

could be taught and trained for self-sufficiency. In the same year when Wilbur started his private institute, Samuel Gridley Howe, the head of Boston's Perkins Institution for the Blind, also returned from a visit to Berne's Abendberg to lobby the Massachusetts legislature for funds to establish public asylums for retarded children.[18] By 1850, reformers in Massachusetts, New York and Pennsylvania were showing great interest in teaching the retarded. The first experimental public asylum of such a kind in the United State finally came out at the New-York State Asylum for Idiots in Albany in 1851, whose success later convinced the state legislature to move beyond the experimental stage and to establish permanently the New York's Syracuse Asylum for Idiots in 1853.[19]

However, the curative philosophy of training and rehabilitating the mentally retarded proved only to be short lived before the custodial principles of the degenerationist creed took over again by the century's end. Twenty-five years after the establishment of Syracuse Asylum, New York had established a second institution, the Newark Custodial Asylum for Feeble-minded Women, on a completely different rationale: not to rehabilitate but to segregate. The Newark Custodial Asylum singled out a category of the mentally retarded population—feebleminded women of childbearing age—and redefined varied social problems in terms of the bad heredity of the

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[18] *See* MARTHA A. FIELD & VALERIE A. SANCHEZ, EQUAL TREATMENT FOR PEOPLE WITH MENTAL RETARDATION: HAVING AND RAISING CHILDREN 66 (Cambridge, MA: Harvard Univ. Press, 1999).

[19] *See* RAFTER, *supra* note 15, at 19-23.

feebleminded.[20] Such new practices were built on two assumptions, which together constituted the turn-of-the-century thinking of degeneracy, holding that the tendency to devolve to a lower, simpler, less civilized state could be brought on by varied forms of immorality originated from feeblemindedness, and that, if left uncontrolled, the bad heredity of feeblemindedness could damage the "germ plasm" of the future generations.[21]

The thinking of degeneracy encouraged social reformers to pivot on the problem of feeblemindedness and to conceive of varied other social problems—such as pauperism, unemployment, intemperance, prostitution, crime, alcoholism, and drug addiction—as interrelated and interchangeable, mere symptoms of the same underlying degeneracy caused by feeblemindedness.[22] But what discursive connections among the feebleminded and other deviant groups brought about was not a return to undifferentiated confinement of the seventeenth century. Rather, the degeneracy of feeblemindedness had provided a ready analogy to think of the degeneracy of other social, moral, physical, and mental qualities. It is such a linking of disparate categories that provoked the collective anxiety about racial deterioration and the loss of national efficiency and ultimately led to a series

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[20] *See id.* at 35-50.

[21] The concept of degeneracy pervaded social policy discourse in the late nineteenth and early twentieth century and helped pave the way for eugenics movement. Conceived as an invisible attribute of the "germ plasm"—the archaic concept of the material of heredity, degeneracy is a kind of dark mirror image of evolutionism, a hereditary tendency to devolve to a lower, simpler, less civilized state. *See* RAFTER, *supra* note 15, at 37; Nicole Hahn Rafter, *Seeing and Believing: Images of Heredity in Biological Theories of Crime*, 67 BROOK. L. REV. 71, 79-86 (2001).

[22] *See* DAVID GARLAND, PUNISHMENT AND WELFARE: A HISTORY OF PENAL STRATEGIES 177 (Brookfield, VT: Gower, 1985).

of social and criminological policies centering on reproductive controls of feebleminded women. It was widely held that the only way to cure all these social problems is not to follow a flowery idea of rehabilitating and returning the feebleminded to the community but to prevent them from breeding by locking them up within the sexually segregated institutions during their childbearing years. Coercive sterilization of the mentally retarded was but another step down the same trend of controlling the reproduction of this population.

Buck was decided in a time when degeneracy theory and the eugenics movement were at their apex. But it certainly did not come out of a painless process. Before Virginia, like a majority of states then, enacted the Eugenical Sterilization Act in 1924, the law challenged in *Buck*, similar legislation allowing eugenic sterilization of prisoners had just been rejected in Virginia's state legislature in 1910.[23] And before *Buck*, coercive eugenic sterilization laws that provided no specific procedural safeguards and that were applied only to institutionalized feebleminded patients had been struck down as unconstitutional in several state courts on grounds of procedural due process[24] and equal protection.[25] The

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[23] *See* Paul A. Lombardo, *Involuntary Sterilization in Virginia: From Buck v. Bell to Poe v. Lynchburg*, DEV. MENTAL HEALTH L., July-Sept. 1983, at 13, 14.

[24] *See, e.g.*, Davis v. Berry, 216 F. 413, 418-19 (S.D. Iowa 1914) (holding a statute, providing for the performance of the operation of vasectomy on, among other categories of population, criminals who have been twice convicted of a felony on an administrative order after a private hearing, unconstitutional as a deprivation of due process of law, as a bill of attainder inflicting punishment without a jury trial, and as cruel and unusual punishment), *rev'd* on other ground, 242 U.S. 468 (1917) (Holmes, J.) (reversing the decree of the district court on ground that the repeal of the law by the state legislature during the case was on appeal had rendered the case moot); Williams v. Smith, 131 N.E. 2 (Ind. 1921) (striking down a law that

introduction of Virginia's Eugenical Sterilization Act into a state legislature at first came about as eugenicist doctors sought to expand their medical prerogative to sterilize institutionalized feebleminded patients. Their eugenics ideal called for broader immunity to perform not only involuntary therapeutic sterilization, which would be done in cases of medical necessity, but also eugenic sterilization whenever there was a need to prevent the propagation of the "socially inadequate" feebleminded.[26] Such an institutional need of eugenicist doctors did not gain sympathy until the state's economic burdens to sustain the function of long-term segregation of the feebleminded became too heavy to bear during economic recession in Virginia. The sterilization of insane, epileptic and feeble-minded persons was seen as one of the most effective measures to relieve the institutions of their crowded condition.[27]

But the justification of *Buck* certainly was not predicated on either the personal

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authorized the performance of an operation of vasectomy on a prisoner but gave the prisoner no opportunity to cross-examine the decision).

[25] *See, e.g.*, Haynes v. Lapeer Circuit Judge, 166 N.W. 938 (Mich. 1918) (holding a law that provided for sterilization of insane mentally defective persons maintained at public institutions as an unconstitutional class legislation because it arbitrarily selected only those confined in state institutions); Smith v. Bd. of Examiners of Feeble-Minded, 88 A. 963 (N.J. 1913) (finding unconstitutional the statute authorizing sterilization of an epileptic woman committed in a state charitable institution on the ground that the law was an unreasonable exercise of police power denying a class of people the equal protection of the Fourteenth Amendment).

[26] *See* Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 38-45 (1985) [hereinafter Lombardo, *New Light on Buck*]. The incident of a medical malpractice lawsuit contesting Dr. Albert Priddy's use of the therapeutic prerogative to sterilize women without their consent, *see* Mallory v. Priddy, (Va. Cir. Ct. Richmond, 1918), prompted Dr. Priddy, the prime mover of the Eugenical Sterilization Act, to push for special authorization of eugenic sterilization.

[27] *See* Lombardo, *New Light on Buck*, *supra* note 26, at 47-48.

penchant of individual eugenics enthusiasts[28] or the fiscal predicament of the state. The rationale that enabled Justice Oliver Wendell Holmes to undisguisedly declare that "[t]hree generations of imbeciles are enough"[29] was an analogy between the catastrophe of infectious diseases and the danger of being swamped with incompetence. The public health law rationale provided the ground for resorting to the vaccination case, *Jacobson v. Massachusetts*,[30] as the relevant authority to justify Virginia's Eugenical Sterilization Act, an argument originally proposed by Harry Laughlin,[31] the then superintendent of the Eugenics Records Office and the author of the Model Eugenical Sterilization Law.[32] As the only precedent cited in *Buck*, *Jacobson* set the tone for Justice Holmes's central reasoning: "[t]he principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes."[33] The Supreme Court at the end upheld the sterilization act by a vote of eight to one.

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[28] Eugenic enthusiasts certainly played important roles in the enactment of the Eugenical Sterilization Act and the making of *Buck*. Among all the participants, three men are most significant: Dr. Albert Priddy, the prime mover of the sterilization law and the doctor who sterilized Carrie Buck; Aubrey Strode, the author of Virginia's sterilization law and later the defense lawyer representing Priddy and the Colony that committed Buck; and Irving Whitehead, the former Colony director and Strode's long-time friend and later the attorney who were arranged to represent Buck. *Buck* was an orchestrated product among these three men, whose personal interests in eugenics ideal blinded their eyes as to the fact that Carrie Buck was not mentally retarded. *See id.* at 32-33, 50-55.

[29] Buck, 274 U.S. at 207.

[30] 197 U.S. 11 (1905) (endorsing a compulsory smallpox vaccination law).

[31] *See* HARRY HAMILTON LAUGHLIN, EUGENICAL STERILIZATION IN THE UNITED STATES 339-40 (Chicago: Psychopathic Laboratory of the Municipal Court of Chicago, 1922).

[32] *See id* at 446-51.

[33] Buck, 274 U.S. at 207.

The implications of *Buck* are twofold. It, on the one hand, endorsed the *descriptive* theory of eugenics that mental, moral, and physical defects were transmitted in predictable patterns through heredity, and, on the other hand, justified *normatively* state reproductive controls in the name of safeguarding public health. Even though *Buck* is the only case that upheld the eugenic law at issue among the three eugenics cases, *Buck*'s tenet that state imposed reproductive controls could be legitimately used against the propagation of inherited mental, moral, or physical defects has never been seriously challenged.

2.1.2 *Skinner v. Oklahoma*: The Naissance of Rights Talk

The second eugenics case, *Skinner*, dealt with the coercive sterilization of the criminal and marked as the watershed of eugenic jurisprudence.

The turn-of-the-century sentiment regarding the retarded in asylums found a parallel in prisons for criminals. Developing from undifferentiated and passive confinement, the prison was once the site for education and rehabilitation of inmates in the 1880s even though the concept of "born criminal"—those thought to have the condition of innate criminality—had been proffered by Cesare Lombroso to explain the persistent failure of the few "incorrigible."[34] The rehabilitation philosophy waned as the born-criminal theory waxed. But it was until the American criminal anthropologists

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[34] *See* CESARE LOMBROSO, CRIME, ITS CAUSES AND REMEDIES 245-46 (Henry P. Horton trans., New York: Legal Classics Library, 1994) (1911).

reformulated the born-criminal theory in hereditarian terms that reproduction controls became a measure of crime control. This second generation of born-criminal theorists sought to locate the general propensity for crime within the brain of criminals. They measured intelligence using Binet's newly developed IQ test on the assumption that the born criminal, if morally and biologically primitive, must also be backward intellectually. The concept of "moral imbecile" unsurprisingly converged with the theory produced in the mental retardation system.[35] Like the development in the asylum for the retarded, sterilization of the criminal was marketed and sold as the cure to the social problem of crime.

At the center of *Skinner* was the challenge to the constitutionality of the Oklahoma Habitual Criminal Sterilization Act of 1933, which authorized coercive sterilization of the "habitual criminal," individuals who had been convicted three times of certain specified felonies, on the ground that their criminality is hereditary. Writing the opinion for the Court, Justice William O. Douglas challenged the notion of hereditary criminality with his newly fashioned constitutional formula—the strict scrutiny for equal protection cases involving fundamental rights. Justice Douglas's application of his formula was based on his categorizing "marriage and procreation"—"the right to have offspring"—as "one of the basic civil rights of man" so "fundamental to the very existence and survival of the race."[36] This was the first time in the Supreme Court's history that reproductive rights

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[35] *See* RAFTER, *supra* note 15, at 114-28.

[36] Skinner v. Oklahoma, 316 U.S. 535, 536, 541 (1942).

were described as fundamental rights.[37] It thus triggered Justice Douglas's review of strict scrutiny to examine the classification which a state makes in a sterilization law.[38] But the Oklahoma law failed to pass strict scrutiny not because of the familiar reasons of lacking a compelling state interest or failing to pursue that interest with a narrowly tailored means, but because the law lacked a rational basis for distinguishing between those crimes that would (larceny) and would not (embezzlement) result in statutorily authorized sterilization.[39] Admittedly, such an equal protection reasoning might be vulnerable to sterilization laws that make no exception to any of the offenses of intrinsically the same quality. Douglas's personal notes from the Court conference on the case, however, as pointed out by Professor Lombardo, suggest that he had great doubt about the concept of hereditary criminality. He wrote, "whether there are any scientific authorities in support is not clear…. No statistics as to criminals—if criminals do not

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[37] Marriage, however, was described as a liberty in dictum of the majority opinion of *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923). ("[Liberty] denotes not merely freedom from bodily restraint but also the right of the individual...to marry, establish a home and bring up children…."). *See also* WALTER WADLINGTON & RAYMOND C. O'BRIEN, DOMESTIC RELATIONS: CASES AND MATERIALS 108-9 (New York: Foundation Press, 5th ed. 2002). Indeed, as early as 1914, a federal court, in finding a law authorizing sterilization of repeat criminals as, inter alia, cruel and unusual punishment, has availed itself of the language of marriage as a right. *See* Davis v. Berry, 216 F. 413, 419 (S.D. Iowa 1914) ("One of the rights of every man of sound mind is to enter into the marriage relation. Such is one of his civil rights, and deprivation or suspension of any civil right for past conduct is punishment for such conduct…."). The right of marriage was not called "fundamental" until *Skinner*.

[38] *See id* at 541.

[39] *See id* at 541-42 ("When the law lays an unequal hand on those who have committed intrinsically the same quality of offense and sterilizes one and not the other, it has made as an invidious a discrimination as if it had selected a particular race or nationality for oppressive treatment.") (citation omitted).

produce their kind, then we have [a] serious question."[40]

However, the reading of *Skinner* is still equivocal. The innovative language of procreation as a fundamental right has led some commentators to enthusiastically argue that *Skinner* all but overruled *Buck*'s *normative* proposition that state imposed reproductive controls could be legitimately used against the propagation of inherited mental, moral, or physical defects for the purpose of preserving public health.[41] The continual use of *Buck* in later cases, such as *Roe v. Wade*,[42] as the "point of reference" for placing limitations on fundamental rights, however, rejects the suggested thesis that individual rights necessarily trump state power.[43] Rather, *Skinner* only distinguished itself from *Buck* with respect to the *descriptive* question of whether the hereditarian rule of the eugenics theory applies to the trait of criminality, if there is any.

But equally undeniable is the persistence of *Skinner*'s language of marriage and procreation as fundamental rights. In *Griswold v. Connecticut*, the great leading case of a discrete, general constitutional right to privacy that struck down anti-contraceptive law, *Skinner* was cited as an authority that supports the penumbral right of privacy

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[40] *See* Lombardo, *From Coercive Sterilization to Reproductive Freedom*, *supra* note 8, at 18 (quoting Justice William O. Douglas, Supreme Court Conference Notes (Apr. 11, 1942).

[41] *See, e.g.*, John A. Robertson, *Genetic Selection of Offspring Characteristics*, 76 B. U. L. REV. 421, 473-74 (1996).

[42] 410 U.S. 113, 154 (1973) ("The Court has refused to recognize an unlimited right of this kind in the past.") (citing Jacobson v. Massachusetts, 197 U.S. 11 (1905), and *Buck*).

[43] *See* Lombardo, *From Coercive Sterilization to Reproductive Freedom*, *supra* note 8, at 24.

surrounding the marriage relationship.[44] Even without expressly citing *Griswold*, *Loving* followed *Griswold*'s lead and relied on *Skinner* as the basis for avowing that "marriage is one of the 'basic civil rights of man,' fundamental to our very existence and survival."[45]

2.1.3 *Loving v. Virginia*: Follower of the Trend

The miscegenation law struck down in *Loving* has a genealogy dated back to the early Colonial Period.[46] Ever since the first blacks were imported into Virginia initially as servants in 1619 and later as slaves in the late seventeenth century,[47] miscegenation, referring either to interracial breeding or interracial marriage, had been a forbidden practice. It was prohibited first in the name of preserving "the honor of Christian,"[48] then in the form of regulating the conduct of slaves and servants.[49] But behind the categories put up by religion and economic class was the regulation of non-white races. While the early anti-miscegenation laws prohibited the marriage between a "free white" and a

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[44] 381 U.S. 479, 485 (1965) ("[Skinner v. Oklahoma and other] cases bear witness that the right of privacy which presses for recognition here is a legitimate one.").

[45] Loving v. Virginia, 388 U.S. 1, 12 (1967).

[46] *See* Walter Wadlington, *The Loving Case: Virginia's Anti-Miscegenation Statute in Historical Perspective*, 52 VA. L. REV. 1189, 1191-99 (1966).

[47] *See* LAWRENCE M. FRIEDMAN, A HISTORY OF AMERICAN LAW 85, 86 (New York: Simon & Schuster, 2nd ed. 1985).

[48] *See* Wadlington, *supra* note 46, at 1191 (citing notes in the official record of the proceedings of the governor and council). First blacks were pagans. Originally, there was a notion that Christians should not be slaves. When slavery was peculiarly associated with the blacks by the end of the seventeenth century, non-Christians generally referred to this race.

[49] *See id*. at 1192 (citing a 1691 Virginia statute).

"colored person," defined as having certain fraction of "Negro," "mulattoes," or "Indian" blood, the Racial Integrity Act of 1924, the law later struck down in *Loving*, forbade any "white person" from marrying anyone other than a "white person." Such a shift of focus from the definition of a "colored person" to the definition of a "white person" made the anti-miscegenation prohibition broader than it had been in the past.[50]

Inheriting the essence of the racist tradition of its predecessors, the 1924 law would have simply been another revision of the old Jim Crow laws. But the eugenics factors that were added to it gave it a fashionable scientific look. Depicting interracial marriages between whites and non-whites as the source of the varied public health problems resulting in the weakening and the destruction of the quality of citizenship, eugenic advocates were able to lobby for the enactment of the 1924 law,[51] which, in addition to the prohibition of interracial marriage, would classify all citizens by race. With the eugenics tone, "racial integrity" would sound more like a public health concept than a blunt expression of racial pride. Science was used to "garner legal imprimatur for the deep-seated southern cultural taboo against interracial sexuality."[52]

The *Loving* Court, however, did not encounter the eugenics rationale of Virginia's

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[50] *See* Wadlington, *supra* note 46, at 1201.

[51] *See* Paul A. Lombardo, *Miscegenation, Eugenics, and Racism: Historical Footnotes to Loving v. Virginia*, 21 U.C. DAVIS L. REV. 421, 425-440 (1988) (detailing the roles played by John Powell and Walter Plecker in the passage of the Racial Integrity Act of 1924).

[52] Gregory Michael Dorr, *Principled Expediency: Eugenics, Naim v. Naim, and the Supreme Court*, 42 AM. J. LEGAL HIST. 119, 121 (1998).

anti-miscegenation law. The Court, instead, relied on the fundamental rights language of *Skinner* and availed itself of the concept of suspect classification just developed under equal protection jurisprudence.[53] As a result, it is not clear whether *Loving* was indeed predicated on a repudiation of *Buck*'s *descriptive* eugenics proposition with regard to interracial marriage, i.e., interracial marriage did not cause the "corruption of blood" or racial deterioration,[54] or whether *Loving* was actually an exception to *Buck*'s *normative* proposition since the forbidden classification of race was used, i.e., even if interracial marriage were to result in the "corruption of blood," anti-miscegenation laws, measures of reproductive controls for the purpose of public health, are still unconstitutional since they violated the praised ideal of racial equality. But again, neither possibilities effectually blemish *Buck*'s central tenet that, in general, state imposed reproductive controls could be legitimately used against the propagation of the confirmed inherited mental, moral, or physical defects.

2.1.4 The Specter of the Leviathan or a Newcomer in Town?

As such, the assertion that there is a legal paradigm shift from the public health

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[53] *See* Loving, 388 U.S. at 10 ("[T]he Equal Protection Clause requires the consideration of whether the classifications drawn by any statute constitute an arbitrary and invidious discrimination."). *See also id*. at 12 ("There can be no doubt that restricting the freedom to marry solely because of racial classifications violates the central meaning of the Equal Protection Clause.").

[54] Professor Walter Wadlington argued before *Loving* was decided that the empirical ground supporting the anti-miscegenation laws had been seriously discredited and that courts should not blind themselves to the new scientific evidence in deciding the constitutionality of those laws. *See* Wadlington, *supra* note 46, at 1218-19.

model to fundamental rights talk may seem to be preposterous. After all, the normative part of *Buck*'s tenet stands intact even though the new human genomics has largely modified the applicability of its descriptive proposition. The rights talk adopted by *Skinner* did not really put an end to the use of state imposed reproductive controls. Rather, it is the charge of pseudoscience that frustrated the application of *Buck* in individual cases. *Buck* is at the most in a state of "hibernation," and is likely to wake up in any minute as new science sharpens *Buck*'s descriptive prong. The blank of "imbeciles" in Holmes's epigram of "three generations are enough" is ready to be filled by any other confirmed genetic condition.[55] *Buck* and the repressive state disciplinary power it represents remain to be the greatest menace to reproductive autonomy.

On the other side of the story, however, the effect of such a legal paradigm shift is nevertheless real and prevalent. Politically, rights discourse did provide strong counter rhetoric to the eugenics rationale. There is a broader dimension of the change reflecting as a general trend of emancipatory endeavors of civil rights and women's rights movement beginning in the mid-nineteenth century and flourishing in the 1960s.[56] The

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[55] *See* Paul A. Lombardo, *Taking Eugenics Seriously: Three Generations of ??? Are Enough?*, 30 FLA. ST. U. L. REV. 191, 207-8, 217-18 (2003).

[56] *See* Sonia Corrêa & Rosalind P. Petchesky, *Reproductive and Sexual Rights: A Feminist Perspective*, *in* POPULATION POLICIES RECONSIDERED: HEALTH, EMPOWERMENT, AND RIGHTS 107 (Gita Sen et al. eds., Boston: Harvard School of Public Health, 1994). Of course, there was inconsonance among feminist activists regarding the proper way to approach reproductive autonomy politically. For example, some suffrage activists opposed an equal rights strategy on the ground that it would undermine long-term gains for women and children. *See* ELLEN CHESLER, WOMAN OF VALOR: MARGARET SANGER AND THE BIRTH CONTROL MOVEMENT IN AMERICA 205, 206 (New York: Simon & Schuster, 1992).

recognition of negative liberty rights regarding procreation is undoubtedly the thrilling upshot of the emancipatory politics that liberates women from the patriarchal constraints of the state's disciplinary power and ensuring them the minimum condition of individuation. The recognition of reproductive rights had led many states to repeal their eugenic reproductive controls.[57] In 2001, Virginia became the first state to pass a resolution expressing its regret for its eugenics past.[58] With the now dominant value of reproductive autonomy, it is common to consider *Buck* and eugenics as nothing more than a temporary aberration[59] and to find Holmes's language plainly offensive.[60] Legally, ever since *Skinner*, an array of cases has been able to appeal to the fundamental rights language devised by *Skinner*. The concept of reproductive liberty finally culminated in *Eisenstadt v. Baird*,[61] in which the Supreme Court held that "if the right of privacy means anything, it is the right of individual, married or single, to be *free from unwanted*

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[57] For example, Virginia repealed its Eugenical Sterilization Act in 1972. Indiana, the first state allowing coercive sterilization, revoked its law in 1975.

[58] The resolution Expressing the General Assembly's Regret for Virginia's Experience with Eugenics, H.D.J. Res. 607, 2001 Gen. Assem., Reg. Sess. (Va. 2001).

[59] In 1972, Justice Marshall openly proclaimed that "this Nation has never formally professed eugenic goals" in his concurring opinion in *Furman v. Jackson*, in which the Court declared unconstitutional the death penalty in situations brought before the Court. *See* Furman v. Jackson, 408 U.S. 238, 357 (1972) (Marshall, J., concurring).

[60] One commentator even places *Buck* along with *Dred Scott v. Sandford*, 60 U.S. 393 (1856), which denied citizenship to blacks, and *Plessy v. Ferguson*, 163 U.S. 537 (1896), which endorsed the principle of "separate but equal," as the Supreme Court's "biggest blunders." *See* Lombardo, *supra* note 55, at 197 (citing Tony Mauro, *In the Shadows of History*, LEGAL TIMES, Feb. 26, 2001, at 12. However, *Buck* is still a good law, strictly speaking, whereas both *Dred Scott* and *Plessy* were clearly overruled.

[61] Eisenstadt v. Baird, 405 U.S. 438 (1972) (finding unconstitutional the Massachusetts statute prohibiting the use of contraceptives by unmarried persons).

governmental intrusion in matters so fundamentally affecting a person as the decision whether to bear or beget a child."[62] Individuals are now accorded with once unavailable negative liberty against state imposed reproductive controls.

This paradigm shift is a change of ethos. Although *Buck* is not overruled, the issue of sterilization of the mentally retarded has been oxymoronically rephrased in the language of right, the right of the mentally retarded to access the once oppressive sterilization.[63] It is believed that, once guarded with rights and the freedom of choice, the previously targeted population may be emancipated from the threat of repressive state disciplinary power even when they are again wading through the same troubled water of eugenic nature. As long as the intrusive hand of government is off individuals, homemade retail eugenics is not to be questioned like its governmental wholesale cousin.[64] Embracing such a rationale, the Supreme Court of California in *In re Valerie N.* struck down a state law prohibiting nontherapeutic sterilization of persons with retardation who could not personally consent to the procedure on the ground that such a law denied to persons with retardation the right of reproductive choice.[65] The role of the

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[62] *Id*. at 453 (emphasis added).

[63] *See, e.g.*, MARTHA A. FIELD & VALERIE A. SANCHEZ, EQUAL TREATMENT FOR PEOPLE WITH MENTAL RETARDATION: HAVING AND RAISING CHILDREN 80-81 (Cambridge, MA: Harvard Univ. Press, 1999).

[64] *See, e.g.*, Arthur L. Caplan et al., *What is Immoral About Eugenics?*, 319 BMJ 1284, 1284-85 (1999) (arguing that there is no moral principle providing sufficient reason to condemn voluntary individual eugenic goals).

[65] 199 Cal. Rptr. 478 (Cal. App. 1984), *aff'd*, 219 Cal. Rptr. 387 (1985).

state is skillfully switched from executing the eugenics decree with its police power to facilitating the same goal through its *parens patriae* role.

Such a reading of this paradigm shift as the utter triumph of negative liberty stands in stark contrast to the resuscitation of repressive state disciplinary power incarnated in the still breathing *Buck*. But if the uneasiness about the repressive disciplinary power lurking behind *Buck* misses a bigger picture, the buoyant confidence in the ability of negative liberty to foreclose outright the exercise of disciplinary power over the human body equally would prove to be too naïve. Governance and management of the condition and quality of the population had always been a major factor in legalizing abortion and other birth control practices even though it is now done in the name of pursuing reproductive liberty.[66] The disciplinary factor in rights discourse does not simply mean that emancipatory politics is still an incomplete enterprise failing to deliver what it has promised, or that because the state still has an interest in the welfare and health of individuals; it naturally retains the power to regulate individuals' exercise of reproductive liberty. Rather, I would argue, reproductive autonomy and the language of rights are positively required as the necessary instrument of a new form of governmentality. Gaining control over one's body in the name of voluntary motherhood[67] or planned

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[66] *See, e.g.*, Mary Meehan, *How Eugenics Birthed Population Control*, 24(4) THE HUMAN LIFE REV. 76 (1998).

[67] "Voluntary motherhood" was the standard name applied to the demand for birth control in the early twentieth century. LINDA GORDON, WOMAN'S BODY, WOMAN'S RIGHT: A SOCIAL HISTORY OF BIRTH CONTROL IN AMERICA 95 (New York: Penguin Books, 1977).

parenthood has been deftly interwoven with the notion of reproduction stressing responsibility, self-regulation and self-discipline. Reproductive autonomy and the language of rights are not the antithesis of disciplinary power. They are from the beginning a potentially disciplinary practice.

The disparity between the two readings of the paradigm shift—one warning the remnant of the Leviathan versus one celebrating the triumph of negative liberty—is thus simply the result of their common failure to account for the channels, apparatus, strategies and techniques of a new breed of governmentality—a new form of governance in supplement to its repressive counterpart. Surely, *Buck* is not quite dead yet. But this new form of governance has undertaken the major tasks that *Buck* used to bear. The question now is, how could reproductive rights with the apparent characters of negative liberty claiming simply the freedom *from* external constraints become something like the instrument of smuggling or implementing those constraints internally? We need to examine and answer this question.

2.2 Reproductive Autonomy as Emancipatory Politics

It is commonly held that reproductive autonomy and the language of privacy rights are devices that can be used to empower individuals to gain control over their bodies. Reproductive rights entrench the sovereign power of women over their own bodies. Indeed, the arguments rooted in bodily autonomy are pervasive in the rhetoric of the Birth-Control movement and occupy a center stage in contemporary feminist theorizing. Margaret Sanger, one of the leading feminists in late nineteenth- and early twentieth-century America, advocated birth control for all women as a matter of right. For Sanger, birth control was the necessary prerequisite for women to ever experience freedom. Sexual liberation for women is to untie sexuality and childbearing and to ask for the choice of planned reproduction.[68] This language resonates much of *Eisenstadt*'s right to decide "whether to bear or beget a child."[69]

Unlike Sanger, who adopted a relatively neutral stance toward pregnancy, Simone de Beauvoir, a French feminist philosopher, brazenly proclaimed that women's unruly reproductive capacities inevitably locate women in the realm of necessity. For Beauvoir, women's automatic biological functioning is inherently threatening to women's autonomy. Freedom is possible only if women achieve control over women's own bodies and avoid pregnancy.[70] "Contraception and legal abortion would permit woman to

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[68] Although Sanger deliberately dissociated birth control from the then already controversial issue of abortion for the reason of political prudence, a new generation of a vigorous feminist movement faithfully follows her original claim that women have a fundamental right to control their own bodies to demand legalization of abortion. *See* CHESLER, *supra* note 56, at 300-3.

[69] Professor John A. Robertson even asserts that the Supreme Court's contraception and abortion cases have "removed most legal barriers to *sex without reproduction* and thus gave women control over a major part of their biological destiny." John A. Robertson, *Procreative Liberty and The Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405 (1983) (emphasis added) [hereinafter Robertson, *Procreative Liberty*].

[70] *See* SIMONE DE BEAUVOIR, THE SECOND SEX 540-88 (H.M. Parshley ed. & trans., New York: Vintage Book, 1974) (1952). For a criticism of this view, see Lealle Ruhl, *Dilemmas of the Will: Uncertainty, Reproduction, and the Rhetoric of Control*, 27 SIGNS 642, 653 (2002) (arguing that Beauvoir's fetishization of freedom makes her objective of reproductive freedom the ability to *prevent* maternity, not to *plan* or *manage* it.)

undertake her maternities in freedom."[71] Beauvoir's outright disdain of procreative functions unique to women invokes controversies even among feminist camps.[72] Resting on an opposite view of pregnancy stressing instead the significance of maternity for women, some contemporary legal scholars go beyond the realm of birth control and abortion to incorporate a right to procreate into the scope of reproductive autonomy. For them, "the biological experience of bearing and giving birth is so important for women that it should be recognized as an independent exercise of procreative freedom."[73]

All this rhetoric, with which we have now become all too familiar, resembles almost every characteristic of negative liberty if not further investigated. It shares the rubric of voluntarism. It exalts the freedom of choice. It defines a sacrosanct area over which only the individual has complete jurisdiction. It insists on the removal of obstacles to the possible fulfillment of one's wishes. It defends ultimately the independence of one's personality.[74] Alternatively, it commands no specific direction of one's will. It identifies no transcendental ideal to be followed. It provides only the basic channel through which one seeks to fulfill his or her own desires. What it depicts is plainly the

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[71] BEAUVOIR, *supra* note 70, at 550.

[72] For example, feminist Irene Diamond criticizes this view as alienating women from their bodies and subjecting them to male sexual dominance. IRENE DIAMOND, FERTILE GROUND: WOMEN, EARTH, AND THE LIMITS OF CONTROL 69 (Boston: Beacon, 1994).

[73] Robertson, *Procreative Liberty, supra* note 69, at 409.

[74] For a discussion of the distinction between "liberty as independence" and "liberty as license," see RONALD DWORKIN, *Liberty and Liberalism, in* TAKING RIGHTS SERIOUSLY 259 (Cambridge, MA: Harvard Univ. Press, 1977).

picture of "a [wo]man struggling against h[er] chains or a people against enslavement" not consciously aiming at any definite further state. "[S]he need not know how [s]he will use h[er] freedom; [s]he just wants to remove the yoke."[75] As the core of liberalism, negative liberty is usually what the classical political philosophers meant when they used the word freedom or liberty.[76] Hobbes in Leviathan said, "a free man, is he that … is not hindered to do what he has a will to."[77] "Liberty, or freedom, signifieth (properly) the absence of opposition; (by opposition, I mean external impediments of motion;) and may be applied no less to irrational, and inanimate creatures, than to rational."[78] J. S. Mill qualified individual liberty by looking to a similar benchmark and said: "The only freedom which deserves the name, is that of pursuing our own good in our own way."[79]

However, upon a closer look at the rhetoric of feminist movements demanding control over one's body, the negative character of reproductive autonomy soon slides into a positive one. Those advocates did not merely advance a liberty of doing *whatever* one wishes regarding one's reproduction. They were promoting certain views with which one

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[75] ISAIAH BERLIN, *Introduction to Four Essays on Liberty*, *in* LIBERTY: INCORPORATING FOUR ESSAYS ON LIBERTY 3, 36 n.1 (Henry Hardy ed., Oxford: Oxford Univ. Press, 2002) (1969) [hereinafter BERLIN, *Liberty Introduction*].

[76] *See* ISAIAH BERLIN, *Two Concepts of Liberty*, *in* LIBERTY: INCORPORATING FOUR ESSAYS ON LIBERTY 166, 170 (Henry Hardy ed., Oxford: Oxford Univ. Press, 2002) (1958) [hereinafter BERLIN, *Two Concepts*].

[77] THOMAS HOBBES, LEVIATHAN 139 (J.C.A. Gaskin ed., Oxford: Oxford Univ. Press, 1998) (1651).

[78] *Id.* at 139.

[79] JOHN STUART MILL, ON LIBERTY 55 (Edward Alexander ed., Peterborough, Ont: Broadview Press, 1999) (1869).

should guide one's desire. On October 16, 1916, Margaret Sanger opened her first pilot birth control clinic in the Brownsville district of Brooklyn, advertising it in English, Yiddish, and Italian: "MOTHERS! Can you afford to have a large family? Do you want any more children? If not, why do you have them?"[80] Certainly, Sanger's rights talk was universal in rhetoric and with humanitarian motivation in mind.[81] Yet, her messages were deliberately aimed at the working classes and the poor who were implicitly perceived to lack the self-control and caught up in poverty owing to devastating economic burdens of caring for too many children. Thus, even if the valorized image of the mother in Sanger's messages is one who rationally decides not to have more children but has no means to avoid that, Sanger deftly juxtaposed an unspoken figure of an indulgent mother entrapped by her uncontrolled desires. For Sanger and other birth controllers alike, lack of self-control presents not in the choices of the poor being hampered by others, but in their having more children than they can support.[82] They are slaves to no man. They are slaves

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[80] *See* CHESLER, *supra* note 56, at 150 .

[81] According to historian Ellen Chesler, Sanger had a genuine and inherent sympathy for the sufferings of poor women and a strong identification with their plight. *See* CHESLER, *supra* note 56, at 62. However, Sanger was anything but sympathetic to what she called the "unfit and undesirable"—groups of the socially troublesome. Worrying the lack of the balance between the birth-rate of the "unfit" and the "fit," she bluntly advocated the sterilization of the feebleminded. *See* Margaret Sanger, *The Function of Sterilization*, 10 BIRTH CONTROL REV. 299, 299 (1926); MARGARET SANGER, *The Fertility of the Feeble-Minded*, *in* THE PIVOT OF CIVILIZATION IN HISTORICAL PERSPECTIVE 202, 207 (Michael W. Perry ed., Seattle: Inkling Books, 2001) (1922). Sanger even argued in a radio talk show for the idea that "morons, mental defectives, epileptics, illiterates, paupers, unemployables, criminals, prostitutes, and dope fiends" ought either to be surgically sterilized or to live a segregated existence in labor camps. *See* ANGELA Y. DAVIS, WOMEN, RACE, AND CLASS 214 (New York: Vintage Books, 1983).

[82] *See* GORDON, *supra* note 67, at 325, 406-7.

to their own unbridled passions. To achieve true freedom, their irrational impulses, their false, empirical or heteronomous selves, need to be guided by their reasons, their true, transcendental or autonomous selves, which calculate and aim at what is good for them in the long run.

It is worth noting that Sanger's emphasis on birth control as the antidote to poverty does not rests on a simple hereditarianism. Rather, "the cell plasms with the best potentialities"[83] would still fall prey to poverty if devastating economic burdens keep on depriving one of skills and preventing one from competing equally. Motherhood therefore becomes crucial in breaking the vicious circle. It is incumbent upon motherhood to ward off the threat of poverty. As Sanger noted, "[t]he philosophy of Birth Control insists that motherhood, no less than any other human function, must undergo scientific study, must be voluntarily directed and controlled with intelligence and foresight."[84] It would "refuse[] to bring forth slaves; refuse[] to bear children who must live under the conditions described."[85] The only way for the poor to pull themselves by their own bootstraps is to learn to control the numbers of poor people born into their communities. This notion of reproductive self-mastery and self-discipline is likewise evident in Beauvoir's work. Her outright disdain of pregnancy expressly rests on a body-

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[83] MARGARET SANGER, WOMEN AND THE NEW RACE 37 (New York: Truth Publishing, 1921) [hereinafter SANGER, NEW RACE].

[84] MARGARET SANGER, *Conscripted Motherhood*, *in* THE PIVOT OF CIVILIZATION IN HISTORICAL PERSPECTIVE, *supra* note 81, at 189, 195.

[85] SANGER, NEW RACE, *supra* note 83, 45-46.

mind dichotomy and the ideal picture of the rational subject taking control over the recalcitrant body. Even J. S. Mill, one of the most devoted champions of negative liberty, denounces in his magnum opus *On Liberty* the working classes' uncontrolled indulgence as responsible for the deterioration of their own economic situation: "[I]n a country either overpeopled, or threatened with being so, to produce children, beyond a very small number, with the effect of reducing the reward of labour by their competition, is a serious offence against all who live by the remuneration of their labour."[86]

Now, the advocacy of reproductive autonomy paradoxically becomes a proposal that smacks of paternalism. Reproductive autonomy and the languages of rights in this sense are not merely pursued to provide the basic channel through which one seeks to fulfill one's unhindered desires. This channel is being used in reverse to instill certain values. Free roaming of one's desire as envisaged in negative liberty is not possible anymore. The image of the "true self" serves authoritatively as the higher instructor in one's exercise of reproductive liberty. But, it is maintained that, self-abnegation of one's "lower self" is all necessary if one is ever to rise to a "higher" level of freedom. Spontaneously obeying rational law and only rational law, one's "true self" is a priori free from being ruled by passions, prejudices and fears springing from ignorance and irrationality. Reason makes genuine freedom possible and disperses the doubt of heteronomous paternalism. Just like mathematical truths no longer obtrude themselves as

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[86] MILL, *supra* note 79, at 158. Mill himself was a staunch supporter of Neo-Malthusianism which accepted Malthus's thesis on the cause of pauperism and added "prevention" to Malthus's original argument. *See* PETER FRYER, THE BIRTH CONTROLLERS 46, 47 (New York: Stein & Day, 1966) (1965).

external entities forced upon a schoolboy who eventually understands the functions of the symbols, the axioms, the formation and the rules and absorbs them as though they are by nature part of his mind, following the lead of one's "true self" is anything but being heteronomously subjected to paternalism. To desire otherwise is simply evidence that one has not listened to one's inner voice of reason and has not gotten away from the bondage of immaturity.[87] To assert that the working class ought to learn to control the numbers of poor people born into their communities is merely to recapitulate what one's "true self" would demand his or her "false self" to do.

To be sure, there still lurks a danger of tyranny in the concept of positive liberty. Even though accusation of paternalism has been theoretically refuted,[88] positive liberty's metaphysical split of self and its proposition of the mastery of the "higher self" over the "lower" one have historically served as the intellectual basis of political despotism, especially, as Isaiah Berlin has eagerly and incessantly warned, when an individual's higher "true self" is bluntly identified with a social whole, such as "institution, Churches, nations, races, States, classes, cultures, parties, and with vaguer entities, such as the general will, the common good, the enlightened forces of society, the vanguard of the most progressive class, Manifest Destiny."[89] Berlin, writing in an era of the prolonged contest between the democracies of the West and the despotisms of the Communist

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[87] *See* BERLIN, *Two Concepts*, *supra* note 76, at 181-200.

[88] As Berlin noted, Kant, one of the most devoted sponsors of positive liberty, viewed paternalism as "the greatest despotism imaginable." *See id*. at 183.

[89] BERLIN, *Liberty Introduction*, *supra* note 75, at 37.

World, constructed his thesis of negative and positive liberty in a way spelling out the antagonism between democratic individualism and authoritative totalitarianism in the real world. It is not surprising that he would investigate the shortcoming of a positive concept of liberty in light of this tug-of-war and identify as the most dangerous element of the concept of positive liberty the almost imperceptible transition of the notion of “true self” from an individual to a collective sense.

The “true self” in a collective sense, under the rationalist project which posits that a total harmony of all values is somewhere to be found by reason, could readily be, and is indeed, conceived transcendentally as the single convergent point of goals and ends of all rational beings. Berlin told us that rationalists’ value neutrality assertions that men are ends in themselves and that human goals are of equal value are meant to be so only in a transcendentally perfect state. Those goals and ends that do not conform to the rules of reason would be treated inferior. The burdens of choices in an empirical world between individuals’ conflicting ends would automatically disappear in the eyes of rational “true selves.” It is a total harmony; it is a monist world in which many equals one, the general will echoes the monologue of any single “true self.”

However, for Berlin, despotism creeps in precisely at the point where no guarantee of realization of the rationalist project is ever actually attainable and tyrants’ desires are camouflaged under the disguise of collective “true selves.” To avoid this danger, Berlin suggested, we must fundamentally eschew the a-priori worldview of rationalist metaphysics and fall back on empiricism, which recognizes the fact that human goals are many and cannot be subsumed under a single formula. Berlin rightly pointed out the distinction between transcendental and empirical value neutrality and insisted that only the later can keep us away from the temptation of authoritative totalitarianism. Negative liberty predicated on an empiricist worldview, he concluded, is the only concept of liberty that is able to truly assure empirical value neutrality and provide independence of personality.[90]

Empirical value neutrality has become the canon of contemporary liberalism, represented most evidently in current bioethics thinking. The limits of individual liberty in general and reproductive autonomy in particular lie not in any transcendental rule of reason. Rather, the limits are to be drawn practically to prevent collisions between varieties of human purposes. This idea is best illustrated by Mill's "harm principle" that the only legitimate cause to restrict individual sovereignty is to prevent harm to others.[91] In constructing a thesis advocating the presumptive primacy of procreative liberty, Professor John A. Robertson maintains that the only cause that justifies limiting procreative liberty is "a clear showing of substantial harm to the tangible interests of others."[92] He further draws the distinction "between harms to individuals and harms to personal conceptions of morality, right order, or offense."[93] When he recognizes only the

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[90] *See* BERLIN, *Two Concepts*, *supra* note 76, at 191-200, 212-17.

[91] *See* MILL, *supra* note 79, at 52 ("That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.").

[92] JOHN A. ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 35 (Princeton: Princeton Univ. Press, 1994) [hereinafter ROBERTSON, CHILDREN OF CHOICE].

[93] *Id*. at 41.

former and dismisses the latter concerns in determining tangible harm in a specific case, he explicitly rests his arguments on the conviction of empirical value neutrality, for "a majoritarian view of 'right' reproduction or 'right' valuation of prenatal life, family, or the role of women should not suffice to restrict actions based on differing individual views of such preeminently personal issues."[94]

Why, then, do the civil rights and women's rights movement's call for negative liberty and its concomitant belief of empirical value neutrality, though seem so neatly distinguished from positive liberty and transcendental value neutrality, collapse into exactly what it opposes? Is it simply the personal agendas of those zealous advocates that tarnish the purity of negative liberty?[95] Or, is it the doom of emancipatory politics' rights talk to fall into the trap of positive liberty? Can the specter of positive liberty be securely locked up by muttering spells of negative liberty? Or, is there an embedded psychological mechanism that tightly connects negative and positive liberty in an era of advanced liberalism?[96]

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[94] *Id*. at 41-42.

[95] Sanger, for example, in order to win acceptance and legitimacy for birth control, turned eagerly to the medical profession and the elite professionals who espoused eugenics for their support. *See* ROSALIND P. PETCHESKY, ABORTION AND WOMAN'S CHOICE: THE STATE, SEXUALITY, AND REPRODUCTIVE FREEDOM 90-95 (Boston: Northeastern Univ. Press, 1990) (1984). Critics have commented that due to this strategic alliance Sanger's birth control movement converted from a radical program of social disruption to a conservative program of social control and from a program of women's rights to a scheme of family planning. *See* DAVID M. KENNEDY, BIRTH CONTROL IN AMERICA: THE CAREER OF MARGARET SANGER 121 (New Haven: Yale Univ. Press, 1970).

[96] Some commentators suggest that the distinction between Berlin's negative and positive liberty is

To decipher those enigmas, we need to look into the way in which rights discourse is discursively formed. Professor Robertson's thesis on procreative liberty provides a model case with which to begin our diagnosis. Robertson's strong commitment to empirical value neutrality leads him, in estimating new reproductive technologies, to a position assuming that reproductive technology is a morally neutral tool that is not an appropriate object of ethical evaluation in its own right, that all available technologies, once being proved to be safe and shown to work, are prima facie moral options for individuals, and that every individual, regardless of economic social status, gender or race, is capable of choosing those options as they see fit. Here, we can identify two elements that form the main plank of this thought: the assumption of voluntarism, and the innocence of life science. I will take up these two issues in turn in this and the following two Chapters.

2.3 Value Neutrality and Voluntarism

There is no denying the fact that empirical value neutrality does not secure a more

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exaggerated. Since all statements about liberty take the form, *x* is free from *y* to do or be *z*, negative liberty's focus on the *y* and positive liberty's focus on the *z* make the distinction illusionary. *See* Gerald C. MacCallum, *Negative and Positive Freedom*, 76 PHIL. REV. 312 (1967). However, this criticism is dubious. The *z* variable does not necessarily appear in negative liberty. *See supra* note 75 and accompanying text. Even when the *z* variable does exist in negative liberty, it does not contain the element of self-discipline as positive liberty does. Negative and positive liberty *are* conceptually different. Nevertheless, I do not wish to argue that the *y* and the *z* variables could never coexist in any single proposal of liberty, or that the advocacies of negative and positive liberty always exclude each other in a real world. Indeed, liberal projects do intermingle and maneuver the concepts of negative and positive liberty in a manner illuminating governmental rationality of liberalism which demands further investigation rather than simply declaring the two are conceptually identical.

absolute status for freedom of choice on a metaphysical scale. It does so, as per Berlin, by recognizing more inclusively freedom of choice, or decisional privacy in constitutional jurisprudence's language, in an empirical world. Taking all ends people desire even-handedly in moral deliberation usually presupposes a kind of voluntarism whose implication is broader than transcendental value neutrality would have allowed, as it "may be applied no less to irrational, and inanimate creatures, than to rational."[97] Accordingly, while only a self with a rational will could voluntarily and autonomously choose its own ends under the benchmark of transcendental value neutrality, empirical voluntarism regards every self as always engaging in voluntary decision-making activities even though they are driven by empirical desires; while only a rational "higher self's" freedom to choose would be conferred with the categorical value by positive liberty, negative liberty praises even the choices of an empirical "lower self" on condition that the choices do not impinge on the interests of others or that the greatest number of individuals can realize as many of their ends as possible in so doing. What is lost in intensity is to be gained in range. Empirical voluntarism, without discriminating against a "lower self," envisages a body image in which more realistic attributes of a self reincarnate back into the body. Not only a super-rational "higher self" but also ordinary people like you and me shall be allowed the liberty to make one's life plan.

Empirical voluntarism, as a reaction to its transcendental counterpart, at first glance seems to effectively outstrip the limitation of rationalist projects. This is an overly

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[97] HOBBES, *supra* note 77, at 139.

optimistic expectation upon a closer look. Transcendental voluntarism, overlooking the empirical contexts in which a self exists and with which a self interacts, has long come under vehement attacks from antagonists of rationalist projects. Professor Michael Sandel satirizes the Kantian voluntarism as embracing a view of "unencumbered self" devoid of any real desire or end. He proposes instead a political philosophy that respects individuals' encumbered identities, such as linguistic, moral, legal and social factors, that shape their natures. For him, to assume a notion of "unencumbered self" free from the sanctions of custom, tradition and inherited status is far from being liberated. It is merely a self-serving illusion that fails to account for duties that may claim individuals for reasons unrelated to their choices.[98] Sandel aptly points out the fact that Kantian liberalism and its voluntarism tend to deny any role that the encumbrances of one's identities would play in making one's life plan. Self-identities do not affect a "true self's" decisions. Nor are they the appropriate objects of those decisions. For transcendental voluntarism, self-identity is a nonissue, a matter of complete indifference.

How about empirical voluntarism? On the questions of how one makes one's life plan, empirical voluntarism, in countering Kantian liberalism, acknowledges the effects

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[98] *See* MICHAEL J. SANDEL, DEMOCRACY'S DISCONTENT 11-17 (Cambridge, MA: Harvard Univ. Press, 1996). Sandel derives from his theory a new perspective to examine the current rights talk of the United States Supreme Court's jurisprudence. One of his eminent examples is religious liberty. Sandel challenges a long-held presumption about the basis underlying religious liberty. Sandel maintains that the reason for protecting religious liberty is not "freedom of choice" but "freedom of conscience" which is not subject to individual choices. Therefore, to protect religious liberty, states shall not simply adopt a neutral stance but shall accommodate each individual's religious encumbrances to the utmost extent since religious duties derive not from individual choices but from sources other than one's will. *See id*. at 65-71.

empirical conditions and factors, such as one's desires and identities, would have on a self's experience and self-understanding. Yet, it goes so far as to assert that self-identities are nonetheless the objects of one's choices. Individuals are the cause rather than the consequence of those empirical factors and conditions. As a free chooser, the empirical self chooses not only whether or not to bear or beget a child or what kind of reproductive technologies to use for implementing or controlling the quality of these decisions, but also the desires that fuel certain decisions or even one's self-identity that psychologically underpins those desires. The empirical self, though different from a transcendental one, is likewise "unencumbered" in the sense that its identities could be freely chosen by oneself. This is exactly what Professor Robertson has in mind when he argues against the feminist critique that his thesis on procreative liberty and his liberal attitude toward reproductive technologies "will further patriarchal domination of women by reinforcing the traditional identification of women with childbearing and childrearing." [99] Robertson does acknowledge that more reproductive choices will not always increase self-determination for all women, because some will in reverse "be pressured to make choices that they previously would not have had to face" due to the appearance of new options.[100] At this point, Robertson seems to acquiesce in the fact that women might sometimes fail to escape the encumbered duties that claim them for reasons other than their choices. But, appealing to a similar rationale enunciated in *Casey*, Robertson sanguinely believes at

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[99] ROBERTSON, CHILDREN OF CHOICE, *supra* note 92, at 228.

[100] *Id.* at 231.

least most women given reproductive freedom would be able to "define [their] own concept of existence, of meaning, of the universe, and of the mystery of human life."[101]

While not completely unfounded, Robertson's optimism is unequivocally at odds with what Anthony Giddens conceived to be the reality when he explained that "in liberating themselves from the home, and from domesticity, women were faced with a closed-off social environment."[102] For Giddens, "[w]omen's identities were defined so closely in terms of the home and the family that they 'stepped outside' into social settings in which the only available identities were those offered by male stereotypes."[103] Emancipatory politics alone is simply not enough to redress the real predicament women face. "[Q]uestions of identity become of pre-eminent importance" for women who have gained a preliminary victory in emancipatory politics.[104] Robertson fails to articulate whether women can really escape the domination of repressive identities and move on to project new identities of their own.[105] He further remains silent on the question of how to distinguish genuine free choices from those claimed by patriarchal traditions yet in the

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[101] Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 851 (1992).

[102] ANTHONY GIDDENS, MODERNITY AND SELF-IDENTITY: SELF AND SOCIETY IN THE LATE MODERN AGE 216 (Cambridge, UK: Polity Press in association with Basil Blackwell, 1991).

[103] *Id*.

[104] *Id*.

[105] Here, I borrow from the concepts developed by sociologist Manuel Castells. He distinguishes between three forms and origins of identity building: legitimizing identity, which is introduced and sustained by systems of domination; resistance identity, which is generated by those marginalized; and project identity, which represents the construction of new identities by social actors that redefines their position under a newly transformed social structure. MANUEL CASTELLS, THE POWER OF IDENTITY 7-10 (Malden, MA: Blackwell, 1997).

guise of individual freedom, a type of question that so much concerns and besets Berlin.

It shouldn't be too abstruse now to notice that the common symptom of emancipatory politics' rights talk is either the entire indifference to or the extreme voluntarism toward the relation between one's freedom of choice and one's self-identity. Neither transcendental nor empirical voluntarism is equipped to tackle the issue of subjectivity formation save admitting that negative liberty is not the sufficient but only a necessary condition for true emancipation[106]—emancipation from dominant identities, from what Professor Wendy Brown would call the "wounded attachments."[107] But if we wish to be more mindful of true human emancipation, which rights discourses have intended to procure, we must accept Giddens's invitation speaking directly to the issues of life politics. It is a politics not primarily concerning increase of "life chances" by removing the institutional constraints that deprive certain groups of suffrage, rights, or citizenship based on their social identity. It is a politics of choice, a politics of lifestyle, and a politics of identities, that concerns the conditions constitutive or reiterative of those repressive social identities.[108]

Why should life politics concern law, or isn't it just a subject for sociology? It must

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[106] *See, e.g.*, Linda C. McClain, *Toleration, Autonomy, and Governmental Promotion of Good Lives: Beyond "Empty" Toleration to Toleration as Respect*, 59 OHIO ST. L.J. 19, 75-76 (1998) ("[T]he negative liberty, or freedom from governmental interference, secured by toleration is a necessary but not a sufficient condition of women's well-being.").

[107] WENDY BROWN, STATES OF INJURY: POWER AND FREEDOM IN LATE MODERNITY 52-76 (Princeton: Princeton Univ. Press, 1995).

[108] *See* GIDDENS, *supra* note 102, at 210-17. *See also* BROWN, *supra* note 107, at 105.

concern law because only if we stand on the vantage ground of life politics can we discern how legal discourses in the form of rights talk are constitutive of our social experience and contribute to the formation of identities or constructed subjectivities; only if we look from the perspective of life politics can we answer the Berlinian questions of why and how negative liberty transforms into positive one; and only if we fathom the conundrum of life politics can we comprehend the implication of the legal paradigm shift from reproductive responsibility to reproductive autonomy.

3/ RIGHTS DISCOURSE IN LIFE POLITICS

In the previous chapter, I have shown the limits of the conventional approach, which seeks to comprehend the implication of the new rights paradigm of the post-eugenics era under the agenda of emancipatory politics. Presupposing a voluntarist image of an individual making free choices, the conventional approach fails to account for the conditions and contexts in which those choices are formed and made. Such a drawback prevents the conventional approach from grasping the role of negative liberty—reproductive autonomy and freedom of choice—as a new form of governmentality in the post-eugenics era. In this chapter, I will suggest an alternative account of the implications of the rights paradigm and specify the mechanism with which rights discourse of negative liberty positively constitutes self-identity.

3.1 Two Prongs of Life Politics

The intricate relationship between identity formation and rights discourse beckons the lingering interests of law and society scholars and foreshadows the proliferation of life politics. Whereas the mission of emancipatory politics is to identify and fight against the illegitimate social domination that adversely affects the "life chances" of individuals or groups, life politics alternatively advocates contesting the sanctioned view of the good life that legal discourses impose upon individuals. Legal scholars who follow the agendas of life politics become more interested in querying the hidden "messages" behind the official story a particular law tells and their constitutive effects upon one's identity than focusing on the mere removal of external constraints of social institutions while leaving the underlying ideology and internal constraints untouched.

Life politics concerns the conditions constitutive of one's identity not only because it has been unmasked that particular positions could masquerade as generic or universal, and that "neutrality" or "point of viewless" in politics and in law said to advance the professed universalism very often serves interests of some and marginalizes others.[1] More importantly, those "messages" conveyed in laws about the view of the good life implicate the formative project the state undertakes to mold its citizens and steer their lifestyle by installing particular identities upon them.[2] Thus, life politics can be seen as a rejoinder to two claims of liberal neutrality: that state does not take sides on moral issues and law reflects universal values or interests, i.e., value neutrality, and that law remains in a neutral position to the conditions of personal choices, i.e., voluntarism. That is, there are two prongs of life politics. The first prong is an unmasking project aimed at revealing what's been privileged and what's been suppressed by law and elucidating the fact that law very often serves to entrench power relations by naturalizing particular visions of the

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[1] See WENDY BROWN, STATES OF INJURY: POWER AND FREEDOM IN LATE MODERNITY 109 & n.28 (Princeton: Princeton Univ. Press, 1995), for a Marxist critique of false universalism of law.

[2] I borrow from both Michael Sandel and Linda McClain's usage of the term "formative project" to denote the practices of identity formation. Sandel uses the term in a civic republican sense to mean the governmental task of forging and cultivating civic virtues or a common citizenship, while McClain attempts to inject into it a synthesis of liberal and feminist components. *See* MICHAEL J. SANDEL, DEMOCRACY'S DISCONTENT: AMERICA IN SEARCH OF A PUBLIC PHILOSOPHY 319-24 (Cambridge, MA: Harvard Univ. Press, 1998) (1996); Linda C. McClain, *Toward a Formative Project of Securing Freedom and Equality,* 85 CORNELL L. REV. 1221, 1222 (2000) [hereinafter McClain, *Formative Project*]; Linda C. McClain, *Toleration, Autonomy, and Governmental Promotion of Good Lives: Beyond "Empty" Toleration to Toleration as Respect,* 59 OHIO ST. L.J. 19 (1998) [hereinafter McClain, *Toleration*].

good life or social order as given or inevitable.[3] The second prong concerns the role legal discourse plays in the context in which personal choices are formed or made and challenges the notion of the voluntarist self-image. From the standpoint of identity formation, the first prong asks what *content* of identity is selectively constituted in laws, while the second prong inquires what *relation* there is between legal discourse and the constituted identity.

Much ink has been spilled over the first prong of life politics in dismantling the unspoken "messages" sent by laws that exclude women from participating in certain activities and that deny them full membership in state and in civil society. Around fifty years after feminist emancipatory politics' victory in winning recognition of women's right to vote by the Nineteenth Amendment in 1920,[4] the radar detecting women's exclusion reached to areas such as women's right to jury service,[5] employment on equal

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[3] *See* Robert W. Gordon, *New Developments in Legal Theory*, *in* THE POLITICS OF LAW: A PROGRESSIVE CRITIQUE 647, 652 (David Kairys ed., New York: Basic Books, 3rd ed. 1998) (observing a development of legal theories directed at examining the way in which law legitimates the existing social order).

[4] Between these years, American feminist politics went into partial hibernation. For a more detailed discussion, see NANCY F. COTT, THE GROUNDING OF MODERN FEMINISM 96-97 (New Haven: Yale Univ. Press, 1987).

[5] *See, e.g.*, Ballard v. United States, 329 U.S. 187 (1946) (striking down a total exclusion of women from the jury service in a federal criminal proceeding on grounds that "the two sexes are not fungible; a community made up exclusively of one is different from a community composed of both"). *But see* Fay v. New York, 332 U.S. 261 (1947) (refusing to find a jury panel excluding women and laborers violated equal protection of the law). Peremptory challenge based solely on gender is prohibited by *J.E.B. v. Alabama ex rel. T.B.*, 511 U.S. 127 (1994) (holding that the Fourteenth Amendment prohibited discrimination in jury selection on the basis of gender regardless of whether the challenge involved a male or female).

terms,[6] opportunity in higher education,[7] participation in social activities,[8] and so forth.[9] Undoubtedly, those laws are the easy targets of emancipatory politics for they adversely and significantly affect women's life chances. They also draw criticisms of life politics because underneath ostensibly legitimate claims to relieve women from hardships that interfere with women's need to maintain the home, to protect women from dangerous work environment, or to preserve gender harmony and the natural and divine order lie implicitly a generalized ideology about sex difference, a particular view of proper gender roles, and an orthodox vision of how men and women can live good lives. Laws that exclude women from jury service do constrain women's chances to participate in judicial processes, but what really matters is that exclusive laws hold a separate sphere ideology

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[6] *See*, *e.g.*, Sail'er Inn, Inc. v. Kirby, 485 P.2d 529 (Cal. 1971) (striking down a state law banning women who were not the licensee or the wife of the licensee from bartending).

[7] *See*, *e.g.*, Kirstein v. Rector & Visitors of the Univ. of Va., 309 F. Supp. 184 (E.D. Va. 1970) (three-judge court) (holding that state's denial to women, on basis of sex, their educational opportunities at University of Virginia that are not afforded in other institutions operated by the state violated equal protection clause, but leaving the question open whether state can operate any educational institution separated according to the sexes). *See also* United States v. Virginia, 518 U.S. 515 (1996) (holding that neither Virginia Military Institute's goal of producing citizen soldiers nor its adversative method of training is inherently unsuitable to women and that state's provision of a separate educational program for women in order to preserve a male-only VMI violated equal protection of the law since women's separate program, which is different in kind from that afforded men and unequal in tangible and intangible facilities, is unable to place women in the position they would have occupied in the absence of discrimination).

[8] *See*, *e.g.*, Gallagher v. City of Bayonne, 245 A.2d 373 (N.J. 1968) (invalidating a city ordinance that prohibited female patrons from standing or sitting at a public bar).

[9] Assimilationism also contributed to the proposal of the Equal Rights Amendment, first introduced in Congress in 1923. However, ERA was not ratified by the necessary thirty-eight states by the July 1982 deadline. *See*, *e.g.*, MARY FRANCES BERRY, WHY ERA FAILED: POLITICS, WOMEN'S RIGHTS AND THE AMENDING PROCESS OF THE CONSTITUTION 70-85 (Bloomington: Indiana Univ. Press, 1986).

prescribing home and family as women's proper place; laws that prohibit women from bartending do deny to them equal employment chances, but what is more troubling is the archaic gender role exclusive laws impose upon women; laws that deprive women of higher educational opportunities do limit the life chances women can expect from being intellectually developed and equipped, but what is equally, if not more, hurtful is the underlying ideology that women are better not exposed to enlightening influences for the sake of a naturally sex-segregated world.

The first prong of life politics inquiring into women's social positioning informs contemporary equal protection doctrine challenging gender-specific classifications that reflect archaic and overbroad stereotypes about sex difference or gender roles.[10] Two distinct developments derive from this point. In one direction, the doctrine of "archaic stereotypes" gives rise to a new breed of empiricism[11] aiming to discover the true nature of sex differences as a gauge against which the challenge of equal protection could be measured. Under this view, gender discrimination is simply the undesirable result of outdated or obsolete ideas of sex differences that misrepresent the present true nature of men and women.[12] It presumes that a truth about the nature of two sexes is out there

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[10] *See, e.g.*, Craig v. Boren, 429 U.S. 190 (1976) (striking down an Oklahoma law that barred the sale of 3.2% beer to males under the age of 21 and to females under the age of 18 on grounds that neither administrative convenience nor overbroad and archaic generalizations regarding men and women's different capacities or roles could justify sex-based classifications).

[11] *See* McClain, *Formative Project*, *supra* note 2, at 1225-32 (comparing feminist empiricism critiques with empiricism informed by evolutionary biology).

[12] Admittedly, the empiricist version of "archaic and overbroad stereotypes" doctrine could have two

somewhere can be found as descriptive accounts of two sexes become more and more accurate, and that getting law more correctly to reflect that truth is the way to eliminate inequality caused by stereotyping. However, viewing “archaic stereotypes” as purely an empirical question oversimplifies the relation between phenomenon description, normative judgment, and political usefulness. First, aside from the fact that accurate phenomenon description is always contested, empiricist version of “archaic stereotypes” doctrine fails to discern the possibility that a gender-specific classification based on accurate phenomenon description still could be an “archaic stereotype.” Substituting normative judgment with phenomenon description, it offers no consistent criteria to distinguish between the cases of “real differences” where no inherently injurious message is thought to accompany a gender-based classification and the situations in which such classification, though accurately describing what appears to be the empirical phenomenon, nonetheless carries with it undesirable cultural norms about gender roles. If accuracy of description did determine what count as “archaic stereotypes,” the phenomenon that women in general lacked experience in formal business matters compared to men would have justified a law favoring male as administrators of estates,[13] and the idea that wives

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kinds of mismatch concern: mismatch between false and true description about men and women each as a group, and mismatch as a result of generalization within a group. However, generalization in law is not entirely prohibited. The use of age to determine major is a well-known example of legitimate generalization where individual variety within each group is generally ignored. Generalization cannot be viewed as problematical per se. In the field of gender equality, I take the first mismatch concern to be the real active factor in the “archaic and overbroad stereotypes” doctrine.

[13] *See* Craig v. Boren, 429 U.S. at 202 & n.13 (citing *Reed v. Reed*, 404 U.S. 71 (1971) in support of the contention that empirical evidence alone does not determine what count as archaic stereotypes).

in general are more economically dependent on husbands than husbands are economically dependent on wives would not have been the target of criticism.[14] These challenges at minimum show that the question whether an "archaic gender stereotype" is present seems less to be an empirical issue than a normative judgment on the desirability of a particular cultural norm about gender roles. Capturing the phenomenon does not amount to adjudicating its normative significance, and sometimes they stand in direct tension with each other.[15] Second, when the professed purpose of a gender-based classification is alleged to remedy a demonstrable phenomenon, empiricist version of "archaic stereotypes" doctrine loses its critical power to review the "messages" such classification sends altogether. Once the phenomenon targeted by remedial measures is proved to exist, the task of spotting empirical mismatches leaves no room for any assessment about the cultural and political implication of those measures.[16] All these difficulties lie in empiricists' one-dimension model of the relationship between culture

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[14] At the time *Califano v. Goldfarb*, 430 U.S. 199 (1977), was decided, the percentage of married women over 55 who would satisfy the dependency criteria was about 88.5%, while the incidence of dependent husbands among all married couples was approximately 1%. *See id*. at 238 n.7 (Rehnquist, J., dissenting).

[15] *See* Craig v. Boren, 429 U.S. at 204 (finding that statistical demonstrations are "in tension with the normative philosophy that underlies the Equal Protection").

[16] *See, e.g.*, Schlesinger v. Ballard, 419 U.S. 498 (1975) (sustaining a law granting women in the Navy a longer period in which to achieve mandatory promotion than men on the grounds that the law reflected the "demonstrable fact that male and female line officers in the Navy are not similarly situated with respect to opportunities for professional services"); Califano v. Webster, 430 U.S. 313 (1977) (sustaining the Social Security Act that allows women, who as such have been unfairly hindered from earning as much as men, to eliminate additional low-earning years from the calculation of their retirement benefit works directly to remedy some part of the effect of past discrimination).

and law, on one hand, and identity and individual preferences, on the other, which sees culture and law can only be either external constraints or external supports coming from without and being imposed upon preexisting gender identities of individual man and woman. The notion of preexisting gender identities acts both as the Archimedean point for empiricists to construct their understanding of "archaic stereotypes" and as the Achilles' heel of this whole construct.

The other branch deriving from the "archaic stereotypes" doctrine proceeds in a direction counter to that of the empiricist line of development, and instead speculates if "archaic gender stereotypes" are embedded in social practices, and gender roles are to a great extent constrained by those social practices, what really divides men and women is contingent socialization rather than immutable biology. It challenges the view that there are preexisting gender identities out there to be encroached by inaccurate "archaic stereotypes." "Archaic gender stereotypes" are not the product of bad empirical science. They are but one artifact of patriarchal power relations that situate women in a subordinated position. When women's self-perceptions are in reality constrained by gender roles ordained by those power relations, it is not difficult to see that the very social practices embracing "archaic gender stereotypes" contribute to the construction of gender identities. In this light, the "truth" that empiricist approach captures by phenomenon description could only at best be the end product of an intricate process of socialization in which cultural norms about gender roles are implemented. Drawing on phenomenon description to determine "archaic gender stereotypes" is simply problematic, if not contradictory. This understanding helps to explain why a gender-based classification, though accurately describing what appears to be the empirical phenomenon, might still qualify as an "archaic gender stereotype." It also vindicates the need of being more vigilant about the danger of entrenching "archaic stereotypes" that remedial measures might pose. This is not to say that remedial measures are all normatively undesirable or politically suspicious. This only suggests that since all legal discourses have constitutive effects on identity formation, a remedial measure cannot be taken at its face value and needs to be evaluated by the political usefulness of the identity it constitutes.

Promising though it is, there are still drawbacks to the first prong of life politics. Inspired by the unmasking project, an array of identity-based movements were mobilized to build trenches of resistance for those being devalued and stigmatized on the basis of their identities. Arising out of anger and *ressentiment* against humiliating dominance,[17] identity politics of this kind is revenge sought to "exclude the excluders by the excluded."[18] It seeks to rehabilitate the stigmatized identity without its insults and to encourage its comrades to take pride in taking up their identity.[19] At the same time that

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[17] Thomas Scheff, *Emotions and Identity: A Theory of Ethnic Nationalism*, *in* SOCIAL THEORY AND THE POLITICS OF IDENTITY 277, 281 (Craig Calhoun ed., Oxford: Blackwell, 1994).

[18] *See* MANUEL CASTELLS, THE POWER OF IDENTITY 9 (Malden, MA: Blackwell, 1997).

[19] Feminist identity politics of this kind takes the form of relational feminism. Relational feminism calls to vindicate woman's unique identity as nurturer and caregiver and to approach moral reasoning in a way taking into account the contextualized relational concerns. Robin L. West, *The Difference in Women's Hedonic Lives: A Phenomenological Critique of Feminist Legal Theory*, 15 WIS. WOMEN'S L.J. 149, 210 (2000) (1987). Relational feminism has sometimes been used against women pursuing work opportunities in male-dominated job categories. *See, e.g.*, EEOC v. Sears, Roebuck & Co., 628 F. Supp. 1264 (N.D. Ill.

boundaries of resistance are secured, identity as victim is also essentialized. As Professor Wendy Brown points out, to gain redress through essentialist identity politics, injured groups' identity as victims is all too often depoliticized as natural and becomes their "wounded attachments."[20] Identity politics expressed in this form is, if anything, "the triumph of the weak as weak," "a wallowing in one's victimhood."[21] Given its ignorance of the constitutive nature of identity, the essentialist notion of identity, though not a logical inference from the first prong life politics, marks the limit of any unmasking project.[22] To expand its firing range, life politics needs to further investigate the way in which legal discourse constitutes identity and the desirability of specific identity

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1986), *aff'd.*, 839 F.2d 302 (7th Cir. 1988) (ruling in employer's favor in a Title VII case and reasoning that women's under-representation in a relatively high-paying commission sales positions was not due to employer's discrimination but because women, who prefer less competitive and more friendly work environment, generally lacked interest in commission sales); Joan C. Williams, *Deconstructing Gender*, 87 MICH. L. REV. 797, 806-9 (1989). Abortion foes also invoked relational thesis to justify restrictions of reproductive freedom, such as spousal- and parental-notification or consent statutes, on grounds that relational thesis, placing a very high value on the relational web in which women are located, demands us to honor both the importance of women's outward family relationship and the significance of the inward mother-fetus relationship. *See* Pamela S. Karlan & Daniel R. Ortiz, *In a Diffident Voice: Relational Feminism, Abortion Rights, and the Feminist Legal Agenda*, 87 NW. U. L. REV. 858, 884 (1993). A relational thesis focusing on the inward relationship of women's pregnancy stresses a mother's obligations toward a fetus. *See* Sidney Callahan, *Abortion and the Sexual Agenda: A Case for Pro-Life Feminism*, COMMONWEAL, Apr. 25, 1986, at 232, 235.

[20] *See* Wendy Brown, *Wounded Attachments*, 21 POLITICAL THEORY 390 (1993), *reprinted in* BROWN, *supra* note 1, at 52-76.

[21] Carrie Tirado Bramen, *Why the Academic Left Hates Identity Politics*, 16 TEXTUAL PRACTICE 1, 4 (2002).

[22] The essentialist element of identity politics has often become the very impediment to many identity-based claims, such as racial hate speech laws promoted by Mari Matsuda, *see* MARI MATSUDA, WHERE IS YOUR BODY? AND OTHER ESSAYS ON RACE, GENDER, AND THE LAW 95-99, 109-14 (Boston, MA: Beacon Press, 1996).

constituted in a formative project. This recognition portends the second prong of life politics.

The second prong of life politics springs from disillusionment with the one-dimension model of the relationship between law and personal identity and proceeds to illuminate the role legal discourse plays in the process of identity formation in place of an essentialist notion of the voluntarist self-image. Instead of viewing law as a unidirectional response to social demands arising in the real, law is understood as a dominant "way of imagining the real."[23] As Robert Gordon keenly asserted, the power of legal discourse lies less in "the force that [a legal regime] can bring to bear against violators of its rules than in its capacity to persuade people that the world described in its images and categories is the only attainable world in which a sane person would want to live."[24] Law in its cultural role is not merely the product of human society that carries with it preexisting concepts such as race, religion, social class, gender, ethnicity, and nationality; it helps produce those social categories, constitutes identity *as* those categories, and endows those categories with preferences.[25]

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[23] CLIFFORD GEERTZ, LOCAL KNOWLEDGE: FURTHER ESSAYS IN INTERPRETIVE ANTHROPOLOGY 173 (New York: Basic Books, 3rd ed. 2000) ("[T]he 'law' side of things is not a bounded set of norms, rules, principles, values, or whatever from which jural responses to distilled events can be drawn, but part of a distinctive manner of imagining the real.").

[24] Robert W. Gordon, *Critical Legal Histories*, 36 STAN. L. REV. 57, 109 (1984).

[25] *See* AUSTIN SARAT ET AL., *The Concept of Boundaries in the Practices and Products of Sociolegal Scholarship: An Introduction, in* CROSSING BOUNDARIES: TRADITIONS AND TRANSFORMATIONS IN LAW AND SOCIETY RESEARCH 4 (Austin Sarat et al. eds., Evanston, IL: Northwestern Univ. Press, 1998); Nancy

To the extent that law is a part of cultural norms, the shift of focus from what is being prohibited to what is being constituted places restrictive laws and empowering rights alike under the scrutiny of life politics.[26] Kristin Bumiller's in-depth interview work demonstrated how anti-discrimination laws contribute to form the ideology of victims and make the victimhood their naturalized attribute.[27] In a more general fashion, Wendy Brown undertook a critical analysis of how liberal rights discourse of liberty and equality produces political identity of egoistic man. She contends that the guarantees of liberal rights that the state will regard us all as equal merely abstract us equally from the real social powers that constitute our existence and decontextualize us equally from the unequal conditions of our lives.[28] By providing the protection of liberty and granting sovereign selfhood, "rights discourse in the very same gesture draws a circle around the

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J. Hirschmann, *Toward a Feminist Theory of Freedom*, 24 POLITICAL THEORY 46, 51-53 (1996) (discussing social construction of gender identity); Frank Munger, *Sociology of Law for a Postliberal Society*, 27 LOY. L.A. L. REV. 89, 100-5 (1993) (co-constitutive theory); Julie A. Nice, *Equal Protection's Antinomies and the Promise of a Co-Constitutive Approach*, 85 CORNELL L. REV. 1392 (2000) (applying co-constitutive theory to equal protection jurisprudence).

[26] For some, the notion that empowering right, in addition to restrictive law, also has disciplinary effect would raise a ruckus. While in English we speak of "law" to mean the legal order instituted and enforced in a society and of "right" to mean a power exercised by each person under this legal order, both notions are combined in generic terms in most European languages, such as the German *Recht*, the French *Droit*, and the Latin *Jus*. *See* Kirstie M. McClure, *Taking Liberties in Foucault's Triangle: Sovereignty, Discipline, Governmentality, and the Subject of Rights*, *in* IDENTITIES, POLITICS, AND RIGHTS 149, 153 n.11 (Austin Sarat & Thomas R. Kearns eds., Ann Arbor: Univ. of Michigan Press, 1997) (citing SIR PAUL VINOGRADOFF, CUSTOM AND RIGHT 65-66 (Oslo: Institute for Sammenlignende Kulturforkning, 1925)).

[27] KRISTIN BUMILLER, THE CIVIL RIGHTS SOCIETY: THE SOCIAL CONSTRUCTION OF VICTIMS 52-77 (Baltimore: The John Hopkins Univ. Press, 1988).

[28] *See* BROWN, *supra* note 1, at 110.

individual… and turns back upon the individual all responsibility for her failure, her condition, her poverty, her madness….”[29] What is liberated in this process is a mere image of an abstract rights-bearer. Rights discourse simply reifies that ideal body image as our true identity.[30] We learn the story about who we are through rights discourse as much as it reads out the promise about what we are permitted to do.

3.2 Abortion Rights and the Formative Project

In the domain of abortion debates, some legal scholars have been arguing that the struggles over abortion are not merely competing efforts to embed particular visions of abortion in law. They are indeed competing “efforts to constitute women and men in a particular way.”[31] From this perspective, anti-abortion laws that deny completely women’s access to abortion, although asserted to protect a discrete interest of the fetus as an already autonomous being in contrast to that of the pregnant woman, force women into maternity while assuming and entrenching a view of gender roles.[32] Relying upon the assertions that human life begins at conception and that a fetus is from that moment a full moral person equipped with a bundle of interests and rights, anti-abortion laws call upon Mill’s harm principle to restrict pregnant women’s autonomy as is usually required when

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[29] *Id*. at 128.

[30] *Id*. at 105-18.

[31] Stephen J. Schnably, *Beyond Griswold: Foucauldian and Republican Approaches to Privacy*, 23 CONN. L. REV. 861, 905 (1991).

[32] *See, e.g.*, Catherine A. MacKinnon, *Reflections on Sex Equality Under Law*, 100 YALE L.J. 1281, 1317 (1991) [hereinafter MacKinnon, *Sex Equality*].

interests of moral persons clash.[33] But a fetus is different from a full moral person in that it could be given rights but bears no obligation. Pregnancy does not bring into being two liberal subjects with both rights and obligations in one skin. Rather, the assertion that fetus is a moral person splits one liberal subject into two bodies.[34] It inevitably rests on a premise that separates a pregnant woman from her womb and relegates her to a mere environment for the fetus. Viewing the woman as a container for the fetus simply reinforces the notion that motherhood not only is a natural but also the sole role available for women. Woman's sex is reduced to a mere maternal function. So if, as Professor Catherine MacKinnon argued, personhood is a political status rather than a biological fact,[35] and if, as Professor Drucilla Cornell contended, how one sees a woman and her sex is central to understanding the status of the fetus,[36] anti-abortion law that rests its justification solely on the claim that a fetus obtains full moral personhood at the moment of conception would be nothing but a formative project undertaken to constitute women in accordance with a sexual orthodoxy.[37]

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[33] *See* JOHN STUART MILL, ON LIBERTY 52 (Edward Alexander ed., Peterborough, Ont: Broadview Press, 1999) (1869) ("That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others.").

[34] *See* P. Lealle Ruhl, *Disarticulating Liberal Subjectivities: Abortion and Fetal Protection*, 28 FEMINIST STUD. 37, 38-39 (2002).

[35] *See* MacKinnon, *Sex Equality*, *supra* note 32, at 1316.

[36] *See* DRUCILLA CORNELL, THE IMAGINARY DOMAIN 49 (New York: Routledge, 1995) [hereinafter CORNELL, IMAGINARY DOMAIN].

[37] This may of course have its cultural/social origin. Some suggest that the contemporary politics of defining the role of women through abortion regulations began in years soon after World War II when

Nevertheless, if legal discourse with its constitutive potential does contribute to making us what we are as a society, law that permits abortion on demand, as Mary Ann Glendon alleged, also creates the mores that show disrespect for the value of life and thus produce a breed of callous people we do not want ourselves to become.[38] This is not an argument derived from Mill's harm principle, in which abortion may be seen as harm to the interests and rights of a moral subject. Quite differently, this is an argument informed by recognition of the constitutive potential legal discourse possesses. Under this view, the real damage abortion causes is to what we have to come to think of as selfhood. Abortion regulations reflect the vision of what personal identity a society wants to shape for individuals. This argument is reminiscent of Professor Ronald Dworkin's often-cited *detached* objection to abortion.[39] Dworkin argues that reasons to protect prenatal life do not derive from rights and interests of the fetus but stem from the shared conviction of an ethical environment that human life has intrinsic value. Despite his appealing to the language of intrinsic value, Dworkin does not make the case internally from the standing of a human life and ask what a sacred human life can claim as does the *derivative*

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demands for the domestication of women loomed as a result of postwar reconversion policies that aimed to eliminate huge numbers of women who had been employed outside of their homes since war years from the workplace. *See, e.g.*, Rickie Solinger, *Pregnancy and Power Before Roe v. Wade, 1950-1970, in* ABORTION WARS: A HALF CENTURY OF STRUGGLE, 1950-2000, at 15, 19 (Rickie Solinger ed., Berkeley: Univ. of California Press, 1998).

[38] *See* MARY ANN GLENDON, ABORTION AND DIVORCE IN WESTERN LAW 61-62 (Cambridge, MA: Harvard Univ. Press, 1987).

[39] *See* RONALD DWORKIN, LIFE'S DOMINION 11 (New York: Knopf, 1993) [herein after DWORKIN, LIFE'S DOMINION].

argument.[40] His detached claim instead relies highly upon an external condition: the shared commitment people in a political community have to the transcendental importance of human life. For Dworkin, individual moral convictions form the collective "ethical environment." Human life is intrinsically sacred because people in the same "ethical environment" share the belief that it is so. Abortion causes deep unease because it has an impact on this "ethical environment" in which people live.[41] Dworkin's depreciation of the derivative approach is indeed a rejection to look for the answer to moral questions from rules of thumb embodied in the general understanding of what moral and legal philosophers mean by a moral/legal subject. Eschewing the ready-made language of rights and interests, he resorts to the authority of moral intuitions in the original position to found his detached approach.[42] If the ethical environment is the milieu from which people's moral intuitions or convictions are begotten, and if moral intuitions determine who one is and what lives one can lead, people would want to engage positively in the formative project to shape the contours of their common ethical environment.[43] For Dworkin, the prima facie justification for states to undertake

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[40] The derivative objection to abortion contends that the reasons to prohibit abortion derive from the rights and interests that all human beings have. *See id*. at 11, 13. The derivative claim would eventually invoke Mill's harm principle to prohibit or to restrict abortion.

[41] *See id*. at 167. Sometimes, Dworkin uses "shared collective values" to mean "ethical environment." *See id*. at 149.

[42] *See id*. at 28-29 (moral reasoning from the inside out).

[43] *See* Ronald Dworkin, *Liberal Community*, 77 CAL. L. REV. 479, 480-84 (1989) ("A community that tolerates homosexuality, and in which homosexuality has a strong presence, provides a different ethical environment from one in which homosexuality is forbidden, and some people believe themselves harmed

formative projects through abortion regulations lies exactly on the concern about what kind of people we want ourselves to become. This does not mean Dworkin believes that abortion should be completely prohibited or that women's procreative autonomy has no place in it. Against the backdrop of the shared ethical environment, Dworkin also stresses that whether human life is intrinsically sacred or how best to respect life's sacred value are the most fundamental questions about the meaning and value of one's life and about one's moral personality that should be left to individuals to answer in accordance with their own consciences and moral convictions.[44] That is, Dworkin views abortion regulations as akin to regulating one's religious belief in the intrinsic importance of human life. The community may engage in shaping and maintaining an ethical environment valuing the sanctity of life, but individual woman should be allowed to make the ultimate decision about the meaning of this "contestable" value for herself.[45] In view of this qualification, the proper formative project takes the form of making people aware of the values that the common ethical environment cherishes and encouraging, as opposed to coercing, them to reflect on these values and to arrive at the same convictions.

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by the difference. They find it much harder, for example, to raise their children to instincts and values of which they approve.").

[44] Dworkin argues that this idea finds its constitutional bases not only in the liberty protected by the Fourteenth Amendment but also in the freedom of conscience secured by the First Amendment. *See* DWORKIN, LIFE'S DOMINION, *supra* note 39, at 160-68.

[45] For Dworkin, this marks the distinction between *Roe* and *Casey*. *See id.* at 151-54 ("[S]tates have no power to impose on their citizens a particular view of how and why life is sacred, and yet… states do have the power to encourage their citizens to treat the question of abortion seriously.").

Dworkin calls this an act of encouraging "responsibility."[46] Several regulatory measures that aim at steering women's decisionmaking process, such as waiting period and abortion counseling, if properly devised, might well be justified as legitimate formative projects purposed to preserve an ethical environment by encouraging reflective and deliberate decisionmaking.[47] On the contrary, those measures, such as denial of governmental funding for abortion, that are not to provide chances of deliberate reflection but simply to substitute women's decisionmaking for one that conforms to values of an ethical environment are tantamount to coercing values upon the individual.[48]

Dworkin's account of what abortion regulations meant to constitute is conspicuously different from that of MacKinnon or Cornell who reads the constitutive effects of anti-abortion laws as acting on gender roles. We may not need to decide which account reflects more accurately the reality of the politics of abortion, since it may well be the case that constitutive effects of any given legal discourse always operate on multiple fronts. It is all possible that anti-abortion laws that are meant to steer how people

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[46] *See id.* at 153. *See also* RONALD DWORKIN, FREEDOM'S LAW 111 (Cambridge, MA: Harvard Univ. Press, 1996) ("people have the moral right—and the moral responsibility—to confront for themselves, answering to their own consciences and convictions, the most fundamental questions touching the meaning and value of their own lives.").

[47] Dworkin believes that Pennsylvania's mandatory waiting period regulations in *Casey* do not qualify as a legitimate formative project because the burden they impose may amount to coercion. He suggests that an alternative waiting period regulation allowing doctors to give the required information on the telephone days before the schedule abortion may achieve the goal of encouraging women to reflect on the shared values of an ethical environment while avoiding the hassles women might encounter in Pennsylvania's current regime. *See id.* at 174.

[48] *See id*. 174-76.

perceive the value of human life may at the same time implement a sexual orthodoxy. But it must be noted that these two different accounts of what is constituted in and through abortion regulations envisage very different pictures about upon whom the constitutive effects act. For Dworkin, the whole population in a political community is the proper category to the discussion, while, for feminists, only women are the prime targets constantly harnessed and shaped by abortion regulations which is a mechanism implementing a sexual orthodoxy. This difference may result from the disparity of power between sexes that makes any universal viewpoint unpalatable to feminists. The concerns that women often suffer social disadvantages from pregnancy indeed have prompted more and more legal scholars to see abortion as an equal protection rather than or in addition to a privacy issue.[49] They contend that government should not use the biological fact that only women can get pregnant as a source of social disadvantage and that laws that prohibit or restrict abortion are unconstitutional because they prohibit a procedure that only women need.[50]

The supposition that different social positions breeds different perspectives surely account for, at least partly, the difference between Dworkin and some feminists. There

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[49] *See, e.g.*, Reva Siegel, *Reasoning from the Body: A Historical Perspective on Abortion*, 44 STAN. L. REV. 261 n.5 (1992); Ruth Bader Ginsburg, *Some Thoughts on Autonomy and Equality in Relation to Roe v. Wade*, 63 N.C. L. REV. 375 (1985); Sylvia A. Law, *Rethinking Sex and the Constitution*, 132 U. PA. L. REV. 955 (1984); Catharine A. MacKinnon, *Reflections on Sex Equality Under Law*, 100 YALE L.J. 1281, 1308-24 (1991).

[50] *See* CASS R. SUNSTEIN, THE PARTIAL CONSTITUTION 274 (Cambridge, MA: Harvard Univ. Press, 1993).

lies, however, a more fundamental disagreement between the two views regarding the relationship between constitutive effects and self-identity that goes beyond the mere difference of standpoints. Dworkin in constructing his detached approach to abortion raises a very serious question of how to distinguish a permissible formative project from impermissible coercion. He draws what he believes is a crucial distinction between encouraging deliberate reflection on the shared values and enforcing those values by dictating the result. This distinction holds only if Dworkin can also carve out from his formative projects a niche of voluntarism in which human agency is still possible. That is, in the face of formative projects intended to steer how people perceive the value of human life, the self must demonstrate a degree of freedom and agency of making otherwise differing decisions despite a prevailing milieu that sets up a commendable model of how an ideal self would perceive that value. For Dworkin, the niche of voluntarism exists because formative projects engage only in delivering the messages to and only to the door of the castle in which the self resides. Self is the king and takes full reins over the fate of any information that arrives at the gate. Self can either discard the messages and throw them in the trashcan or act in accordance with what the messages instruct out of his/her own will. This may suggest that, even though Dworkin's discussion of encouraging deliberate reflection centers on the values concerning the existential question as deep as religious beliefs, he would have permitted a formative project purposely designed to uphold a sexual orthodoxy in an ethical environment so long as that formative project does no more than "message delivery." It would not be inconceivable to further formulate an "everything-goes" scenario[51] in which the state is free to encourage individuals to reflect upon any value or concept of the good life that is less fundamental than religious belief but is still deemed as intrinsic to people in an ethical environment.[52] While it is not all that clear whether Dworkin will agree with the inference, he does delegate the authority to the political community to provide the "substance" of the formative projects and avows only to stipulate the "form." Having an orthodoxy about the concept of good life would not be the problem for him; whether the sidetaking is enforced by compulsion or persuasion is the issue. If Dworkin can placidly retreat from the battleground fighting over the subject matters and allow an "everything-goes" scenario, that is all because he believes that he still holds sway over the whole "castle of self." But Dworkin's "castle of self" hints at the notion of a preexisting identity redolent of the liberal thesis of personhood. The personhood thesis maintains that one is able to and must be free to define one's personal identity, and that there is a core of

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[51] Although Professor Linda McClain suggests that Dworkin's theory of ethical individualism would only treat "reflective self-government" as a good that should be fostered by formative project, *see* McClain, *Toleration*, *supra* note 2, at 91-92 (citing DWORKIN, *supra* note 46, at 26; Ronald Dworkin, *Foundations of Liberal Equality*, *in* XI THE TANNER LECTURES ON HUMAN VALUES 16-22, 55-57 (Grethe B. Peterson ed., Salt Lake City: Univ. of Utah Press, 1990)), the "everything-goes" scenario is still possible in Dworkin's formulation since encouraging reflection upon any value deemed intrinsic by the ethical environment would at any rate qualify encouraging reflective self-government.

[52] Dworkin even suggests that coercion can be justified to advance an intrinsic value devoid of religious nature: for example, collecting taxes to finance national museums or imposing conservation measures to protect endangered animal species. *See* DWORKIN, LIFE'S DOMINION, *supra* note 39, at 154.

inviolate personality that must be insulated from external interference.[53] It has become the most common rationale behind the arguments supporting liberal neutrality against formative projects. Professor Linda McClain has faulted liberal neutrality for its "empty toleration" because it erroneously insists on leaving persons alone and fails to recognize the room in which government can seek to promote values and help citizens live good lives.[54] She praises Dworkin's theory for attesting to what she thinks is a better model of "toleration as respect."[55] And yet, both Dworkin and McClain's grips of the flaws of liberal neutrality are too narrow to comprehend what has been made clear by two prongs of life politics: not only that it is almost impossible for law to be neutral since it always takes sides on values, but also that law is not in a neutral position to the conditions of personal choices since legal discourse always contributes to forming one's identity and preferences. Dworkin's thesis on formative projects falls short of a theory of identity formation. His not being able to go beyond the gate of the "castle of self" leaves him only procedural means to manage his formative projects, that is, holding fast to the distinction between encouragement and coercion as the bottom line of formulating permissible or impermissible formative projects.[56]

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[53] *See* Jed Rubenfeld, *The Right of Privacy*, 102 HARV. L. REV. 737, 753 (1989).

[54] *See* McClain, *Toleration*, *supra* note 2, at 38-40, 42.

[55] *See id*. at 23-24, 28-34, 91-100. (alleging that toleration as respect "aims to secure more than pale civility or grudging toleration by appealing to the protection of such good as autonomy, moral independence, and diversity and through seeking to assure mutual respect and civility among citizens").

[56] Most liberal scholars adopt some version of this procedural approach. For example, John Locke distinguished compulsion and persuasion when he argued for religion toleration. *See* JOHN LOCKE, A

Those who view abortion regulations as a mechanism implementing a sexual orthodoxy are generally less sanguine than Dworkin about the voluntarist self-image. Their understanding of how women's agency is constituted in and through legal discourse animates their skepticism toward formative projects. For them, the formative projects undertaken by anti-abortion laws to define what it means by being a woman, although not necessarily made all resistance impossible, have an immense impact on women's identity. Once unselfish motherhood becomes a defining attribute of womanhood or femininity, abortion experience is necessarily a major act of social deviance, an unnatural rejection of being a "real" woman and a selfish denial of the inborn responsibility of childbearing, that brings about both great shame and emotional tragedy. The formative projects of defining womanhood and establishing a sanctioned model of what it means by a real woman have made any other differing identity extremely difficult, if not completely impossible. But why is the model image of a "real" woman not simply an advertising message delivered to the gate of the "castle of self" but more like a Trojan horse that in the end usurps the throne? If legal discourse has constitutive effects on identity formation, we certainly need a theory to explain how the internalization process translates the outside model image into the inner sense of self.

Professor Drucilla Cornell's writings offer an exciting clue to that question.

LETTER CONCERNING TOLERATION, http://etext.lib.virginia.edu/toc/modeng/public/LocTole.html (Charlottesville, VA: University of Virginia Library, 2001) (1689) ("[T]rue and saving religion consists in the inward persuasion of the mind….[I]t cannot be compelled to the belief of anything by outward force."). Justice Stevens's distinction between internal and external constraints is another example. *See* McClain, *Toleration*, *supra* note 2, at 90.

Drawing upon the thesis of the psychologist Jacques Lacan, Cornell charges that formative projects of abortion regulations to define womanhood as motherhood curtail a woman of her "imaginary domain" in which her imagination of herself can be projected as her own identity. She relies on Lacan's mirror stage theory[57] to explicate how one comes to perceive oneself as a coherent whole or self. The process of identity formation begins at a time when an infant, while is still completely dependent on others, display jubilation at the recognition of its mirror image because of its first experience of perceiving itself as a whole. The infant's complete dependency on others to produce and reproduce this experience makes the sight of another human being crucial for infant's identity formation. The infant's actual image in a mirror brought by an adult or in the eyes of the mother or primary caretaker, with which the infant narcissistically wishes to identify itself, functions "both as a projection and an anticipation of what the infant might become but is not now." It is in and through the anticipation of the future as imagining what has yet to be as already given, i.e., the unattainable image of perfection, that the infant is able to project its sense of self. Owing to this imagined anticipation that carries with it a factor of the future anterior, identity formation becomes an endless mirroring process that extends well beyond the stage of infant development. It is a continuing project of becoming a person that is always open to each one of us. Protecting the ever-

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[57] JACQUES LACAN, ECRITS: A SELECTION 1-7, 18-19 (Alan Sheridan tans., London: Tavistock Publications, 1980) (1966). *See also* ELLIE RAGLAND-SULLIVAN, JACQUES LACAN AND THE PHILOSOPHY OF PSYCHOANALYSIS 16-30 (London: Croom Helm, 1986); Tamise Van Pelt, *Lacan in Context: An Introduction to Lacan for the English-Speaking Reader*, 24 COLLEGE LITERATURE 57 (1997) (for a brief introduction to Lacan's theory).

progressing "future into which we project our unity and have our bodily integrity respected by others" thus becomes imperative. What needs to be protected here is not the actual power of control but the need to retain some image of coherence in future anticipation, in spite of the loss of actual control that threatens a return to the experience of the body. "To reduce the self to just 'some body' is to rob it of this future anterior."[58] A law prohibiting abortion deprives a woman of the future projection of her bodily integrity threatened by unwanted pregnancy. Lacan's thesis, however, offers more than viewing restrictive laws as potential barriers to one's future anticipation. Cornell, following the lead of many Lacanian psychologists,[59] propounds to think of a legal system also as a symbolic Other that provides the very mirror image for one to engage in imagined anticipation.[60] It would then be an unequal formation of a woman's sense of self if the mirror image provided by law constructs women's womb as a container for the fetus and defines womanhood as motherhood because she is not established and confirmed as a full person. Abortion regulations, such as a waiting period and abortion counseling, that imply a view of woman as irresponsible, as killing mothers who do not take maternity seriously, similarly constitute serious symbolic assaults on the opportunity of a woman's perceiving herself as a fully individuated being. Cornell then advocates

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[58] Drucilla Cornell, *Bodily Integrity and the Right to Abortion, in* IDENTITIES, POLITICS, AND RIGHTS, *supra* note 26, at 21, 27-29, 58 [hereinafter, Cornell, *Bodily Integrity*]; CORNELL, IMAGINARY DOMAIN, *supra* note 36, at 38-43.

[59] *See* RAGLAND-SULLIVAN, *supra* note 57, at 16 (citing Stuart Schneiderman, Psychoanalysis and Hamlet (1975) (unpublished Ph.D. dissertation, Indiana University)).

[60] Cornell, *Bodily Integrity, supra* note 58, at 31, 77.

preserving a room for the expression of one's "imaginary domain" as the minimum conditions of individuation, in which one can project one's own bodily integrity, "consistent with [one's] imagination of [one]self," and not be forced to have another's imaginary imposed upon oneself.[61]

Treading the path of Cornell's thesis, there is no such thing as pure message delivery as implicitly imagined by Dworkin. Even without the delivery through active acts of encouragement or persuasion, let alone coercion, the existence of a model image itself is invariably a part of the mirroring process that constitutes one's identity.[62] It is a process through which the self must always come around, again and again, to face the challenge posed by the disjuncture between the ideal body image and the real body. Identifying oneself with the ideal image is a function of a desire, in response to the disciplinary gaze of the Other, to overcome the unsatisfactory reality by the ideal.[63] It brings about a symbiotic relationship between identificatory function and disciplinary effect. On the one hand, the ideal body image serves as an observing self watching over our real body and urging the latter to come along.[64] On the other hand, we obtain our

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[61] *Id*. at 43; CORNELL, IMAGINARY DOMAIN, *supra* note 36, at 8, 232.

[62] I do not mean that the distinction between coercion and encouragement is unsustainable or meaningless in formulating the measures of public policies. This is only a call to confront the formative projects directly, instead of hiding behind the "castle of self."

[63] *See* DAVID S. CAUDILL, LACAN AND THE SUBJECT OF LAW 35 (Atlantic Highlands, NJ: Humanities Press, 1997).

[64] In an effort to articulate the psychological origin of egoism of rights, Peter Gabel also contended that legally substantiated image of discrete individuals serves as the "observing self," with disciplinary

identity and autonomy at the same time when we feel at one with the ideal image in the imaginary. Self-differentiation becomes the very source of one's autonomy. We claim to have autonomy either because we retain some image of coherence with the ideal in future anticipation, or we are able to self-criticize our not so satisfactory reality so as to valorize that ideal image. It is by overcoming the disjuncture between the decentered selves in the endless mirroring process that one's identity and autonomy is established and confirmed.

Nevertheless, Cornell's call to protect the imaginary domain for individuals to project their own bodily integrity in accordance with their imagination of themselves sounds surprisingly similar to Dworkin's argument that individuals should be allowed to make the ultimate decision about the meaning of the value of their life in accord with their own consciences and moral convictions. It looks as if Cornell also contended that there is a core of selfhood acting as one's imagination instructor, or instructor for one's consciences and moral convictions as in Dworkin's case, that needs to be protected from outside interferences. Arguably, Cornell's rhetoric of "one's imagination of oneself" is the source of the possible misunderstanding. But if Lacan's thesis is taken seriously enough, Cornell's imaginary domain should not be read as a pre-defined area of selfhood that can be specified in advance and then be guarded by a castle against the intrusion of the Other. The imaginary domain is not to request an unfettered room for imagination independent of mirror images provided by the symbolic Other. The Other is always the

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gazes, to ensure that this image is properly adopted and preserved as self-identity by the "observed self." *See* Peter Gabel, *The Phenomenology of Rights-Consciousness and the Pact of the Withdrawn Selves*, 62 TEX. L. REV. 1563, 1572-74 (1984).

source of our imagination. Rather, the imaginary domain should be understood as a demand imposed directly upon the symbolic Other to accord those mirror images that allow more room for imagination. Viewing in this light, it would not be consistent with the idea of imaginary domain to retreat from battlegrounds fighting over the subject matters of formative projects and to hope to hold fast only to the "castle of self."

Cornell's thesis of identity formation stands in line with the critique of neutrality that second prong of life politics holds up to challenge the notion that law is in a neutral position to self-identity or the conditions of individual preferences and choices. It attests to the idea that legal discourse always contributes to forming one's identity and preferences. With this understanding in mind, we are now in a better position to answer the conundrum with regard to the intricate relationship between negative and positive liberty.

3.3 Liberal Neutrality Revisited

In the paradigm of emancipatory politics, liberal neutrality is deemed imperative in maintaining a proper boundary between individual autonomy and state sovereignty. As mentioned earlier in this chapter,[65] liberal neutrality contains two distinct but interrelated claims. On the one hand, value neutrality demands that the state must not take sides on values, and the undertaking of formative projects tends to be discredited. On the other hand, voluntarist personhood thesis holds that law is in a neutral position to self-identity.

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[65] *See supra* text accompanying notes 2-3.

It denounces and renounces the interplay between law and self-identity. Voluntarist self-image, as both the objective pursued and the presumption held by liberal neutrality, demands individuals be accorded with negative liberty and negative liberty only as a weapon against external constraints in defense of their freedom of choice. These two claims of liberal neutrality form the major axes of contemporary liberal legal thoughts. The traditional version of liberal neutrality regards value neutrality as an indispensable element of securing negative liberty. The modified view, as propounded by Dworkin, is more willing to loosen the injunction of value neutrality and accepts that so long as the minimum space for free choice is secured by negative liberty, any danger that formative projects would have will be minimized to an extent that mere procedural means, whether it is a standard distinguishing encouragement from coercion[66] or a criteria favoring indirect to direct constraints,[67] is enough to handle the situations.

In the realm of human reproduction, the legal paradigm shift from the public health model of reproductive responsibility to fundamental rights talk of reproductive autonomy

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[66] *See, e.g.*, DWORKIN, LIFE'S DOMINION, *supra* note 39, at 151-59.

[67] Justice Stevens adopted this procedural approach in his dissent to *Casey*. He considered as permissible state's promotion of its preferences for childbirth by selectively funding it, by creating and maintaining alternatives to abortion, and by espousing the virtues of family, while disapproving the state's power to "inject into" informed consent its own views of what is best. *See* Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 916 (1992) (Stevens, J., dissenting in part, concurring in part). As suggested by Professor Linda McClain, Justice Stevens's is a criterion distinguishing between the permissible external and the impermissible internal constraints. *See* McClain, *Toleration*, *supra* note 2, at 90. I use the terms "indirect" and "direct" here as opposed to "external" and "internal" because the latter pair of concepts is more appropriate in the discussion of negative and positive liberty in which negative liberty is to guard against external constraints while positive liberty concerns the issue of internal constraints.

is widely heralded as standing for the tenets of liberal neutrality. The entire development of this paradigm shift in the past fifty years or so is a progressive history of ridding personal procreative decisions of the shade of state compulsion. The state is in general no longer allowed to dictate procreative choices or to determine who can or cannot reproduce. State intervention with outspoken eugenics purposes, either negative eugenics or positive eugenics, is unmistakably a violation of liberal neutrality. The risk-free role for the state in the business of human reproduction becomes one that provides value-neutral information. Even when the state is to assume formative projects and to favor one value over the other, it must be undertaken in a way that leaves enough room for an individual to retain the final say. Under this political climate, it is counterintuitive that the avowal of reproductive negative liberty, aiming to preserve the infinite possibilities for voluntary choices, would lend a hand to the implementation of finite governance goals as envisioned by the concept of positive liberty. Negative liberty's out-and-out assurance of infinite possibilities for choices allows liberals to accept individual agreement with those finite goals as unproblematic coincidences out of infinite options. They are inclined to see the problem with eugenics as lying only in the coercion historically and contingently associated with eugenics programs.[68] Free choices to advance eugenics goals are just like any other goal pursued by individuals that incurs no other restriction than heeding the harm principle overall. Moreover, when freedom is defined negatively as the absence of external legal barrier to choices, internal constraints imposed by legal discourse through

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[68] *See, e.g.*, Arthur L. Caplan et al., *What is Immoral About Eugenics?*, 319 BMJ 1284 (1999).

identity formation are of no or lesser concern. The indifference to the issues of internal constraints and constituted identity breeds two extremes of liberal legal thoughts with regard to formative projects. They either deny the constituted effects of law and stringently disapprove any formative project as does the traditional version of liberal neutrality, or like the modified view, leniently accept any formative project without even questioning its substantive value.

Yet, if our earlier discussion of life politics holds true, both negative liberty's promise of infinite possibilities for choices and liberal indifference to the substantive value of formative projects need to be reconsidered. First, Lacan and Cornell's analysis of identity formation suggests that negative liberty is always ready in a position of ensuring not infinite possibilities but individual pursuit of finite preferences and goals. As conventionally understood, negative liberty carves out a realm for infinite free expression of one's voluntarist personhood or self-identity. Yet, if personhood is not given and self-identity is to be projected in the reflex of the gaze of the Other, the absence of external constraints preserves not a wide world of free roaming but a conduit through which identificatory function can operate without interferences. Negative liberty in the form of rights builds and secures the *conduit* of identity formation even though it does not itself supply the *substances*, i.e., the concrete images in Lacan's mirroring process, that flow through it. Deprivation of negative liberty surely obstructs that identificatory function and thus obliterates the sense of autonomy. Preservation of negative liberty nonetheless never leads to free roaming of one's personhood or independent identity formation. The impoverishment of liberal personhood thesis smashes the myth of negative liberty's promise of infinite possibilities for choices. And it is precisely through entrenching the identificatory process, in which the ideal body image is internalized into one's identity, that negative liberty is tethered to the concept of positive liberty. Indeed, negative liberty makes possible a new mode of liberal governance that relies on individuals to internalize the mandate of governance goals. Viewed in this light, if we are to comprehend the full ramification of the paradigm shift to reproductive negative liberty, we need to uncover what lies beneath the surface of the conduit, that is, to ask "what substances are passed on through legal discourse to constitute self-identity."

As a result, we should now be more lucid on the question of why we need to confront directly the substantive value of formative projects and the desirability of self-identity constituted by such projects. All selves are always already "encumbered" by culture, history, ethnicity, and other social institutions, legal systems included, in Sandel's sense. There is no such thing as an "unencumbered self" sitting back and choosing its ends, needs, wants, and purpose in accord with what rights allow them to choose. There is no such thing as an "unencumbered self" that can be guarded against the constitutive effects of legal discourse, either. To embrace a view that once a woman is equipped with a bundle of procreative liberty rights, she can be free from the "majoritarian view of 'right' reproduction or 'right' valuation of prenatal life, family, or the role of women"[69] is certainly too naïve. Nevertheless, the insight of life politics into

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[69] JOHN A. ROBERTSON, CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES 41 (Princeton: Princeton Univ. Press, 1994) (arguing that procreative liberty should offer

the questions of whether and how self-identity is constituted in and through legal discourse is itself an ontological claim about the nature of human being. It does not automatically lead to any normative or legal conclusions. The critique of life politics, however, does help substantiate the contention that we need to take more seriously the substantive value of formative projects. That is, while ontological investigation cannot, on its own, offer proposals about normative advocacy, it points to the necessity of assessing more directly the political desirability of the specific *substances* conveyed through the conduit of legal discourse.[70] We need to ask not only "what substantive content is passed on through legal discourse to constitute self-identity," but also "what good can that identity do to establishing a more tolerant society." That second question is apparently a normative one whose foundation cannot be derived directly from any ontological proposition. But if we are to justify a formative project in a pluralistic society, we should not rely upon a fictitious "castle of self" to back up our claim. We need to instead come to terms with how to form a kind of self-identity that can be more rather than less apt for social cooperation in a pluralistic society. Contrary to what Professor

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protection for action based on differing individual views regarding the symbolic or constitutive meaning of prenatal life, family, and maternal gestation from the restrictions holding a majoritarian view of right reproduction or right valuation of parental life, family, or the role of women).

[70] One example espousing this perspective is Professor Tracy Higgins's thesis on women's "incomplete agency" and democracy. She suggests that the proper target for feminist political and legal theorists is not the accuracy of liberalism's voluntarist self-image but the political implications of the inaccuracy of those assumptions. Given that the combination of incomplete agency (as an empirical or ontological claim) and liberal constitutionalism (as a political scheme) perpetuates women's inequality in a liberal democracy scheme, ontological investigation informs an analysis of alternative structures. *See* Tracy E. Higgins, *Democracy and Feminism*, 110 HARV. L. REV. 1657, 1690-94 (1997).

Sandel thinks of the fixity of the "encumbered selfhood," identity can well be unfixed even though it is constituted. To cooperate in a pluralistic society, we may need to make a kind of self-identity as flexible and porous as possible that allows more room for imagination and expansion.

This stance is consistent with the philosopher Richard Rorty's minimalist liberalism,[71] and goes along with it a new stripe of liberal neutrality whose connotation resembles none of the two traditional claims. It does not renounce the constitutive effects of law on identity and does not denounce the undertaking of formative projects per se. Neither does it fall back on negative liberty to defend a voluntarist self-image. On the other hand, minimalist liberal neutrality's undertaking of formative projects does not necessarily lead to a Sandelian pluralistic republicanism that commits to pursuing a common good. Sandelian pluralistic republicanism calls upon the citizens to engage in the substantive moral deliberation about moral ideals and the notion of good life, and demands the state to accommodate or even cultivate those identity-constitutive encumbrances that qualify as the source of good civic virtues that in the end subserve the pursuit of the common good.[72] Professor McClain further propounds that to achieve the goal of deliberating substantive moral goods, the state must engage in a formative project

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[71] Richard Rorty, *A Defense of Minimalist Liberalism*, *in* DEBATING DEMOCRACY'S DISCONTENT 117 (Anita L. Allen & Milton C. Regan, Jr., eds., New York: Oxford Univ. Press, 1998).

[72] *See* SANDEL, *supra* note 2, at 4-7.

fostering persons’ capacity to participate in deliberative democracy.[73] To the contrary, minimalist liberal neutrality does not take on the concept of the common good or the capacity for self-government as the proper contents of formative projects. Instead, it aims to produce through formative projects only the kind of citizenship that can bracket value differences which come between the self and the others and devote to more extended social cooperation. The only virtue, if any, that minimalist liberal neutrality would attempt to cultivate is one’s sensitivity, one’s responsiveness to the needs of a larger and larger variety of people and things. That is because the sense of solidarity is not created by any capacity of rational deliberation but derives from our willingness to extend the boundary of our selfhood to encompass others. To constitute a flexible self-identity as such, we are able to imagine a more tolerant and better society.[74] Here thus lies the substantive value of any formative project.

With this normative attitude in mind, our inquiry should be directed to interrogate if the *substances* conveyed through current rights discourse of reproductive autonomy helps constitute a self-identity that satisfies that goal. It is increasingly obvious that the source of the *substances* passed on through rights discourse has undergone a significant change from traditional social institutions, such as religion, family, ethnicity, and gender, to life

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[73] McClain, *Toleration*, *supra* note 2, at 41, 50, 57; McClain, *Formative Project*, *supra* note 2, at 1237.

[74] *See* RICHARD RORTY, *Ethics Without Principles, in* PHILOSOPHY AND SOCIAL HOPE 72 (New York: Penguin Books, 1999).

science.[75] We will need to address this change later in the following chapter. Other than that, I find no single judgment about the desirability of reproductive rights. They can be used to constitute the identity that is less reflective, less tolerant of difference, less sensible to other's needs, and less willing to expand its boundary. Or they can be used to constitute quite the opposite types of identity. It all depends upon how rights discourse is mustered in response to each political battle in the current legal and political contexts. The whole debates about reproductive rights being employed to enforce eugenics purposes should be reread in this light.

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[75] On Anthony Giddens's account, social relationships in high modernity are lifted out by "expert systems" from their local contexts and rearticulated across indefinite tracts of time-space. Expert systems are not confined to areas of technological expertise but extend to social relations themselves and to the intimacies of the self. Life sciences mediated by doctors, counselors, therapists and psychiatrists are as important as other natural sciences operated by scientists, technicians or engineers. *See* ANTHONY GIDDENS, MODERNITY AND SELF-IDENTITY: SELF AND SOCIETY IN THE LATE MODERN AGE 18, 29-30 (Cambridge, UK: Polity Press in association with Basil Blackwell, 1991).

4/ BODY, IDENTITY, AND THE LIFE SCIENCE OF GENOMICS

In the previous chapter, I suggested that we understand negative liberty as the conduit of identity formation. The proposal is consonant with Anthony Giddens's call to shun the notion that the self is a passive entity, determined merely by external influences and instead to see self-identity as a "reflexively organized endeavor," in which "individuals are forced to negotiate lifestyle choices among a diversity of options."[1] It is through the exercise of negative liberty that individuals, on Giddens's account, can "contribute to and directly promote social influences" and thereby participate "in forging their self-identities."[2] Yet, negative liberty as such does not itself supply the substances that flow through the conduit it builds and secures or designate the leitmotif that imbues lifestyle choices.

On the other hand, the body has long occupied a privileged status in the making of self-identity. The study of the body sheds new light on the understanding of the nexus between the body and society. In a sense, the nexus lies in the juncture of disciplines, for the body is the common concern of both science and the state, which renders medicine a kind of hybrid technology, existing between the demands of truth and the commands of governmentality.[3] That is to say, the body is an interface between different domains:

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[1] ANTHONY GIDDENS, MODERNITY AND SELF-IDENTITY: SELF AND SOCIETY IN THE LATE MODERN AGE 5 (Cambridge, UK: Polity Press in association with Basil Blackwell, 1991).

[2] *Id.* at 2.

[3] Thomas Osborne, *Of Health and Statecraft, in* FOUCAULT, HEALTH AND MEDICINE 173, 182 (Alan Petersen & Robin Bunton eds., 1997). This view of medicine is first proposed by Kant when he discussed the adequate spheres of philosophy (truth), medicine (health), and law (government). IMMANUEL KANT, THE CONFLICT OF THE FACULTIES 40-43 (Mary J. Gregor trans., Abaris Books 1979) (1798).

biological and social, collective and individual, constrained and free.[4] However, from another viewpoint, without the *discovery* of the body, there can be no human sciences—Sciences of Man—at all, such as economics, sociology, science of biology and psychology.[5] The body renders all these disciplines possible. Thus, the body, on the one hand, is the site at which power struggles are enacted and become real. On the other hand, it is a point of reference of almost every human science, at least for the past two centuries. In what follows, I will first investigate the relationship between the body and self-identity and then explicate how the development of human genomics eventually exerts its formative influence on self-identity.

4.1 Between the Body and Self-Identity

Overdetermined by influences of varied sources, self-identity is at once elusive and substantial. Wrote sociologist Charles Cooley a century ago, "[a]nything whose depreciation makes me feel resentful is myself, whether it is my coat, my face, my brother, the book I have published, the scientific theory I accept, the philanthropic work to which I am devoted, my religious creed, or my country. The only question is, Am I

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[4] J.M. Berthelot, *Sociological Discourse and the Body*, *in* THE BODY: SOCIAL PROCESS AND CULTURAL THEORY 398 (M. Featherstone et al. eds., 1991). *See also*, Nicholas J. Fox, *Is There Life After Foucault?*, *in* FOUCAULT, HEALTH AND MEDICINE 31, 41 (New York: Routledge, 1997).

[5] Michel Foucault argued that with the advent of Man arose the specific studies of man in the form of the human sciences. MICHEL FOUCAULT, THE ORDER OF THINGS: AN ARCHAEOLOGY OF THE HUMAN SCIENCES 128 (New York: Pantheon Books, 1970).

identified with it in my thought, so that to touch it is to touch me?"[6] Cooley must have a keen awareness of the influence of consumer capitalism—the synthesis of negative liberty and consumer culture—on self-identity, for he consciously used the word "depreciation." And once tradition loses its hold and life is detached from the monopoly of a socially and historically rooted narrative, the list that Cooley could have made can virtually go on and on. The car you drive, the clothes and watch you wear, the neighborhood you live in, the furniture in your room, the collection on your walls, the music you listen to, the hairstyle you have, the tattoo on your neck, and so on.

A freely made-to-order self, for some, offers new possibilities for personal liberation and creativity. Others, however, have qualms about the idea that self-identity would become as transient as commodities.[7] They start to wonder, aren't there some things money can't buy?[8] Isn't the claim of being true to oneself a big charade, and mere role-playing that could be easily retained or discarded as circumstances demand? Doesn't the commodification of everything in the end alienate people from themselves rather than enable them to attain their authenticity? Underlying such criticisms is a familiar distinction between self and self-presentation, between our experience of ourselves from the inside and the way we appear to others on the outside[9]—a contemporary version of

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[6] CHARLES HORTON COOLEY, HUMAN NATURE AND THE SOCIAL ORDER 254 (New York: Schocken Books, 1967) (1902).

[7] *See* Joseph E. Davis, *Introduction: Questions of Identity*, 1 HEDGEHOG REV. 5, 7 (1999).

[8] *See, e.g.*, Michael J. Sandel, *What Money Shouldn't Buy*, 5 HEDGEHOG REV. 77 (2003).

[9] *See* CARL ELLIOTT, BETTER THAN WELL 3 (New York: W. W. Norton, 2003).

the age-old Platonist distinction between reality and appearance. In search of a point of reference to judge whether the public performance one presents in front of others is as genuine as one's "inner self" or a fakery that is sometimes a necessary evil but nevertheless betrays the authentic identity, the contenders take it that there must be a composite of characteristics that represents who one "really" is and that any departure from it is a sign of alienation.

Among all the sources that exert influences on the constitution of the self, human embodiment—the biological body—has long occupied a privileged status. The relationship between the body and self-identity intrigues scholars and lay people alike, even though, as suggested by Professor Carl Elliott, such a relationship is sometimes hidden from us. While telling the story that he never noticed the distinctiveness of his local accent until one day he pulled back and saw it from the position of a third person as he watched someone from his little southern town interviewed on television over a local incident, Elliott asserted that one's identity, complacently or not, actually bound up with this trivial body trait—the voice.[10] As immutable and invariable as it seems to be, the body and its varied traits—the voice, the skin color, the facial complexion, the anatomical sex, just to name a few—are commonly appealed to be the Archimedean point against which meanings are determined, values are measured, and the authenticity of the way people present themselves to the world is scaled.[11]

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[10] *See* ELLIOTT, *supra* note 9, at 4-9.

[11] *See* David Harvey, *The Body as Referent*, 1 HEDGEHOG REV. 41, 43 (1999); Berthelot, *supra* note

But even though one can be cynical about those who seek to reduce their accent to conceal the heritage of a presumedly lower cultural status, be unreceptive to Michael Jackson's surreptitious transformation into a white man,[12] or even be somewhat critical about John Howard Griffin's project in 1959—undergoing dermatological treatment, darkening his skin, and then spending six weeks disguised as a black man in the deep South to document racial prejudice he experienced *as* a black man,[13] one cannot deny the fact that even the once irreducible body can no longer be taken as a fixed physiological entity. The advance in life science makes it possible now to do more for, with, and to the human body than ever before. Like other sources of identity formation, which have largely been commodified, the body, its parts and varied traits—including arguably the physical embodiment of the elusive mind, i.e., the brain—are also plunged into consumer culture[14] by cosmetic surgery, bioprosthetics,[15] bioenhancement technologies, personality-altering psychotropic drugs, or even the unsophisticated old-fashioned solutions such as an "accent-reduction clinic."[16] Once the human capability to manipulate

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4, at 391.

[12] *See* ELLIOTT, *supra* note 9, at 206.

[13] *See* Carl Elliott, *Dark Passage: Bioenhancement and Boredom*, 3 HEDGEHOG REV. 24, 26-28 (2001) (referring to JOHN HOWARD GRIFFIN, BLACK LIKE ME (New York: Signet, 1996) (1961)).

[14] *See* Joseph E. Davis, *The Commodification of Self*, 5 HEDGEHOG REV. 41 (2003); Mike Featherstone, *The Body in Consumer Culture*, *in* THE BODY: SOCIAL PROCESS AND CULTURAL THEORY, *supra* note 11, at 170.

[15] *See* JOHN O'NEILL, FIVE BODIES: THE HUMAN SHAPE OF MODERN SOCIETY 11 (Ithaca: Cornell Univ. Press, 1985).

[16] *See* ELLIOTT, *supra* note 9, at 4-14.

the body goes beyond the purpose of restoring the body to its "authentic" or "original" mode, the body is no more immutable than less essential "accessories" or "appendages." The body ceases to be constant in a world of flux; it is the epitome of that flux.

For essentialists, who believe in a preexisting self, the relationship between the body and the self is at most tangential and incidental. Anchoring self-identity on the body is no less likely to alienate self-presentation from self than chasing fashion to gratify vanity. Still, the possibility of actually altering and manipulating the body, including its physical and physiological appearance as well as its psychological personality, gives rise to deep misgivings. It is worried that the self would be removed from its long-standing seat and, in return, be driven to adapt itself to the new body form. Self-presentation acting with the new body, it is envisaged, must make us somehow feel or behave in ways that are alien to us. The adaptation that the self passively takes on, for the better or the worse, is a betrayal. Residing in a phony carcass, the self can only drift in a nostalgic state hankering for the return to its original home.

The essentialist fear of alienation, the apprehension that impulsive self-presentation would not follow the lead of our inner fixed self and even threaten to usurp the throne, however, does not conform to many people's modern life experiences. After taking the antidepressant drug Prozac, one patient, like many others, buoyantly said, "This is who I am. I just feel strong. I feel resilient. I feel confident."[17] The remark bewildered the

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[17] *See* PETER D. KRAMER, LISTENING TO PROZAC 219 (London: Fourth Estate, 1994).

essentialist contenders because, to their surprise, the patient did not describe that Prozac made her feel like a *different* person and instead stated that it made her feel like *herself*. The essentialist contenders could not but wonder: is the striking transformation "a metamorphosis to a new, better self?" They would rather consider it as merely "the restoration of a true self that had been masked by pathology."[18] For others, the distinction that essentialists made is purely rhetorical. A new person or not, what is critical is that the alteration of the body form brings to the patient not the angst of alienation but a sense of bliss and self-fulfillment. She obviously identified herself with her self-presentation and seemed near to mutter the words that "I am my body."[19]

As Professor Elliott argued, [technology-mediated alterations of the body form] may initially make people feel awkward or uncomfortable, but with enough time and practice it comes to feel natural, even an extension of the self," just like a new driver may feel it difficult to manage to shift gears and steer a car at the same time, "but in time she can maneuver the car as easily and naturally as she can maneuver her own body."[20] What Elliott describes is not the "body" as a fixed phenomenon but "embodiment" as "the effect or consequence of ongoing practices of corporalization"—"a life process that requires the learning of body techniques," such as walking, sitting, dancing, eating, and

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[18] *See* ELLIOTT, *supra* note 9, at 51.

[19] *See* MAURICE MERLEAU-PONTY, PHENOMENOLOGY OF PERCEPTION xii (Colin Smith trans., New York, Humanities, 1970) (1962).

[20] *Id*. at 25.

speaking.[21] "Embodiment" is the lived experience of the subjective body, a process of making and becoming a body; it is also the project of making a self. In the language of British sociologist Bryan Turner, "[t]he body is simultaneously an object that I can observe and a mode of being that makes that observation possible."[22] The relationship between the self and its own body "is never an external, objective, or neutral relationship, because identity is inextricably bound up with subjective being in the material world."[23] After all, there is no such thing as a preexisting, concrete, unitary self. The body is not only the often inconvenient and inadequate seat of the self; the body in its making constitutes, at least in part, the self.

But what constitutes the process of "embodiment" that in turn constitutes self-identity? Two elements are to be considered here: the *corporeality* of the body and *discourses* about the body. Cooley himself noted that our sense of ourselves is formed by a process of social reflection—the imagination of the way we appear to others, the imagination of their judgments about us, and some sort of self-feeling reaction to that judgment, such as pride or mortification.[24] Cooley used the metaphor of the looking glass to illustrate his theory of the self. In one sense, the *corporeality* of the body, as the self-image that one sees in the looking glass, is the most intuitive and immediate source of

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[21] Bryan S. Turner, *The End(s) of Humanity: Vulnerability and the Metaphors of Membership,* 3 HEDGEHOG REV. 7, 12-13 (2001).

[22] *Id.* at 14.

[23] *Id.*

[24] *See* COOLEY, *supra* note 6, at 184.

how one recognizes oneself. In another sense, the corporeal body exists as the obdurate fact that prescribes the boundary of possibly deranged identities. When the court convicted thirty-something Treva Throneberry for perjury and false pretense (second degree theft in Washington state), it was the corporeal body of the defendant who furiously insisted that she was not Treva Throneberry but Brianna Stewart—a teenage runaway from a stepfather who had subjected her to cult ritual abuse and pornography—that frustrated the defense of identity mismatch.[25] The fingerprints as well as the complete healing of the gums over the wisdom teeth accidentally revealed during a dental checkup bore out that the "body" of the self-proclaimed teenage runaway was indeed that of the 32-year-old Throneberry who, over a 15-year period, had used several aliases to tell similar stories in at least eight states.[26] People do not find it difficult to conclude that what "Stewart" did was simply an attempt to reject her past and what she claimed was just a sheer lie.

However, it would certainly be misleading to think that since the body constitutes the self, a freely malleable corporeal body hints at liberation in making one's self-identity. Indeed, it would be a major error to assume that the body exists merely in its corporeality. The process of "embodiment" is formed not just by the corporeality of the body but also

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[25] *See* Washington v. Throneberry, Nos. 28167-8-II, 28977-6-II, 2003 WL 21174881 (Wash. App. 2003), *cert. granted*, 81 P.3d 120, 150 Wash. 2d 1018 (2003).

[26] For a summary of the story, see *Search for Identity*, ABC NEWS, July 8, 2004, *at* http://abcnews.go.com/sections/Primetime/US/briannastewart040708.html.

discourses about the body.[27] Intuitive and obdurate though it is, the corporeality of the body is very often constituted in a discourse at any given time and space that seeks some "truth" of bodies.[28] Discourses about the body form the normative parameters of how the body can understand itself. This point is perhaps most evidently shown in Professor Elliott's own examples. Elliott did not perceive the corporeality of his accent until one day it was contrasted and confronted under the imagined gaze of a third person—the lens of the television camera. But it is through discourses about the ways in which the body with the very body technique—speaking—should perform in different socio-cultural contexts that the distinctiveness of one's accent becomes perceivable to oneself. A television news reporter should speak like a Yankee. "If you don't, you sound like a hick." A bluegrass fiddler had better have the lowly southern drawl. And while a perfect upper-class English accent may drive your social status up for your day job at the phone company, it may drive you down for your night job at the bar.[29] Similarly, when a patient identifies more with her corporeal body exhibiting "charisma, courage, character and social competency" while on Prozac than with the one that lost these attributes without the drug, it is discourses about how the body should behave as a productive, exploitable body that make one corporeal body rather than the other more palpable and palatable. Different institutions in different time generate different discourses about the truth of the

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[27] *See* Arthur W. Frank, *For A Sociology of the Body: An Analytical Review*, *in* THE BODY: SOCIAL PROCESS AND CULTURAL THEORY, *supra* note 11, at 36, 48-49.

[28] *See id.* at 49.

[29] *See* ELLIOTT, *supra* note 9, at 6, 11.

body.[30]

As a matter of fact, while deriving his notion of the “looking-glass self” from the relatively intuitive idea that what one sees in the mirror is what others see, Cooley stressed that he did not speak of the mere mechanical reflection of one’s corporeal body. Rather, it is “the imputed sentiment, the imagined effect of this reflection upon another’s mind” that moves us to pride or shame and that gives rise to the effect of identity formation.[31] As Cooley put it, “We always imagine, and in imagining share, the judgments of the other mind.”[32] The body image emerges as the imagined gaze of others brings our sense of ourselves in line with our imagination of the way we appear to and are judged by others. What Cooley’s looking glass actually reflects on oneself is not one’s corporeal body but discourses of others about that body. We literally see ourselves in the judging eyes of others.[33] This reading of Cooley’s theory of the source of the self

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[30] John O’Neill outlined discourses about the body in three different levels of body politics. At the level of the bio-body, discourses about the body are about well-being, health, and sickness; at the level of the productive body, discourses are about self-control and exploitation; at the level of the libidinal body, discourses are about happiness, creativity, and discontent. *See* O’NEILL, *supra* note 15, at 80.

[31] COOLEY, *supra* note 6, at 184.

[32] *Id*. at 184-85.

[33] *Cf.* DAVID RIESMAN ET AL., THE LONELY CROWD: A STUDY OF THE CHANGING AMERICAN CHARACTER 31 (Garden City, NY: Doubleday, 1953) (1950) (identifying the “outer-directed” personality as the dominant personality type of mid-century America, which looks outward for a guide to action by monitoring what others think, registering their approval or disapproval, and manipulating self-presentation to match). However, even the more stable “inner-directed” personality, which Riesman contrasted with the “outer-directed” type, is inculcated in childhood by their “parents” and “other figures of authority.” That is to say, even though different in the range of other people, both the “outer-directed” and the “inner-directed” personality obtain the self-image from the Other.

converges with Jacques Lacan's symbolic Other that furnishes the mirror image.[34]

Establishing the ideal body image in different time and for different institutions, discourses about the body delineate the permissible range of the formative effect that the corporeality of the body could have on self-identity in the process of "embodiment." That is, whereas the corporeal body is rendered more and more malleable, discourses about the body, whose deployment centers around the ideal body image, would eventually steer the way that the body is actually altered and manipulated as well as the way that the self is made. Malleability of the corporeal body is to be hinged upon its conformity to such discourses about the truth of the body. For instance, sex-reassignment surgery and the training for new body techniques make one's gender identity literally malleable. Dominant discourses about the sexual bodies nevertheless become the yardstick that finally determines what counts as a successful transsexual passage. Those discourses very often involve cultural stereotypes about sex difference. For male-to-female transsexuals, the body techniques that they have to learn in addition to the surgery are "the way that women wave their hands and let their voices move up and down in pitch while they talk, the way their speech is passive and indirect." But as one male-to-female transsexual aptly pointed out, the point of getting the body transformed in the case of sex-reassignment "is not to challenge stereotypes." It is "to *become* a stereotype."[35]

The phrase of "the ideal body image" at once raises the specter of social conformity.

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[34] *See supra* text accompanying notes 57-64 of Chapter 3.

[35] ELLIOTT, *supra* note 9, at 23 (emphasis original).

Historian David Rothman expressed the exact concern when he criticized the "cosmetic" use of surgery, psychopharmacology or even endocrinology to enforce social values—to "enable 'them' to become more like 'us'."[36] But the fear that the human capacity to alter and manipulate the corporeal body would be used to conform to a narrow, restricted cultural ideal also encounters objection dismissing the charge as unrealistic or absurd. For those who object, there are—at least in America—always people who want to stretch the limits of convention, who thrive on being different, who defy cultural norms, who have been primed from an early age to celebrate resistance, who see getting ahead of others by shifting one's very identity to win the approval of others as shallow, as a form of weakness. Even if America did not deserve to be called a land of rebels, at least it is definitely not a land of social conformists who follow whatever discourses about the body embraced by the majority.

As eloquently argued by Elliott, there is, however, an ironic ambivalence about the American rebellion. In public, people seem to be officially anti-conformist and blame "other" Americans for being either too crooked or deluded to resist the temptation of "caving in" to dominant discourses about the body. And yet in private, people get cosmetic surgery, take Prozac, and have their children received growth hormone, while at the same time "nagging anxieties about social conformity, about getting too much too easily, about phoniness and self-deception"[37] As Elliott sees it, what prompts most of the

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[36] *See* David J. Rothman, *Listening to Prozac*, 210 NEW REPUBLIC 34, 36-37 (1994) (book review).

[37] ELLIOTT, *supra* note 9, at 298.

lukewarm rebels to become conformists is not the temptation of getting ahead of others, but "the terror of being left behind, and the humiliation of crossing the finish line dead last, while the crowd points at you and laughs."[38] Americans do not want authority or tradition to tell them what to do, but they are constantly looking over their shoulder at their peers, neighbors, bosses, experts, the anonymous public.[39] Elliott admitted that there are still alleged diehard rebels who would organize protest movements to fight against majority norms. American society is never scant of countercultural emblems, such as dreadlock, neck tattoo, tongue stud, or man's earring, that are attempted to defy the discourses of the established society about how the body should dress up itself. The Canadian feminist philosopher Kathryn Morgan even suggested that women engage in a subversive movement to fight against oppressive standards of beauty by having their breasts pulled down, bleaching their hair gray, and asking cosmetic surgeons to induce wrinkles into their faces.[40] But the rebels of such protests simply subscribe themselves to another set of discourses about the body, i.e., that of the protests themselves, which can be just as conformist as the ones that they are intended to undermine.[41] For Elliott, the rebels and the conformists are birds of a feather. They all cannot help submitting to discourses about the body one way or another.

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[38] *Id.*

[39] *See id.* at 44, 201-3.

[40] *See* Kathryn Pauly Morgan, *Women and the Knife: Cosmetic Surgery and the Colonization of Women's Bodies, in* SEX/MACHINE: READING IN CULTURE, GENDER AND TECHNOLOGY 278-79 (Patrick D. Hopkins ed., Bloomington: Indiana Univ. Press, 1998).

[41] *See* ELLIOTT, *supra* note 9, at 204-5.

Elliott's criticism towards American ambivalence about rebellion and social conformity seems to suggest that unless we, conformists and rebels alike, give up the bad habit of peeking in and following what others do and instead establishing our own contact with and understanding of our corporeal body, we are at a dead-end.[42] The problem is that there is hardly a process of "embodiment" that is free from discourses about the body. But Elliott is at least correct about the point that the ideal body image constituted by any single discourse about the body is never at once universal and dominant. Competition and struggle among discourses are rather a common state. Therefore, the real challenge that Elliott might have argued would be rooted in what Giddens called the phenomenon of the "disembedding" of social institutions—"the 'lifting out' of social relations from local contexts:"[43] whereas it was possible in pre-modern societies to carry on one's life almost solely in terms of one's own local knowledge/discourses about the body, or that of the immediate kinship group if one so wished, no such disengagement is possible in modern societies.[44] Expert systems penetrate virtually all aspects of social life and occupy a dominant position in generating discourses about the body. As a result, while it is possible to find alternative discourses to contend or even to substitute the established ideal body image in pre-modern societies, it would be extremely difficult, if not entirely impossible, to locate such alternatives. This difficulty would stymie even Elliott's diehard

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[42] *See id.* at 206 ("As long as we live in a society in which a person's own happiness is so dependent on the opinions of others, we will always have the problem of people feeling oppressed by cultural standards.").

[43] *See* GIDDENS, *supra* note 1, at 17-18.

[44] *Id*. at 29-30.

rebels. It is against this backdrop that the role of life science—the expert system with regard to the body and body techniques—becomes the focus of our investigation of the relationship between the body and self-identity.

Yet if, as Elliott would argue, neither conformists nor rebels can claim that the discourses they espouse are *better* than what their rivals adopt, the mere fact that there is no alternative to discourses of life science about the body should be no more objectionable than otherwise. Indeed, Elliott did not provide any clue as to how to determine which discourse is *better*. We might need to locate such a normative standard if we are to argue that discourses of life science about the body are indeed objectionable for any reason. But I shall first turn to human genomics—the newest life science of the human body—and discourses it generates.

4.2 Discourses of Human Genomics and Two Features of Genomic Medicine

As the source of identity formation, discourses about the body exist and are reproduced only through bodies and their techniques.[45] The access to the body and the capacity to develop or improve body techniques thus become critical in generating effective and authoritative discourses. Discourses of life science, however, do not always produce the ideal body image in a straight manner. More often than not, it is through discourses about the diseases, about the ill-bodies, that the ideal body image embedded in life science is brought to light and comes to life.

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[45] *See* Frank, *supra* note 27, at 91.

With the anatomy of the human genome at hand, the progress that leads to a new understanding of genetic contributions to human disease has naturally promised wide-ranging applications in developing more rational and powerful strategies to anticipate, diagnose, treat, and prevent human diseases at both individual (individual medicine) and population (public health) level. Such a capacity allows human genomics to disseminate its discourses about the body more easily and thoroughly.

The most intuitive application of human genomics in health-related areas comes from the knowledge about specific mutations as the genetic cause of human disease. This knowledge enables anticipation of disease before the symptoms of the disease even emerge and makes early preemptive intervention possible.

By far, the most celebrated example of this application is the presymptomatic diagnosis of phenylketonuria (PKU), an autosomal recessive metabolism disorder that causes mental retardation, organ damage, and unusual posture, and, in cases of maternal PKU, severely compromises pregnancy.[46] Unlike diseases for which information about the function of the responsible gene is mysterious to scientists before or even after disease-related genes are identified,[47] it has been known long before the boom of modern human genomics that PKU results from a deficiency in the enzyme phenylalanine

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[46] *See* ROBERT F. MUELLER & IAN D. YOUNG, EMERY'S ELEMENTS OF MEDICAL GENETICS 154 (New York: Churchill Livingstone, 2001).

[47] *See* Francis S. Collins, *Positional Cloning: Let's Not Call It Reverse Anymore*, 1 NATURE GENETICS 3, 3 (1992).

hydroxylase (PAH), whose function is to convert phenylalanine, an amino acid found in most foods, to tyrosine.[48] This knowledge about the basic biochemical defect alone allows scientists to diagnose people with PKU without even resorting to any DNA-based technology.[49] Treatment of PKU is also simple. A low or phenylalanine free diet, supplemented by a formula combining extra tyrosine with other essential amino acids and vitamins and minerals, has proved to prevent the disease from manifestation,[50] and early adequate dietary treatment during pregnancy may also provide some protection to the fetus for later intellectual development.[51]

Presymptomatic diagnosis together with effective preemptive intervention has made PKU an exemplary model of *phenotypic prevention*—the prevention of disease and death among people with specific genotypes—that is so complacently praised by advocates of genomic medicine.[52] But not every disease amenable to presymptomatic

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[48] *See* George A. Jervis, *Studies on Phenylpyruvic Oligophrenia: The Position of the Metabolic Error*, 169 J. BIOLOGICAL CHEMISTRY 651 (1947).

[49] Indeed, although all cases of classical PKU arises from a deficiency of phenylalanine hydroxylase, more than 100 different mutations in the responsible PAH gene have now been identified. *See* Per Guldberg et al., *A European Multicenter Study of Phenylalanine Hydroxylase Deficiency: Classification of 105 Mutations and a General System for Genotype-based Prediction of Metabolic Phenotype*, 63 AM. J. HUM. GENETICS 71 (1998). This makes a simple biochemical test seem more preferable than DNA-based technology.

[50] *See* Horst Bickel, *Influence of Phenylalanine Intake on Phenylketonuria, 2* LANCET 812 (1953); Susanne Schweitzer-Krantz & Peter Burgard, *Survey of National Guidelines for the Treatment of Phenylketonuria*, 159 Supp. 2 EUR. J. PEDIATRICS S70 (2000).

[51] *See* Centers for Disease Control & Prevention, *Barriers to Dietary Control Among Pregnant Women with Phenylketonuria—United States, 1998-2000,* 51 MMWR 117 (2002).

[52] *See, e.g.*, Charles R. Scriver, *Phenylketonuria—Genotypes and Phenotypes*, 324 NEW ENG. J. MED.

diagnosis permits full-fledged phenotypic prevention.[53] For example, DNA-based detection of the HbSS mutation of hemoglobin beta gene (HBB) helps to identify people who may develop sickle cell anemia,[54] an autosomal recessive blood disease that causes hemolytic anemia, pain crises, susceptibility to serious infection, stroke, and eventually chronic damage to the lungs, bones and kidneys.[55] However, there is no cure, as yet, for the disease.[56] Treatment, including use of a combination of prophylactic antibiotics, painkillers, and red blood cell transfusions, is only good for symptom management as well as complications and deterioration prevention.[57] Nonetheless, this *tertiary* or limited *secondary* preventive medicine[58] has still reduced disease mortality caused by bacterial

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1280 (1991).

[53] *See* Eileen Treacy et al., *Response to Treatment in Hereditary Metabolic Disease: 1993 Survey and 10-year Comparison*, 56 AM. J. HUM. GENETICS 359 (1995) (assessing the efficacy of treatment for 65 hereditary metabolic diseases).

[54] A more common protein-based hemoglobin electrophoresis test is also used to detect sickle cell anemia. *See* Dale Halsey Lea & Janet K. Williams, *Genetic Testing and Screening*, 102 AM. J. NURSING 36, 37 (2002). Earlier test could only detect the existence of HbS mutation but was unable to distinguish individuals with homozygous HbS mutations that cause sickle cell anemia from those who are only the carriers of one HbS mutation (sickle cell trait).

[55] *See* Richard S. Olney, *Preventing Morbidity and Mortality from Sickle Cell Disease: A Public Health Perspective*, 16 AM. J. PREVENTIVE MED. 116, 116 (1999).

[56] Recent progress has increased hope for the future of somatic gene therapy for sickle cell anemia. *See* William Mentzer &Yuet Wai Kan, *Prospects for Research in Hematologic Disorders: Sickle Cell Disease and Thalassemia*, 285 JAMA 640, 641 (2001).

[57] *See* Sally C Davies & Lola Oni, *Management of Patients with Sickle Cell Disease*, 315 BRIT. MED. J. 656 (1997).

[58] In the domain of preventive medicine, *secondary* prevention means early detection and intervention before the condition is clinically apparent, and has the aim of reversing, halting or at least retarding the progress of a condition, while *tertiary* prevention means minimizing the effects of disease and

infections during infancy.[59] Statewide public health measures, as exemplified in the passage of the National Sickle Cell Anemia Control Act of 1972, which provided for establishment of voluntary sickle cell anemia screening and counseling programs,[60] has led to a 41% decrease of mortality rate for 1-to-4-year-olds, 47% for 5-to-9-year-olds, and 53% for 10-to-14-year-olds.[61] With good health care, many people with the "first molecular disease" of the 20th century[62] are now in reasonably good health much of the time, and living productive lives with a median life expectancy of 42 and 48 years respectively for men and women.[63]

The wide spread of human genomics's discourses about the body (knowledge about specific mutations as disease etiology) also subserved the reduction of incidence of the

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disability by preventing complications and premature deterioration. *See* John M. Last, *Scope and Methods of Prevention*, *in* MAXCY-ROSENAU-LAST PUBLIC HEALTH AND PREVENTIVE MEDICINE 3, 4-5 (John M. Last & Robert B. Wallace eds., Norwalk, CT: Appleton & Lange, 13th ed. 1992).

[59] *See* Marilyn H. Gaston et al., *Prophylaxis with Oral Penicillin in Children with Sickle Cell Anemia*, 314 NEW ENG. J . MED. 1593 (1986).

[60] Pub. L. No. 92-294, May 16, 1972 86 Stat. 136 (repealed 1981).

[61] *See* Harold Davis et al., *National Trends in the Mortality of Children with Sickle Cell Disease, 1968 Through 1992*, 87 AM. J. PUB. HEALTH 1317 (1997). *See also* Centers for Disease Control & Prevention, *Mortality Among Children with Sickle Cell Disease Identified by Newborn Screening During 1990–1994—California, Illinois, and New York*, 47 MMWR 169 (1998).

[62] Linus Pauling and his colleagues found in 1949 that the cause of sickle cell anemia could be traced to an alteration in the molecular structure of a protein, and, as this disease was known to be inherited, argued that genes precisely determine the structure of proteins. Pauling and his colleagues then called sickle cell anemia "a molecular disease." *See* Linus Pauling et al., *Sickle Cell Anemia, a Molecular Disease*, 110 SCIENCE 543 (1949); Bruno J. Strasser, *Sickle Cell Anemia, a Molecular Disease*, 286 SCIENCE 1488 (1999).

[63] *See* Orah S. Platt, *Mortality In Sickle Cell Disease—Life Expectancy and Risk Factors for Early Death*, 330 NEW. ENG. J. MED. 1639 (1994).

disease in general population through individual manipulation of reproductive decisions, including whether to get married with a carrier, whether to procreate, or whether to obtain an abortion once a pregnancy has occurred. A hospital-based study in New York City reported that 51% of 83 pregnancies with fetuses affected by sickle cell anemia (HbSS) were terminated, and 12% of 25 pregnancies were terminated when a clinically less serious form of sickle cell disease (HbSC) was prenatally diagnosed.[64] Another study in Cuba reported that a nationwide sickle cell prenatal screening program initiated in 1983 resulted in termination of 74% of 243 pregnancies with fetuses affected by either HbSS or HbSC by the end of 1992.[65] With few exceptions, reproductive manipulation resulting in case reduction, together with amelioration of suffering and disability by secondary and tertiary prevention measures, characterizes the achievement that knowledge about specific mutations as disease etiology has contributed to improvement in human health.

4.2.1 Risk Management

But this picture covers not even half of the landscape that genomic medicine has envisaged. Two features, *risk management* and *individualization*, characterize the outlook of the newfound land mapped out by genomic medicine. Through the risk management paradigm and the individualized approach of genomic medicine, the formative influences

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[64] Xiuhua Wang et al., *Experience with 500 Prenatal Diagnoses of Sickle Cell Disease: The Effect of Gestational Age on Affected Pregnancy Outcome*, 14 PRENATAL DIAGNOSIS 851 (1994).

[65] Hilda Granda, *Results from a Reference Laboratory for Prenatal Diagnosis of Sickle Cell Disorders in Cuba*, 14 PRENATAL DIAGNOSIS 659 (1994).

of human genomics penetrate virtually all aspects of human life.

First, risk management substitutes for sheer prediction. As advances in human genomics bring about a paradigm shift in biomedical research from static identification of specific mutation as disease etiology to dynamic understanding of the mechanism of disease pathogenesis,[66] new genomic medicine also foresees an innovative way of thinking of disease prevention.[67] Even though the old paradigm of disease prevention comes pat to the controlling of fully penetrant single-gene (and chromosomal) disorders,

Table 4-1 Paradigm of Disease Prevention vis-à-vis Types of Disorders

	Focus of Genomic Research	Prevention of Single-Gene Disorders	Prevention of Multifactorial Disorders
Prediction Paradigm	Etiology	Genotypic prevention as the strategy of primary prevention raises "eugenics" concerns	Not suitable
Risk-Management Paradigm	Pathogenesis	Identification and interruption of cofactors in the pathogenetic pathway	Identification and interruption of cofactors in the pathogenetic pathway

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[66] *See* Leena Peltonen & Victor A. McKusick, *Dissecting Human Disease in the Postgenomic Era*, 291 SCIENCE 1226 tbl. (2001).

[67] *See* Muin J. Khoury, *Relationship Between Medical Genetics and Public Health: Changing the Paradigm of Disease Prevention*, 71 AM. J. MED. GENETICS 289, 290 (1997) [hereinafter Khoury, *Changing the Paradigm*]; Muin J. Khoury, *From Genes to Public Health: The Applications of Genetic Technology in Disease Prevention*, 82 AM. J. PUB. HEALTH 1717, 1717-18 (1996) [hereinafter Khoury, *From Genes to Public Health*].

prevention of multifactorial diseases often defies this simple linear approach. Plagued by incomplete penetrance, knowledge about susceptibility genes alone is of limited use for clinical prediction and seldom leads to successful prevention of multifactorial disorders, whose etiological origins involve the complex interplay between multiple genetic factors and between genetic factors and non-genetic environmental influences. Moreover, because generally lacking knowledge about complex metabolic pathways through which genes and gene products develop disease,[68] the *therapeutic gap* separating discovery of etiology and full phenotypic prevention often exists in the old paradigm of disease prevention. Unless blessed with additional knowledge about the functions of specific mutations as in the case of PKU, the old paradigm thus far has focused on strategies of preventing the conception and/or birth of affected individuals to achieve the public health goal of primary prevention.[69] This shortcoming inevitably summons the specter of eugenics and fires up a bitter controversy over whether *genotypic prevention*—the prevention of births of individuals with specific genotypes—is a proper public health pursuit.[70]

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[68] *See* C. Thomas Caskey, *Presymptomatic Diagnosis: A First Step Toward Genetic Health Care*, 262 SCIENCE 48, 49 (1993).

[69] *See* Khoury, *From Genes to Public Health*, *supra* note 67, at 1717-18. In the domain of preventive medicine, *primary* prevention means preventing the occurrence of disease or injury. *See* Last, *supra* note 58, at 4.

[70] Those who oppose genotypic prevention as a public health goal argue that the living individuals should be the subjects to be benefit from disease prevention and stress the private nature of the reproduction decision-making. *See*, Eric T. Juengst, *"Prevention" and the Goals of Genetic Medicine*, 6 HUM. GENE THERAPY 1595, 1596-97 (1995); Benjamin S. Wilfond & Elizabeth J. Thomson, *Models of*

On the contrary, the new paradigm of human genomics seeks to elucidate environmental cofactors as well as the coordinated genetic networks, in which gene products, i.e., proteins, perform their functions by interacting with each other,[71] and therefore opens up great opportunities to discern new prevention strategies at different points in the entire pathogenetic pathway. The new way of thinking of disease prevention proves to be especially valuable for multifactorial disorders. With more knowledge about how genes through pathogenetic pathway develop into diseases, prevention of disease under the new paradigm will be carried out via identification and interruption of environmental cofactors that interact with disease-related genes in the eventual development of the disease.[72] The emphasis on predictive power of genomic medicine in traditional paradigm is substituted with new strategy of risk management. Incomplete penetrance no longer prevents the information of susceptibility genes from being practically useful. The purpose of detecting one's disease-related genes is not, as in the case of prediction paradigm, to prophesy with certainty the future manifestation of a clinical disease but to formulate a comprehensive plan of risk management of the disease.

Public Health Genetic Policy Development, *in* GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY: USING GENETIC INFORMATION TO IMPROVE HEALTH AND PREVENT DISEASE 61, 66 (Muin J. Khoury et al. eds., New York: Oxford Univ. Press, 2000). On the other hand, the proponents of public health genotypic prevention focus on the public duty to prevent harm. *See* Ellen Wright Clayton, *What Should Be the Role of Public Health in Newborn Screening and Prenatal Diagnosis?*, 16 AM. J. PREVENTIVE MED. 111, 114-15 (1999).

[71] *See* Francis S. Collins et al., *A Vision for the Future of Genomics Research*, 422 NATURE 835, 837-39 (2003).

[72] *See* MUIN J. KHOURY ET AL., FUNDAMENTALS OF GENETIC EPIDEMIOLOGY 325 (New York: Oxford Univ. Press, 1993).

The information of disease-related genotype, regardless of its penetrance, acts as a pivot on which effective risk reduction can be leveraged.

For instance, as a well-studied example of multifactorial disease, coronary heart disease (CHD) involves at least 19 disease genes and 26 other susceptibility genes contributing small to moderate effects on increased risk for the disease.[73] Four of these disease-related genes are of illustrative value here. First, the best known risk factor for CHD is familial hypercholesterolemia (FH) characterized by elevated LDL cholesterol level. Heterozygous status of the LDL receptor gene is thought to be associated with FH and is found in 5% of persons with early CHD and in 0.2% of general population.[74] Second, another common CHD caused by disorder of body fat metabolism is familial combined hyperlipidemia (FCHL), which accounts for 10% of premature CHD cases. Five percent of persons with FCHL have heterozygous status of the LPL gene mutations.[75] Third, a mutation of MTHFR gene affects the level of an enzyme, whose

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[73] *See* Darrell L. Ellsworth et al., *Coronary Heart Disease: At the Interface of Molecular Genetics and Preventive Medicine*, 16 AM. J. PREVENTIVE MED. 122, 123 tbl.1 (1999).

[74] *See* Diane E. Bild et al., *Identification and Management of Heterozygous Familial Hypercholesterolemia: Summary and Recommendations from an NHLBI Workshop*, 72 AM. J. CARDIOLOGY, Sep. 30, 1993, at 1D (1993); Online Mendelian Inheritance in Man, OMIM #143890, *Hypercholesterolemia, Autosomal Dominant*, http://www.ncbi.nlm.nih.gov/htbin-post/Omim/dispmim?143890 (last edited Aug. 29, 2003) (Baltimore, MD: Johns Hopkins Univ., 2003).

[75] *See* Wei-Shiung Yang et al., *A Mutation in the Promoter of the Lipoprotein Lipase (LPL) Gene in a Patient with Familial Combined Hyperlipidemia and Low LPL Activity*, 92 PROC. NAT'L ACAD. SCI. 4462 (1995); J. D. Brunzell, *Myocardial Infarction in the Familial Forms of Hypertriglyceridemia*, 25 METABOLISM: CLINICAL & EXPERIMENTAL 313 (1976).

high concentration in blood is highly associated with myocardial infraction and stroke.[76] Fourth, the angiotensinogen gene has been linked to essential hypertension and increased blood pressure that substantially increase the risk of CHD.[77]

In spite of their distinct contribution to the disease, the relationship between those disease-related genes and increased risk of CHD has been noted to differ by contextual cofactors such as cigarette smoking, high saturated fat and cholesterol diets,[78] hypertension, low intake of folic acid,[79] inactivity (daily exercise of less than 30 minutes), over-weight (body mass index of more than 25), and stress. As incision points upon which public health initiatives or preventive medicine intervention can act, these cofactors found in several different pathogenetic pathways provide disease prevention avenues that are far more feasible and available than other techniques intending to manipulate directly the genetic etiology.[80] Among others, cholesterol screening in men 35 to 65 years of age and women 45 to 65 years of age who may have heterozygous FH or other risk factors for CHD is a commonly accepted strategy designed to identify high-risk

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[76] *See* Paul F. Jacques et al., *Relation Between Folate Status, a Common mutation in methylenetetrahydrofolate reductase, and plasma homocysteine concentrations*, 93 CIRCULATION 7 (1996).

[77] *See* Xavier Jeunemaitre et al., *Molecular Basis of Human Hypertension: Role of Angiotensinogen*, 71 CELL 169 (1992).

[78] *See* Elena L. Navas-Nacher et al., *Risk Factors for Coronary Heart Disease in Men 18 to 39 Years of Age*, 134 ANNALS INTERNAL MED. 433 (2001).

[79] *See* Jacques et al., *supra* note 79, at 7-9.

[80] *See* Roger R. Williams et al., *Primordial Prevention of Cardiovascular Disease Through Applied Genetics*, 29 PREVENTIVE MED. S41, S42 (1999).

groups and modify the effects of genetic factors on disease risk.[81] Similarly, smoking cessation programs are targeted toward individuals with mutations for heterozygous FH since the increased chance of having CHD, especially acute myocardial infarction or angina pectoris,[82] in people under age 50 years who smoke (relative risk for smoking) is four times greater among those with a positive family history than those without,[83] and the effect of smoking cessation is reflected on its association with a 36% reduction in all-cause mortality among all CHD patients.[84] The value of manipulating other cofactors nonetheless depends on the underlying genetic factors. Physical activity and weight reduction may not be effective in preventing CHD in those with heterozygous FH, but they are beneficial for persons with FCHL; [85] weight loss and sodium restriction diets are especially beneficial to reduce CHD risk for people with the angiotensinogen gene mutation; dietary intake of folic acid as risk reduction is only effective for those with

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[81] *See* American College of Physicians, *Guidelines for Using Serum Cholesterol, High-density Lipoprotein Cholesterol, and Triglyceride Levels as Screening Tests for Preventing Coronary Heart Disease in Adults*, 124 ANNALS INTERNAL MED. 515 (1996).

[82] Study also found that smoking is not associated with aorto-coronary calcification, another possible symptom of CHD. *See* J. M. Jensen et al., *Linking Genotype to Aorto-coronary Atherosclerosis: A model Using Familial Hypercholesterolemia and Aorto-coronary Calcification*, 63 ANNALS HUM. GENETICS 511 (1999).

[83] *See* Paul N. Hopkins et al., *Magnified Risks from Cigarette Smoking for Coronary Prone Families in Utah*, 141 W.J. MED. 196 (1984).

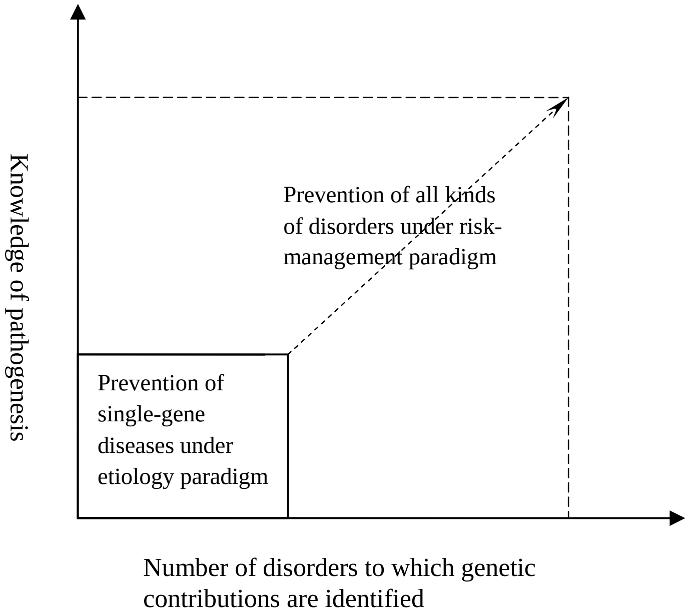
[84] Relative risk of smoking cessation against continued smoking among CHD patients is 0.64. *See* Julia A. Critchley et al., *Mortality Risk Reduction Associated With Smoking Cessation in Patients With Coronary Heart Disease—A Systematic Review*, 290 JAMA 86, 94 fig.2, 95 (2003).

[85] *See* Williams et al., *supra* note 80, at S44.

mutations for MTHFR gene.[86]

Figure 4-1

Potential Incision Points of Public Health or Preventive Medicine Intervention



All these examples suggest that discourses of human genomics about the risks that the body might encounter (the information of disease-related genes) have the capacity to drive those at increased genetic risk to adopt healthier lifestyles and to render appropriate public health advices aimed at controlling the background pathogenesis by setting the appropriate exposure standards. Although it might as well be true that misinterpretation

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[86] *See* Jacques et al., *supra* note 76, at 7-9.

of the implication of disease-related genes very often leads to a sense of fatalism about health, disease and life chances in general and consequently compromises the motivation to change behavior,[87] it is undeniable that genomic medicine through risk management has exerted its formative influences deep into daily activities and personal lifestyle choices. Together with the analytic power, with which human genomics expands its jurisdiction over the entire list of human phenotypes,[88] genomic medicine is gaining unprecedented dominance over every aspect of human life. (Figure 4-1)

4.2.2 Individualized Approach

The second feature of discourses of genomic medicine about the body is its *individualized* approach to health improvement. The use of an individual's genetic profile to direct the practice of medicine has been greatly enabled by human genomics. It is generally assumed that genetic variations underlie differences not only in our susceptibility or resistance to all kinds of disease, in the age of onset and severity of illness, but also in the way our bodies respond to drug treatment in terms of efficacy and side-effects.[89]

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[87] *See, e.g.*, Victoria Senior et al., *Will Genetics Testing for Predisposition for Disease Result in Fatalism? A Qualitative Study of Parents Responses to Neonatal Screening for Familial Hypercholesterolaemia*, 48 SOC. SCI & MED. 1857 (1999); Sally Macintyre, *The Public Understanding of Science or the Scientific Understanding of the Public? A Review of the Social Context of the 'New Genetics'*, 4 PUBLIC UNDERSTANDING OF SCIENCE 223 (1995).

[88] *See supra* text accompanying notes 35-40 of Chapter 1.

[89] *See* Aravinda Chakravarti, *Single Nucleotide Polymorphisms: To a Future of Genetic Medicine*, 409 NATURE 822, 823 (2001).

Since the 1980s, FDA has been concerned about different drug effects among population subgroups, and it has also been the practice for pharmaceutical companies to take into account differences in drug responses among various subpopulations when designing drugs.[90] But not until the emergence of the promising pharmacogenomics, which incorporates the use of genetics and genomics into the development of pharmaceutical products, is the vision of *personalized medicine* really charted.[91] Prescribing tailormade medication to individuals conceivably offers great potential to solving the immense clinical problems that have long frustrated biomedical science, such as serious adverse drug effects and the poor response to the available treatments for a given condition.[92]

For example, Tacrine, current drug therapy for Alzheimer's disease, has, at best, modest effects on 20-50% of patients and is associated with a high frequency of side effects, including liver transaminitis.[93] Scientists now find that variations of a single DNA letter at a specific position in the BCHE gene lead to patients at risk or diagnosed

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[90] *See* U.S. FOOD & DRUG ADM', DRAFT GUIDANCE FOR INDUSTRY COLLECTION OF RACE AND ETHNICITY DATA IN CLINICAL TRIALS 9 (2003), *available at* http://www.fda.gov/cber/gdlns/racethclin.pdf; Draft Guidance for Industry on the Collection of Race and Ethnicity Data in Clinical Trials for FDA Regulated Products, 68 Fed. Reg. 4788 (2003) (proposed Jan. 24, 2003).

[91] *See* Joanne M. Meyer & Geoffrey S. Ginsburg, *The Path to Personalized Medicine*, 6 CURRENT OPINION IN CHEMICAL BIOLOGY 434 (2002).

[92] *See* Mark A. Rothstein & Carlton A. Hornung, *Public Attitudes about Pharmacogenomics*, *in* PHARMACOGENOMICS: SOCIAL, ETHICAL, AND CLINICAL DIMENSIONS 3 (Mark A. Rothstein ed., Hoboken, NJ: Wiley-Liss, 2003).

[93] *See* Sarah A. Eagger & Robert J. Harvey, *Clinical Heterogeneity: Responders to Cholinergic Therapy*, 9 Supp. 2 ALZHEIMER DISEASE & ASSOCIATED DISORDERS 37 (1995).

with Alzheimer's disease having differing responses to Tacrine.[94] This finding helps doctors to identify patients who may benefit from the current drug therapy and save other non-responding patients from being exposed to the unnecessary side-effects that accompany the drug. Another even more impressive example is the newly developed anticancer drug Herceptin, which is specially designed to treat 25% to 30% of breast cancer patients whose cancer cells over express a growth-related protein receptor called her-2/neu.[95] Herceptin has not only proven valuable in treating finely targeted patients but also brought in sales of $385 million for its manufacturing company Genentech in 2002.[96]

Indeed, the idea of pharmacogenomics is most praised by the biopharmaceutical industry. And the reasons for this are not difficult to figure out. By pre-screening clinical trial participants for non-respondents and people with high risk of severe adverse effects, pharmaceutical companies can increase the success rate of clinical trials and streamline the drug development process.[97] Given the high cost of bringing a new drug to market

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[94] *See* Barbara Ann Binzak, *How Pharmacogenomics Will Impact the Federal Regulation of Clinical Trials and the New Drug Approval Process*, 58 FOOD DRUG L.J. 103, 121-22 & n.102 (2003) (citing U.S. Patent No. 6,291,175 (issued Sept. 18, 2001)).

[95] *See* M. J. Piccart, *Proposed Treatment Guidelines for HER2-positive Metastatic Breast Cancer in Europe*, 12 Supp. 1 ANNALS ONCOLOGY S89 (2001).

[96] *See* Robert F. Service, *Recruiting Genes, Proteins for a Revolution in Diagnostics*, 300 Science 236 (2003).

[97] *See* G. Emilien et al., *Impact of Genomics on Drug Discovery and Clinical Medicine*, 93 Q J MED. 391, 394 (2000); Binzak, *supra* note at 94, 113, 122-23. It is estimated that pharmacogenomics could save pharmaceutical companies an average of $300 million and two years per new drug as a result of increased

(around $802 million in 2000)[98] and the fact that most drugs introduced never recoup the average cost of their development if no other cost-saving methods can be found,[99] competitive pharmaceutical companies certainly will take advantage of pharmacogenomics to scramble for shares in a lucrative market with the potential to drive the growth of the worldwide market to more than $1.5 billion by 2008.[100]

It is however not entirely clear whether this driving force behind the growing attention to pharmacogenomics paid by biopharmaceutical industry will really bring about a dream of *personalized medicine* for *everyone*, rather than some small fraction, or pharmacogenomics is only meant to be a corporate tool for implementing cost control more efficiently, targeting potential consumers more precisely, and creating a market "niche" more securely.

Aside from this skepticism, genomic medicine's individualized approach to health improvement perhaps is most clearly expressed in the words of those who plotted the

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efficiency. *See* PETER TOLLMAN ET AL., THE BOSTON CONSULTING GROUP, A REVOLUTION IN R&D: HOW GENOMICS AND GENETICS ARE TRANSFORMING THE BIOPHARMACEUTICA INDUSTRY 12, 13 (Boston: Boston Consulting Group, 2001), *available at* http://www.bcg.com/publications/files/eng_genomicsgenetics_rep_11_01.pdf.

[98] *See* Joseph A. DiMasi et al., *The Price of Innovation: New Estimates of Drug Development Costs*, 22 J. HEALTH ECON. 151 (2003).

[99] The study was conducted on new drugs introduced during 1990 and 1994. *See* Henry Grabowski et al., *Returns on Research and Development for 1990s New Drug Introductions*, 20 Supp. 3 PHARMACOECONOMICS 11 (2002).

[100] *See* FRONT LINE STRATEGIC CONSULTING, PHARMACOGENOMICS: A STRATEGIC MARKET OUTLOOK AND BUSINESS ANALYSIS 1 (San Mateo, CA: Front Line Strategic Consulting, 2003).

vision for the future of genomics research. According to the director of the National Human Genome Research Institute, Francis Collins, and his colleagues, the steps by which genomic medicine would lead to improved health are: “(1) an individual obtains genome-based information about his/her own health risks; (2) the individual uses this information to develop an individualized prevention or treatment plan; (3) the individual implements that plan; (4) this leads to improved health; (5) healthcare costs are reduced.”[101] Researchers predict that, in 10 years, it will be possible to get a printout of one’s personal genetic make-up detailing differences and susceptibilities for $1000. This information will be in the form of a credit card-size chip that one can carry in one’s wallet.[102]

The idea that knowledge of one’s disease risk, harm exposure, or physical damage may alter one’s intent to change risky behavior is not new. Preliminary empirical studies also suggest that biological information conveying one’s susceptibility to disease may increase “motivation” to make lifestyle change.[103] In the case of smoking cessation, a study found that information of one’s CYP2D6 genetic marker for lung cancer susceptibility provided during quit-smoking counseling had about 6.2 times greater effect on an individual’s perceived risk, a 4.2 times greater effect on perceived benefit of

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[101] Collins et al., *supra* note 47, at 842.

[102] *See* Judith G. Hall, *Individualized Medicine: What the Genetic Revolution Will Bring to Health Care in the 21st Century*, 49 CANADIAN FAM. PHYSICIAN 12 (2003).

[103] *See* Jennifer B. McClure, *Are Biomarkers Useful Treatment Aids for Promoting Health Behavior Change? An Empirical Review*, 22 AM. J. PREVENTIVE MED. 200 (2002).

quitting, and a 4.7 times greater effect on fear arousal than did a minimal counseling, and thus increased individuals' motivation to quit smoking.[104] A similar finding is presented in another study investigating the association between smoking behavior and perceived family histories of CHD. People who think they have a family history of heart disease and see themselves as at risk of the same disease are less likely to smoke.[105]

Interestingly, those who with increased motivation to quit smoking, although making more attempts to quit, were no more likely to actually stop smoking in the end than the general population in which around 10% of the 70% or so of smokers who would like to quit actually stop smoking after one year.[106] Overall, intent alone predicts only about 30% of the variance in behavior change,[107] and individualized genetic risk information does not increase actual behavior change beyond that can be achieved with

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[104] Caryn Lerman et al., *Incorporating Biomarkers of Exposure and Genetic Susceptibility Into Smoking Cessation Treatment: Effects on Smoking-related Cognitions, Emotions, and Behavior Change*, 16 HEALTH PSYCHOL. 7, 93 & tbl.2, 94 (1997).

[105] The possibility of smoking is 31% less comparing to those who do not think they have a family history of heart disease. *See* Kate Hunt et al., *Are Perceptions of a Family History of Heart Disease Related to Health-related Attitudes and Behaviour?*, 15 HEATH EDUC. RES. 131, 140 & tbl.VIII (2000).

[106] *See* Lerman et al., *supra* note 104, at 94 & tbl.3; Janet Audrain et al., *Genetic Susceptibility Testing in Smoking-cessation Treatment: One-year Outcomes of a Randomized Trial*, 22 ADDICTIVE BEHAV. 741, 746, 747 fig.1, 748 (1997). For abstinence rates in general population, see, for example, Shu-Hong Zhu et al., *Smoking Cessation with and Without Assistance: A Population-based Analysis*, 18 AM. J. PREVENTIVE MED. 305 (2000). *But cf.* Centers for Disease Control & Prevention, *Cigarette Smoking Among Adults—United States, 1993*, 43 MMWR 925, 928 tbl.2, 929 (1994) (reporting the prevalence of cessation among total ever smokers was around 50% in 1993). This is because abstainers usually make several tries, each with a low abstinence rate, to achieve a successful cessation.

[107] *See* Theresa M. Marteau & Caryn Lerman, *Genetic Risk and Behavioural Change*, 322 BRIT. MED. J. 1056, 1057 (2001).

non-genetic-biomarker information.[108]

But the essence of individualization brought by genomic medicine does not simply mean that the provision of health care can be personally customized or that individualized “genetic” information on risk is more likely to produce spontaneous individual compliance. The real strength of genomic medicine’s individualized technique lies in its unprecedented *classifying power* that knows no boundary, until the last person is individually evaluated, classified and assigned to a position preferably in correspondence to an effective but not necessarily personalized correction/therapeutic plan.

This point is again illustrated by the example of smoking cessation. Recognizing that not every smoker with intent to quit, motivated by individualized information on lung cancer or CHD risk, will end up in actual behavior change, that more than 80% of attempted quitting failed, and that the most common reason reported for failed attempts was lack of “willpower” or self-control,[109] researchers are now more interested in finding a genetic explanation for nicotine addiction with the potential value of isolating real nicotine addiction from cases of simply lacking self-control.

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[108] *See* Lerman et al., *supra* note 104, at 93 & tbl.2 (showing that genetic biomarker was not significantly more effective than non-genetic biomarker in producing movement to the preparation stage of smoking cessation).

[109] For example, in a study conducted in a Saudi community, 34% subjects reported that failed attempts were attributed to lack of willpower. Saima Siddiqui et al., *Smoking in a Saudi Community: Prevalence, Influencing Factors, and Risk Perception*, 33 FAM. MED. 367, 369 (2001). *See also* Susan J. Curry et al., *Reasons for Quitting: Intrinsic and Extrinsic Motivation for Smoking Cessation in a Population-based Sample of Smokers*, 22 ADDICTIVE BEHAV. 727 (1997); Pau Norman et al., *The Theory of Planned Behavior and Smoking Cessation*, 18 HEALTH PSYCHOL. 89 (1999).

A number of plausible candidate genes susceptible to nicotine dependence are now under investigation.[110] Again, a better understanding of the molecular mechanisms of nicotine addiction could lead to more effective pharmacogenomic drugs for those with a predisposition to nicotine dependence.[111] But since the difference in the prevalence of currently defined candidate genes between smokers and non-smokers is relatively small, ranging from 1.12 to 1.23 times more frequent in the relevant groups,[112] they confer minor to moderate effect on the variation in susceptibility to tobacco dependence and may account for only a small fraction of the causes of failed attempts. This means that,

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[110] For studies investigating the association between smoking and the CYP2A6 genotype, see, for example, Michael L. Pianezza et al., *Nicotine Metabolism Defect Reduces Smoking*, 393 NATURE 750 (1998). *But see* Mikael Oscarson et al., *Genotyping of Human Cytochrome P450 2A6 (CYP2A6), A Nicotine C-oxidase*, 438 FEBS LETTERS 201 (1998) (indicating genotyping errors in Pianezza and colleagues' original report); Stephanie J. London et al., *Genetic Variation of CYP2A6, Smoking and Risk of Cancer*, 353 LANCET 898 (1999) (finding no consistent evidence proving the association). For studies investigating the role of SLC6A3 and DRD2 genes, see, for example, Caryn Lerman et al., *Evidence Suggesting the Role of Specific Genetic Factors in Cigarette Smoking*, 18 HEALTH PSYCHOL. 14 (1999); Sue Z. Sabol et al., *A Genetic Association for Cigarette Smoking Behavior*, 18 HEALTH PSYCHOL. 7 (1999). For studies of the association between CCK gene and smoking, see, for example, David E. Comings et al., *Cholecystokinin (CCK) Gene as a Possible Risk Factor for Smoking: A Replication in Two Independent Samples*, 73 MOLECULAR GENETICS & METABOLISM 349 (2001). See W. Hall et al., *The Genetics of Tobacco Use: Methods, Findings and Policy Implications*, 11 TOBACCO CONTROL 119 (2002), for a general review.

[111] *See, e.g.*, Robert Walton et al., *Genetic Clues to the Molecular Basis of Tobacco Addiction and Progress Towards Personalized Therapy*, 7 TRENDS MOLECULAR MED. 70, 73-75 (2001)

[112] According to Lerman et al., the prevalence of DRD2-A1 genotype, which is thought to be positively associated with smoking, is 39.1% (113/289) among smokers and 34.7% (81/233) among non-smokers. Lerman et al., *supra* note 110, at 17 tbl.4. According to Sabol et al., the prevalence of SLC6A3-9 genotype, which is thought to be negatively associated with smoking cessation, is 42% among current smokers and 51.9% among former smokers. Sabol et al., *supra* note 110, at 9 & tbl.1. *But see* David E. Comings et al., *The Dopamine D2 Receptor (DRD2) Gene: A Genetic Risk Factor in Smoking*, 6 PHARMACOGENETICS 73 (1996) (finding that DRD2-A1 genotype is approximately twice as common in smokers (48.7%) compared with non-smokers (25.9%)).

despite the therapeutic plan aiming to fight against genetic roots of smoking, traditional strategies that rely on individual's willpower are still needed to achieve successful smoking cessation.[113]

Genotyping current smokers desiring help with cessation may serve to differentiate the situations in which pharmacological intervention could be justifiably warranted from those where use of individual willpower must be uncompromisingly demanded.[114] Imaginably, new strategies for treating lack-of-willpower quitters who cannot be confirmed to be nicotine addicted need to be devised. In addition to the traditional social support treatment or group behavioral therapy,[115] genomic medicine may once again be expected to play a path-breaking role in further classification and management of this remaining subgroup.

Whether the classifying power of genomic medicine that leads to ever-refining individualization would be taken full advantage of depends on other considerations such as the burden of the specific health-related condition on public health, the magnitude of

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[113] *See*, *e.g.*, Tim Lancaster et al., *Effectiveness of Interventions to Help People Stop Smoking: Findings from the Cochrane Library*, 321 BRIT. MED. J. 355, 355-56 (2000) (discussing the efficacy of traditional strategies).

[114] Admittedly, providing information of genetic predisposition to nicotine dependence may decrease a smoker's perceived control over quitting because of genetic fatalism, and further weaken his or her own willpower. *See* A. J. Wright et al., *The Impact of Learning of a Genetic Predisposition to Nicotine Dependence: An Analogue Study*, 12 TOBACCO CONTROL 227 (2003).

[115] *See* Erol Digiusto & Kevin D. Bird, *Matching Smokers to Treatment: Self-Control Versus Social Support*, 63 J. CONSULTING & CLINICAL PSYCHOL. 290 (1995); John R. Hughes, *An Algorithm for Smoking Cessation*, 3 ARCHIVES FAM. MED. 280 (1994).

risks posed by disease-related genotypes, and the availability of effective intervention.[116] However, the health categories endlessly developed by genomic medicine are always ready for the next run of individualization.

4.3 Malleable Body and Fixed Identity: Cases of Wrongful Birth and Wrongful Life Claims

With the risk management paradigm and the individualized approach of genomic medicine, discourses of human genomics about the body cover virtually all aspects of each individual's entire life. The ideal body image that these all-encompassing discourses put forward is commonly introduced as something for which an individual must hanker and with which she must identify herself. Thus, the right to pursue such an ideal seems to be all that is needed for full development of her self-identity. After discussing the pros and cons of prenatal genetic testing, Professor Ellen Wright Clayton concluded that "[g]iving these individuals this sort of information demonstrates respect for their autonomy and rights to privacy…."[117] Clayton apparently was not aware of the role that such a "right" plays in constituting self-identity. However, it is exactly through the conduit secured by negative liberty rights that the body image envisaged by human genomics is made an imperative and domineering source of identity formation.

The result of the dominance of discourses about the body generated by human

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[116] *See* Neil A. Holtzman & Theresa M. Marteau, *Will Genetics Revolutionize Medicine?*, 343 NEW ENG. J. MED. 141 (2000).

[117] Clayton, *supra* note 70, at 114.

genomics is discernible in cases such as wrongful birth and wrongful life actions. These cases are based on the claim that the birth of children with certain genetic conditions would have been averted had the opportunity to pursue the ideal body image been properly provided.[118] And if pursuing the ideal body image is indeed a "right," it follows that some form of judicial redress is needed once that "right" is violated. For example, in *Phillips v. United States* a federal district court considered a wrongful birth claim for relief of parents who alleged they would have had avoided conception or terminated the pregnancy by abortion but for the negligence of the medical provider who was charged with prenatal testing, genetic testing, or counselling parents as to the likelihood of giving birth to a child with Down's syndrome.[119]

Courts admitting wrongful birth claims generally allow only the extraordinary expenses relating to the child's condition that must be borne by the parents, but not the costs of raising a "normal" child.[120] Some courts have also compensated the parents for

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[118] *See* Rochelle Cooper Dreyfuss & Dorothy Nelkin, *The Jurisprudence of Genetics*, 45 VAND. L REV. 313, 331-32 (1992).

[119] *See* Phillips v. United States, 575 F. Supp. 1309 (D.S.C. 1983).

[120] *See, e.g.*, Naccash v. Burger, 290 S.E.2d 825, 830 (Va. 1982); Siemieniec v. Lutheran Gen. Hosp., 512 N.E.2d 691, 706 (Ill. 1987); Haymon v. Wilkerson, 535 A.2d 880, 886 (D.C. 1987); Viccaro v. Milunsky, 551 N.E.2d 8, 11 (Mass. 1990). There is, however, disagreement as to the period of time over which the extraordinary expenses are projected. *But see* Robak v. United States, 658 F.2d 471 (7th Cir. 1981) (allowing recovery of the cost of raising and supporting a normal child); Jones v. Malinowski, 473 A.2d 429, 435 (Md. 1984) (refusing to adopt a per se rule that denies recovery by parents of child rearing costs from the physician whose negligence has caused their expenditure).

their pain and suffering or mental anguish,[121] although they have also generally held that such damages should be offset by the emotional benefits derived by the plaintiffs from the child.[122] However, the similar cause of action—wrongful life—claimed not by the parents but by the affected child, encounters much more hurdles and remains rarely successful because of an apparent difficulty of comparing a defective life to no life at all. The trend nevertheless is that those courts that grant wrongful life claims would permit the child to recover damages for the extraordinary costs of the medical care necessary to treat the genetic disorder.[123]

Wrongful birth and wrongful life cases present a myriad of public policy problems: difficulty in ascertaining damages, the concern of increased litigation, and distinction between legislative and judicial roles.[124] Nevertheless, the underlying premise of the wrongful birth and wrongful life claims is that prudent medical care would have detected the risk of giving birth to offspring with a congenital or hereditary genetic disorder either prior to conception or during pregnancy. Relying primarily on the rationales that the negligence denies parents' opportunity to make informed decision with regard to their

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[121] *See*, *e.g.*, Naccash v. Burger, 290 S.E.2d at 830-31; Harbeson v. Parke-Davis, Inc., 656 P.2d 483, 496-97 (Wash. 1983). *But cf.* Berman v. Allan, 404 A.2d 8, 14-15 (N.J. 1979) (rejecting damages based on extraordinary support expenses, while allowing damages for the parents' emotional distress).

[122] *See*, *e.g.*, Phillips v. United States, 575 F. Supp. at 1319; Harbeson v. Parke-Davis, Inc., 656 P.2d at 494; Gallagher v. Duke University, 852 F.2d 773, 776-77 (4th Cir. 1988). *But see* Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557, 562 (Ga. 1990) (rejecting to apply the "benefits rule").

[123] *See*, *e.g.*, Turpin v. Sortini, 643 P.2d 954 (Cal. 1982); Procanik v. Cillo, 478 A.2d 755 (N.J. 1984).

[124] *See* Hickman v. Group Health Plan, Inc., 396 N.W.2d 10, 13 (Minn. 1986).

procreative choices and that refusing to recognize wrongful birth would frustrate the fundamental policies of tort law: to deter negligence, to encourage due care, and to compensate for the extra needs of living, wrongful birth and wrongful life actions depoliticize the volatile claim inferred from discourse of human genomics that life of a child with genetic defects is itself an injury.

While the sanctity of life might be an untouchable, politically correct belief, discourses of human genomics about the reproductive body and the fetus remain influential. California requires that all women be offered maternal serum alpha-fetoprotein (MSAFP) testing,[125] a kind of genetic testing performed primarily to detect fetuses with spinal tube defects. The director of the genetic disease branch of California's Department of Health Services, who has been highly critical of states that fail to provide MSAFP screening as their state-run programs, argued that such services should be made available for the "public good" of, among others, reducing the number of children born with genetic disorders.[126] Some courts similarly acknowledged the societal interest in reducing and preventing the incidence of genetic defects.[127] The influence of discourses of human genomics is expansive and indiscriminate in its scope. The genetic disorders claimed in wrongful birth and wrongful life cases cover a wide array of conditions, ranging from life threatening disorders that may result in early death, such as Tay-Sachs

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[125] *See* CAL. ADMIN. CODE tit. 17 § 6527 (Deering's 2004).

[126] *See* George C. Cunningham & KW Kizer, *Maternal Serum Alpha-Fetoprotein Screening Activities of State Health Agencies: A Survey*, 47 AM. J. HUM. GEN. 899 (1990).

[127] *See, e.g.*, Blake v. Cruz, 698 P.2d 315, 318 (Idaho 1984).

disease,[128] and disorders that only mildly shorten the life expectancy but affect life quality, such as Down's syndrome,[129] to those disorders that only affect life quality in some way, such as hereditary deafness.[130]

Admittedly, not all governmental actions manifestly promote discourses of human genomics about the body. North Carolina is one of the few states that, by judicial decision, forbid cause of action for wrongful birth and wrongful life on the rationale that judicial recognition of wrongful birth or wrongful life actions would be an encroachment on the legislature.[131] In the last several years, several legislatures, such as Michigan[132] and Pennsylvania,[133] have enacted statutes entirely forbidding claims for "wrongful life" and even for "wrongful birth." Aside from the distinction between legislative and judicial roles, cases against wrongful birth and wrongful life claims bear an abiding concern about the derogation of the sanctity of life. Warning against the eugenics history of the Third Reich and the America's own eugenics movement as exemplified in *Buck v. Bell*, a

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[128] *See, e.g.*, Naccash v. Burger, 290 S.E.2d at 827 (finding that the child in question lived less than 3 years).

[129] *See, e.g.*, Phillips v. United States, 575 F. Supp. at 1313 (estimating a life expectancy of approximately 50 years).

[130] *See, e.g.*, Turpin v. Sortini, 643 P.2d at 339.

[131] *See* Azzolino v. Dingfelder, 337 S.E.2d 528 (N.C. 1985). *See also* Atlanta Obstetrics & Gynecology Group v. Abelson, 398 S.E.2d 557 (Ga. 1990) (refusing to recognize "wrongful birth" actions absent clear mandate for such recognition by the legislature).

[132] MICH. COMP. LAWS § 600.2971 (2004).

[133] 42 PA. CONS. STAT. § 8305 (2004).

Michigan appellate court in *Taylor v. Kurapati*[134] expressed the worry that the acceptance of the wrongful birth tort would re-invite the practice of preventing the birth of the "unfit" and of "defectives" once enthusiastically promoted by Charles Davenport and Harry Laughlin.[135]

In a sense, the message sent by the states denying the cause of action for wrongful birth or wrongful life is that all lives are invaluable, which can be understood as a formative project aimed at inculcating the kind of self-identity that believes in equal value of lives. Commenting on a California appellate court's decision permitting a wrongful life claim in *Curlender v. Bio-Science Laboratories*,[136] Professors Rochelle Dreyfuss and Dorothy Nelkin similarly criticized that allowing the wrongful life claim by rejecting the "sanctity of life" principle, the court implied "a willingness to treat wrongful life as, indeed, wrongful."[137] *Curlender* was later overruled by California Supreme Court in *Turpin v. Sortini*, but that does not really disentangle the knot of the difficulty. As lofty as the moral belief that any life is invaluable may be, discourses of human genomics about the body still invoke unbearable emotions: "It upsets me knowing that he'll never be able to do the things that *normal* kids can do," said the plaintiff of a wrongful birth

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[134] Taylor v. Kurapati, 600 N.W.2d 670 (Mich. Ct. App. 1999) (abrogating previous cases that recognized cause of action for wrongful birth).

[135] *Id*. at 688-90 (citing Paul A. Lombardo, *Medicine, Eugenics and the Supreme Court: From Coercive Sterilization to Reproductive Freedom*, 13 J. CONTEMP. HEALTH L. & POL'Y 1, 1-2 (1996); James E. Bowman, *The Road to Eugenics*, 3 U. Chic. L. Sch. Roundtable 491 (1996)).

[136] 165 Cal. Rptr. 477 (Cal. Ct. App. 1980), *overruled by* Turpin v. Sortini, 643 P.2d 954 (Cal. 1982).

[137] Dreyfuss & Nelkin, *supra* note 118, at 312-13.

action.[138] Accepting wrongful birth or wrongful life claims seems less the cause than the symptom of a deep-rooted ailment. The cause of that ailment lies more in, as Bruce Jennings argued, "the humanly one-sided and morally corrupting effects" of the "genetic imaginary" of the future child, which confine the possible "range of realities and possibilities that the moral imaginations of prospective parents should have been able to explore."[139] The "homunculus" offered by discourses of human genomics has proved to dominate the parent's vision and become an imperative and domineering source of identity formation. Such limitation certainly also has something to do with the unavailability of social resources—such as family and kinship network, civic community, the assistance of health care—that are needed to bolster and nurture a well-rounded moral imagination, that is, the imagination that is essential to produce a more open selfhood and make the "we" community more inclusive rather than exclusive. But, as equally influenced by discourses of human genomics, it is highly unlikely that a society would make favourable decisions regarding resource allocation that provide more room for imagination.

The advance of human genomics and medical technology makes it more possible than ever to manipulate the physical body and to alter and mold its lifestyle. And yet in the mean time, the increasing ability to distinguish "normal" from "abnormal," or

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[138] Phillips v. United States, 575 F. Supp. 1309, 1317 (D.S.C. 1983) (emphasis added).

[139] Bruce Jennings, *Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability*, *in* PRENATAL TESTING AND DISABILITY RIGHTS 124, 138 (Erik Parens & Adrienne Asch eds., Washington, DC: Georgetown Univ. Press, 2000).

“preventable” from “inescapable,” intensifies people’s penchant for designating “otherness” to those who are different. Holding human genomics and genetic technology as the weaponry against the unknowable, people fight hard to adhere to, rather than challenge, the boundary between others and us. This brings the “closure” to the selfhood, which embodies an obdurate conception of otherness and legitimates our loss of interest and curiosity in exploring the life experiences of the excluded, the others, the strangers. A society excludes when it is more interesting in exploring “who are different” and “how to fix those who are different to become more like us” than “how to use the term ‘we’ to include more and more different sorts of people.” In a society where differences are viewed as a debt rather than a resource and science becomes the constraint rather than the source of the political imagination, social cooperation is as difficult as unattainable. Ironically, as human bodies are made more malleable than ever, flexibility is just the opposite word to describe people’s self-identity.

PART II IN SEARCH OF A POSSIBLE REGULATORY SCHEME

He that is good with a hammer tends to think everything is a nail.

~ Abraham H. Maslow

Of Course they are social constructions…. Once we give up the idea that the point of discourse is to represent reality accurately, we will have no interest in distinguishing social constructs from other things. We shall confine ourselves to debating the utility of alternative constructs.

~ Richard Rorty[≅]

[≅] RICHARD RORTY, *Ethics Without Principle*, *in* PHILOSOPHY AND SOCIAL HOPE 72, 85-86 (New York: Penguin Books, 1999).

5/ MITIGATING THE ADVERSE CONSEQUENCES

—MAINSTREAM APPROACH AND THE CURRENT REGULATORY SCHEME

The unveiling power of human genomics not only cracks the secret of human life. It also possesses the capacity to expose the composition of one's genetic assets and to assess, based on one's genetic endowment, one's risk to an array of traits. It should not be an exaggeration to say that the unveiling power of human genomics creates a category of people genetically at risk.[1] Many people are now concerned about the adverse consequences of the unveiling power of human genomics. Those people at genetic risk are most likely also at social risk of suffering from potential harms of stigmatization, social hostility and the concomitant discrimination in employment and health insurance, which were not expected before the advent of the new science. According to a CNN-Time poll in 2000, 46 percent of respondents said they expected harmful results from the Human Genome Project.[2]

The fears that people with genetic risks would be adversely treated have instigated much debate about measures to counter the potential menace accompanied the apparent benefits brought about by human genomics.[3] In what follows, I will investigate and assess preliminarily three mainstream approaches to the issues and the related regulatory

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[1] *See* Carlos Novas & Nikolas Rose, *Genetic Risk and the Birth of Somatic Individual,* 29 ECON. & SOC'Y 485-513 (2000).

[2] *Genome Announcement a Milestone but Only a Beginning*, CNN, June 26, 2000, *at* http://www.cnn.com/2000/HEALTH/06/26/human.genome.05/index.html (posted June 26, 2000).

[3] The point that such debate is to ensure the benefits of human genomics is brightly shown in the title of a hearing held in the United States Senate. *Fulfilling the Promise of Genetics Research: Ensuring Nondiscrimination in Health Insurance and Employment: Hearing on S.318 Before the Senate Comm. on Health, Educ., Labor, and Pensions*, 107th Cong. (2001).

schemes: (1) regulating genetic information flows, (2) banning decisionmaking based on genetic information, and (3) combating prejudice as a matter of increasing rationality. The purpose of this investigation is not simply to compare the pros and cons of the different approaches. The investigation is also intended to uncover what different notions of the adverse consequences of human genomics are conceived by the mainstream approaches. The result of the investigation provides a basis of the next chapter examining the limits of current approaches to address what is really wrong with the unveiling power of human genomics.

5.1 Regulating Genetic Information Flows

The first strategy to counter the potential abuse of the predictive power of human genomics is to regulate the information flow. This strategy is commonly associated with the concept of informational privacy asserting the moral right of "an individual to determine what information about himself or herself should be known by others."[4] The concept of genetic privacy gains much currency among both legal academia[5] and the public.[6] Despite its moral overtone, the purpose of genetic privacy is, however,

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[4] Alan F. Westin, *Privacy and Genetic Information*, *in* THE GENETIC FRONTIER: ETHICS, LAW, AND POLICY 53, 53 (Mark S. Frankel & Albert H. Teich eds., Washington, DC: American Association for the Advancement of Science, 1994).

[5] *See, e.g.*, Lawrence O. Gostin, *Genetic Privacy*, 23 J.L. MED. & ETHICS 320 (1995); George J. Annas et al., *Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations*, 23 J.L. MED. & ETHICS 360 (1995).

[6] Ninety-three percent of respondents of a Gallup survey said that medical and government

practically to keep employers and insurers from learning enough about a person's individual genetic risk to allow them to discriminate.[7] As an information regulation strategy, genetic privacy serves as a means to the anti-discrimination ends.

5.1.1 Health Insurance

Current federal and state laws afford only a patchwork regulatory scheme. In the health insurance settings, policy designs range diversely from a complete blockage preventing genetic information from passing to insurers to a total laxity permitting literally unrestricted access. For example, New Hampshire prohibits a group or an individual health plan insurer from requesting or requiring any individual or a member of the individual's family to undergo genetic testing,[8] and Georgia's insurance law prohibits a health insurer from seeking any genetic information for purposes other than therapeutic or diagnostic,[9] whereas almost half of the states do not have laws governing in this

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researchers should not be allowed to study an individual's genetic information unless they first obtain his or her consent. Eighty-six percent felt a physician should ask permission first before running genetic tests. THE GALLUP ORGANIZATION, PUBLIC ATTITUDES TOWARDS MEDICAL PRIVACY 14-16 (2000), *available at* http://www.forhealthfreedom.org/Gallupsurvey/IHF-Gallup.html (Sep. 26, 2000). According to a CNN-Time survey indicated eighty percent of Americans support genetic privacy protections.

[7] *See* Henry T. Greely, *Health Insurance, Employment Discrimination, and the Genetics Revolution, in* THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 264, 277 (Daniel J. Kevles & Leroy Hood eds., Cambridge, MA: Harvard Univ. Press, 1992).

[8] N.H. REV. STAT. ANN. § 141-H:4 (2003).

[9] G.A. CODE ANN. § 33-54-3 (2003). According to the survey conducted by the National Conference of State Legislatures, *see* National Conference of State Legislatures, *State Genetic Nondiscrimination in Health Insurance Laws* (2001), *at* http://www.ncsl.org/programs/health/genetics/ndishlth.htm, (last updated Aug. 7, 2002), twenty-three states have similar legislation. *See, e.g.*, CAL. INS. CODE § 10148 (Deering supp.

respect. Falling in between these two poles is a design of access management controlled by individual informed consent. It allows the insurers to obtain genetic information or to request genetic tests on the condition that the individual concerned authorizes the information flow. New York[10] and at least two other states[11] adopt this approach.

In compliance with the mandate of the Health Insurance Portability and Accountability Act of 1996 (HIPAA),[12] HHS promulgated the first-ever medical data privacy regulation on the federal level in 2000—the HIPAA Privacy Rule.[13] Notwithstanding the general impression of its extensive impact on the health care industry[14] and the wide range of the regulated entities,[15] the HIPAA Privacy Rule does

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2004) ("No insurer shall require a test for the presence of a genetic characteristic for the purpose of determining insurability other than for those policies that are contingent on review or testing for other diseases or medical conditions."); MD. CODE ANN., Insurance § 27-909(c)(2) (2003) ("An insurer may not request or require a genetic test, the results of a genetic test, or genetic information for the purpose of determining whether or not to issue or renew health benefits coverage.").

[10] N.Y. INS. § 2612*(a) (Consol. 2004) ("No authorized insurer or person acting on behalf of an authorized insurer shall request or require an individual proposed for insurance coverage to be the subject of a genetic test without receiving the written informed consent of such individual prior to such testing, in advance of the test.").

[11] OR. REV. STAT. §746.135(1) (2001); N.M. STAT. ANN. § 24-21-3(A) (Michie 2003).

[12] Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, § 264, 110 Stat. 1936, 2033 (1996) (codified as amended as 42 U.S.C.A. § 1320d-2 (2004)).

[13] Standards for Privacy of Individually Identifiable Health Information (Final Rule), 67 Fed. Reg. 53,181 (2002) (to be codified at 45 C.F.R. pt. 160 and 164).

[14] *See, e.g.*, Jennifer Guthrie, *Time Is Running Out—The Burdens and Challenges of HIPAA Compliance: A Look at Preemption Analysis, the "Minimum Necessary" Standard, and the Notice of Privacy Practices*, 12 ANNALS HEALTH L. 143 (2003).

[15] There are three categories of covered entities under the HIPAA Privacy Rule: (1) a health care

not generally prohibit the collection of genetic information by the health insurers or health plans. To the extent that genetic information is treated and protected as other health information, the HIPAA Privacy Rule only requires written authorization be sought prior to obtaining genetic information.[16] Besides the requirement of informed consent, the HIPAA Privacy Rule does not prohibit insurers from conditioning enrollment in the health plan or eligibility for benefits on provision of an authorization if the genetic information is collected for the purposes of determining eligibility, underwriting, or risk rating.[17] As a federal floor, the HIPAA Privacy Rule leaves conspicuous gaps to be addressed.

5.1.2 Employment

In comparison with the hodgepodge in the health insurance setting, the genetic information regulatory scheme in employment settings is largely structured along the framework put forth by the information regulations of the Americans with Disabilities Act (ADA).[18] The ADA distinguishes three categories of information gathering practices by employers: (1) preemployment inquires; (2) employment entrance or preplacement

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provider that conducts certain transactions in electronic form, (2) a health care clearinghouse, or (3) a health plan, including group health plans except for those self-administered by the employer with less than 50 participants, individual health insurance insurers, HMO's, government-funded health plans, such as Medicaid and Medicare. *See* 42 U.S.C.A. §§ 1320d-1, 1320d. *But cf. infra* notes 71 (HIPAA insurance-related regulation).

[16] 45 C.F.R. § 164.508 (2003).

[17] *Id*. § 164.508(4).

[18] 42 U.S.C.A. § 12112(d) (2004).

examinations; and (3) examinations conducted at any point thereafter on existing employees.

The ADA imposes more restrictions on the practices of collecting information about future or current employees at the first and the third stage. During the preemployment stage, an employer is only permitted to “make inquiries into the *ability* of an applicant to perform job-related functions, and/or may ask an applicant to describe or to demonstrate how, with or without reasonable accommodation, the applicant will be able to perform job-related functions.”[19] Inquires and examinations of current employees after the commencement of employment duties are also required to be job-related and consistent with business necessity.[20]

By contrast, during the preplacement stage, no similar restriction is imposed and the employer is allowed to condition an offer of employment on the results of such examinations.[21] The permissible range of employers’ information gathering practices thus are determined by the condition of whether the “job-related” restriction applies in a specific case.

For those with a “job-related” restriction, the applicability of genetic testing hinges

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[19] 29 C.F.R. § 1630.14(a) (2003) (emphasis added). *See also* 42 U.S.C. § 12112(d)(2).

[20] 42 U.S.C.A. § 12112(d)(4); 29 C.F.R. § 1630.14(c).

[21] 29 C.F.R. § 1630.14(b). The requirement that, if the results of the examination exclude an individual on the basis of disability, the exclusionary criteria must be job-related and consistent with business necessity, *see id*. § 1630.14(b)(3), is not itself an information regulation.

primarily on the issue of whether predicting *future* conditions by genetics amounts to inquiries about *present* ability to perform the job. Some states explicitly prohibit conditioning employment on the acceptance of genetic testing.[22] On the federal level, former U.S. President Clinton also signed an executive order on February 8, 2000 to prohibit federal employers from requiring or requesting genetic tests to evaluate an employee's ability to perform the job or as a condition of being hired.[23] The Equal Employment Opportunity Commission (EEOC) supports the view that "any test which purports to predict future disabilities, whether or not it is accurate, is unlikely to be relevant to the employee's present ability to perform his or her job."[24]

Employers' information gathering practices not required to adhere to the "job-related" requirement are in the same way not prohibited from accessing genetic information about an employee. The rationale behind such a generous arrangement might be that, since employers are obligated to make "reasonable accommodations" for workers with known disabilities to perform the essential function of the job,[25] unrestricted access

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[22] *See*, *e.g.*, N.H. REV. STAT. ANN. § 141-H:3(I)(a) (2003) ("No employer, labor organization, employment agency, or licensing agency shall directly or indirectly solicit, require or administer genetic testing relating to any individual as a condition of employment, labor organization membership, or licensure.").

[23] *See* Exec. Order No. 13,145, 3 C.F.R. 235, 236 (2001).

[24] *See* U.S. Equal Employment Opportunity Comm'n, *EEOC Petitions Court to Ban Genetic Testing of Railroad Workers in First EEOC Case Challenging Genetic Testing Under Americans with Disabilities Act* (Feb. 9, 2001), http://www.eeoc.gov/press/2-9-01-c.html (last modified Feb. 12, 2001) (press release).

[25] 42 U.S.C.A. § 12112(b)(5)(A).

to medical information should be warranted during the preplacement stage.[26] To the extent that genetic information about employees is necessary to make "reasonable accommodations," employers should also be allowed to obtain genetic information about employees provided that certain procedural protections, such as informed consent, are followed.[27] The ADA, however, does not stop states from adopting more stringent laws imposing the same "job-related" standard to medical examinations at the post-offer, preplacement stage to close up the gap.[28]

Even if the more stringent "job-related" standard is in place, there are at least two possible grounds on which employers could be granted access to certain genetic information about employees at least after an offer of employment is made: (1) workers compensation, and (2) worker's own safety.

First, since workers' compensation would require that employers cover medical expenses and lost wages resulting from "work-related" injuries,[29] employers should be

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[26] *See* Anita Silvers & Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1366 (2002).

[27] *See* Norman-Bloodsaw v. Lawrence Berkeley Lab., 135 F.3d 1260 (9th Cir. 1998) (finding a preplacement genetic test for sickle cell trait without employees' informed consent violating constitutional right of privacy but not the ADA).

[28] See CAL. GOV'T. CODE § 12940(e)(3) (Deering supp. 2004); MINN. STAT. § 363A.20 (2003). See also Mark A. Rothstein et al., *Protecting Genetic Privacy by Permitting Employer Access Only to Job-Related Employee Medical Information: Analysis of a Unique Minnesota Law*, 24 AM. J.L. & MED. 399 (1998) (assessing the effects of a state law with a comprehensive job-relatedness limitation).

[29] Such a design is based on the theory that, in exchange for the employees giving up their right to sue, employers' obliged but limited-scope coverage can substantially reduce unnecessary tort litigation. *See*

allowed to investigate employees' medical information to determine if the injuries are really "work-related." It is, however, not without dispute with regard to whether genetic information can be made available to the determination of work-related injuries. The EEOC in its first court action challenging the use of workplace genetic testing against Burlington Northern Santa Fe Railroad took the position that, even though the ADA allows medical examinations to investigate worker's compensation, employers are still prohibited from acquiring information about a current employee that is not job-related or is not consistent with business necessity even in the context of a compensation claim.[30] In its petition, the EEOC called for Burlington Northern to end a policy of requiring employees who file workers' compensation claims for carpal tunnel syndrome (CTS) to undergo mandatory genetic testing for Chromosome 17 deletion, which is claimed to predict some forms of CTS. Without solving the issue of whether an injury possibly caused by genetic factors can still be considered "work-related," Burlington Northern soon settled the case out of court and agreed to stop testing its employees.[31]

But the ADA does not preempt state workers' compensation laws, which constitute the main plank of the worker's compensation system. Compliance with these state laws does not violate the ADA.[32] Several states, despite their wide-ranging prohibition on

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Cheye Calvo, *From Laboratories to Legislatures*, ST. LEGISLATURES, Sep. 2001, at 26, 28.

[30] *See* EEOC v. Burlington N. Santa Fe R.R. Co., No. C01-4013 (N.D. Iowa) (filed Feb. 9, 2001).

[31] *See* U.S. Equal Employment Opportunity Comm'n, *EEOC Settles ADA Suit Against BNSF Genetic Bias* (April 18, 2001), http://www.eeoc.gov/press/4-18-01.html (press release).

[32] Burlington Northern is federally regulated and thus exempt from state (Iowa) workers'

employers' genetic information gathering practices, explicitly permit genetic testing of an employee when it is used for the purpose of investigating a compensation claim.[33]

Second, even one can argue that "[i]t is only fair and reasonable to prevent an invasion of privacy that may be used to deny people benefits or put them at a disadvantage"[34] in workers' compensation claims, information gathering practices whose purpose is ostensibly benign and is essential to the protection of the health of an employee him/herself seems to justify employer's access to certain information about genetic predisposition of the employee. Worker safety may be a legitimate ground for an employer's genetic information gathering practice when it is sought to identify employees with increased risk of health hazards in the workplace. Current laws place a general duty to maintain worker safety on employers.[35] To the extent that removing or reducing dangerous substances from workplace to a level that is safe and healthful for all workers is technologically possible and economically feasible, genetic information helps to define the scope of an employer's duty and to facilitate a safer work environment.[36]

But such information can also be used to an employee's detriment when employers invoke for their discriminatory practices the defense of preventing a "direct threat" to the

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compensation laws.

[33] *See, e.g.*, IOWA CODE § 729.6(7)(a) (2003); N.Y. EXEC. § 296 (19)(c)(1) (Consol. 2004); N.H. REV. STAT. ANN. § 141-H:3(IV)(a) (2003); WIS. STAT. § 111.372(4)(a) (2003).

[34] *See* Calvo, *supra* note 29, at 28 (quoting Maryland Delegate Tony Fulton).

[35] *See* The Occupational Safety and Health Act, 29 U.S.C. 654(a)(1) (1994).

[36] *See, e.g.*, David Orentlicher, *Genetic Screening by Employers*, 263 JAMA 1005, 1008 (1990).

health or safety of the employee under the ADA.[37] Also, even if the direct threat defense should apply only when the threat is “immediate and severe,”[38] an employee’s susceptibility to workplace hazards could be argued to prevent the employee from executing the “essential functions” of the job when removing or reducing workplace hazards to a level safe to that employee would amount to imposing an “undue hardship” on the employers.[39] This outcome shifts the economic burden of working in a dangerous environment from the employer to the employee.[40]

To avoid the externalization of costs while keeping the potential benefits of genetic testing, some suggest that employer’s access to information about an employee’s genetic susceptibility be allowed only when used in that employee’s favor.[41] States such as New York, New Hampshire, Wisconsin, and Iowa, all explicitly permit genetic testing to be taken to determine the employee’s susceptibility or level of exposure to potentially toxic chemicals or potentially toxic substances in the workplace provided that no adverse

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[37] *See* 42 U.S.C.A. § 12113(b) (2004); Chevron USA, Inc., v. Echazabal, 536 U.S. 73, 78, 84 (2002) (interpreting that a “direct threat” defense under the ADA includes those situations in which a worker endangers his own health).

[38] *See* Mark A. Rothstein, *Genetics and the Work Force of the Next Hundred Years*, 2000 COLUM. BUS. L. REV. 371, 397 (citing Rizzo v. Children’s World Learning Ctr., Inc., 213 F.3d 209, 213 (5th Cir. 2000) (en banc)).

[39] *See* 29 C.F.R. 1630.15(d) (2004).

[40] *See* Rothstein, *supra* note 38, at 394.

[41] Another possibility is giving the employee rather than the employer the option of learning whether he or she is at increased risk of occupational illness based on genetic factors. The employee in this design is the only person who determines how to use that information. *See, e.g.*, *id.* at 394-95.

action is taken against the employee as a result of the genetic testing.[42]

5.1.3 Problems with Banning Genetic Information Flows

The approach of banning genetic information flows intends to construct an airtight shield around individual genetic information so as to keep health insurers and employers closely behind a "veil of ignorance." Two difficulties prevent such an attempt.

First, construction of an airtight shield is practically difficult and theoretically problematic. Practically, no legal frameworks intend to entirely ban genetic information flows in society. Insulating health insurers and employers from genetic information about individuals relies not only on legal restrictions formally placed on insurers and employers but also on more proactive measures to install secure firewalls between them and unregulated flows emanating from entities such as pharmaceutical companies and medical researchers. Moreover, many derivative activities in relation to the genetic information—such as taking preventive or mitigating measures for people found to be at increased genetic risk, or medical bills for such treatments—are also as revealing as the genetic test itself.[43] Theoretically, it is difficult to properly define the scope that the airtight shield needs to cover. If the covered scope is to be defined by the *methodology* used, such as the DNA-based technology, it apparently leaves out much information about conditions that are genetically based or influenced. If, on the other hand, the

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[42] N.Y. EXEC. § 296(19)(b) (Consol. 2004); N.H. REV. STAT. ANN. § 141-H:3(I)(b) (2003); WIS. STAT. § 111.372(4)(b) (2003); IOWA CODE § 729.6(7) (2003).

[43] *See* Silvers & Stein, *supra* note 26, at 1377, 1378-79.

covered scope is defined by the *etiology*, i.e., any information about conditions that are genetic in nature, events or activities observable in daily life, such as epilepsy or the signs of panic attack, all have genetic implications.[44] The debate over whether family history should be counted as protected genetic information epitomizes the difficulty.[45]

Second, as shown in the discussion of worker safety, advocates for the information regulation approach are willing to concede that genetic information could have beneficial uses in the hands of employers. But once the approach of banning genetic information flows starts to negotiate the "proper use" of the information, it gives in its ability to maintain an airtight shield around genetic information. And if what really matters is the unfair and discriminatory uses, it should not be that crucial whether or not the airtight shield around genetic information can hold. As cogently pointed out by Professor Paul Lombardo, employing tools of informational privacy to address the issues of discrimination might be a misplaced enterprise.[46]

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[44] *Cf.* Michael J. Malinowski, *Separating Predictive Genetics Testing from Snake Oil: Regulation, Liabilities, and Lost Opportunities*, 41 JURIMETRICS J. 23, 28-29 (2000) (for a similar critique).

[45] For example, Michigan prohibits insurers from requesting genetic testing but allows them to request information about family history. *See* MICH. COMP. LAWS § 500.3407b(2) (2003).

[46] Paul A. Lombardo, *Genetic Confidentiality: What's the Big Secret?*, 3 U. CHI. L. SCH. ROUNDTABLE 589, 612 (1996) ("Most of the arguments against discrimination in health insurance are not confidentiality arguments, but health policy arguments about who should get care and at what cost."). *But see* Karen Rothenberg, *The Social Implications of the Use of Stored Tissue Samples: Context, Control, and Community*, *in* GENETIC TESTING AND THE USE OF INFORMATION 84, 86 (Clarisa Long ed., Washington, DC: The American Enterprise Institute Press, 1999) (arguing that it is still important to protect access to the information even with safeguards against discrimination because an individual who believes that he has been discriminated against usually has difficulty proving it or does not even know that his information was

5.2 Banning Decisionmaking Based on Genetic Information

Supposing it is unfeasible to keep health insurers and employers firmly behind the "veil of ignorance," it might still be possible to demand that they act *as if* they are behind it by banning decisionmaking based on genetic information. By delineating the proper occasion of using genetic information, the antidiscrimination approach allows a more sophisticated classification of genetic information. Indeed, states that adopt the approach of regulating genetic information flows almost all adopt a parallel law banning the use of genetic criteria for distinguishing among people.[47] More and more states not agreeing to genetic informational privacy laws now accept the antidiscrimination approach.[48]

5.2.1 The Emergence of the Category of Presymptomatic Individuals

Unlike the indiscriminate attitude of the informational privacy approach toward genetic information, at least three possible categories of people can be distinguished with the antidiscrimination approach: (1) discriminatory practice against people with a condition having a genetic root, including those who are already symptomatic, (2) discriminatory practice against presymptomatic individuals with varied degree of increased risk because of their genetic compositions, and (3) discriminatory practice

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actually used).

[47] The only exception is Michigan's health insurance law, which prohibits health insurers from requesting genetic testing but does not prohibit discriminatory insurance practice itself. *See* MICH. COMP. LAWS § 550.1401(3)(e) (2003).

[48] *See* Rothstein, *supra* note 28, at 401-3 (classifying the anti-discrimination approach as the third generation of genetic discrimination statutes).

against people who actually present no adverse risk on genetic grounds, such as heterozygous carriers of recessive or X-linked[49] disorders.

The definition of "genetic discrimination" was originally formulated by Paul Billings and his colleagues as discrimination against persons in good health who are at increased risk of becoming ill in the future.[50] It assumes that discrimination against people who are symptomatic or visibly affected by their genetic conditions is not caused by the unveiling power of genetic testing. However, many laws adopting the anti-discrimination approach do not always make the distinction. Several states, such as Georgia,[51] have indiscriminate laws regarding genetic discrimination against people with a genetic condition without specifying whether the use of genetic information about symptomatic individuals is excluded or not. More noticeably, Alabama in 1982 enacted a law specifically prohibiting health or disability insurers from discriminating against people with sickle-cell anemia, an autosomal recessive blood disease.[52] Unlike sickle cell

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[49] An X-linked genetic disease is one that is generally passed on from mother (xX or xx) to son (xY). X-linked disorders manifest when no healthy X chromosome exists. A healthy X chromosome would mask the diseased x chromosome. A female with one mutated chromosome is a healthy carrier, who would not be affected by the disorder.

[50] *See* Paul R. Billings et al., *Discrimination as A Consequence of Genetic Testing*, 50 AM. J. HUM. GENETICS 476, 477 (1992).

[51] G.A. CODE. ANN. § 33-54-4 (2003) ("Any insurer that receives information derived from genetic testing may not use the information for any nontherapeutic purpose.").

[52] ALA. CODE § 27-5-13 (2004) ("Notwithstanding any other provision of law, any insurance company doing business within the state which offers health or disability insurance, is hereby prohibited from denying coverage to applicants because the applicant has been diagnosed as having sickle-cell anemia, and is hereby required to pay any valid claim made involving treatment or care of sickle-cell anemia in

trait, which has only one mutated gene and will not entail the disease, sickle cell anemia with the presence of the fully penetrant HbSS mutation will almost certainly manifest signs and symptoms of the blood disorder not long after the birth. Alabama law that prohibits insurance discrimination against people with sickle cell anemia would certainly cover those manifest signs and symptoms of the disease.

The term "genetic discrimination" used in most of the studies was also often defined broadly to include discriminatory practices against persons who were symptomatic or visibly affected by their genetic disorders. For example, a 1996 survey of the perceptions of 332 members of genetic support groups showed that 25 percent of the respondents or affected family members believed they were refused life insurance, 22 percent believed they were refused health insurance, and 13 percent said that they or a family member had been denied a job or fired from a job because of a genetic condition in the family.[53] This survey did not exclude those who were symptomatic or visibly affected by their genetic conditions from the result because of the problem in the survey design.[54] Indeed, according to Philip R. Reilly, there are only two published papers[55] that

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accordance with other policy provisions.").

[53] *See* E. Virginia Lapham et al., *Genetic Discrimination: Perspectives of Consumers*, 274 SCIENCE 621-4 (1996).

[54] *See id.* at 624 n.20.

[55] *See* Paul R. Billings et al., *supra* note 50, at 476-82 (1992); L.N. Geller et al., *Individual, Family, and Societal Dimensions of Genetic Discrimination: A Case Study Analysis*, 2 SCI. & ENGINEERING ETHICS 71–88 (1996).

purport to offer evidence of genetic discrimination as originally defined.[56] The loose usage of the concept of "genetic discrimination" is criticized to compound the real problem of genetic discrimination even among advocates for the antidiscrimination approach because it confuses rational and legitimate disparate treatment with irrational discrimination.[57]

Discriminatory practices against people in the third category concern an apparent public irrationality and prejudice. A 1998 British survey investigated this issue rather clearly.[58] It found that 11 percent of unaffected carriers of recessive disorders,[59] 46 percent of healthy non-carriers from families with members affected by late onset autosomal disorders,[60] and 8 percent of non-carrier parents of children with disorders of spontaneous mutation[61] had problems in life insurance applications. The study argued that this phenomenon evidences the existence of unjustified genetic discrimination since those people do not present any adverse actuarial risk. In the 1970s, owing to a similar misunderstanding, many people with sickle cell trait, the heterozygous carrier status that

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[56] *See* Philip R. Reilly, *Public Concern About Genetics*, 1 ANN. REV. GENOMICS HUM. GENETICS, 485, 490 (2000).

[57] *See, e.g.*, Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, 29 AM. J.L. & MED. 77, 84-85 (2003).

[58] *See* Lawrence Low et al., *Genetic Discrimination in Life Insurance: Empirical Evidence From a Cross Sectional Survey of Genetic Support Groups in the United Kingdom*, 317 BMJ 1632, 1634, 1634 tbl.3 (1998).

[59] 28/264 in support groups for CF and Duchenne muscular dystrophy. *See id*.

[60] 27/59 in support groups for Huntington's disease and myotonic muscular dystrophy. *See id*.

[61] 16/210 in support groups for Marfan's syndrome, tuberous sclerosis, neurofibromatosis. *See id*.

will not develop sickle cell disease, were refused health insurance in the United States. States, such as North Carolina[62] and Louisiana,[63] now have laws expressively prohibiting discrimination against people with sickle cell trait or hemoglobin C trait. New York[64] and New Jersey[65] have laws prohibiting discrimination against unaffected carriers of other forms of recessive disorders, such as thalassemia trait, Tay-Sachs trait, or cystic fibrosis trait. Maryland and California even have a general prohibition of insurance discrimination against a person with a genetic trait that is "harmless in itself,"[66] or with a gene "which may, under some circumstances, be associated with disability in that person's offspring, but which causes no adverse effects on the carrier."[67]

> [62] No insurance company…shall refuse to issue or deliver any policy…which affords benefits or coverage for any medical treatment or service…by reason of the fact that the person to be insured possesses sickle cell trait or hemoglobin C trait, nor shall any such policy…carry a higher premium rate or charge by reason of the fact that the person to be insured possesses said trait.

N.C. GEN. STAT. § 58-51-45 (2003) (enacted 1975). *See also id.* § 58-65-70 (health care provider); *id.* § 58-58-25 (life insurance); *id.* § 95-28.1 (employment). In 1997, North Carolina expanded the scope of its anti-discrimination law to cover all employment discrimination based on any genetic testing or genetic information. *Id.* at § 95-28.1A (2003).

[63] LA. REV. STAT. ANN. § 23:352 (West 2003) (prohibiting employment discrimination).

[64] N.Y. CIV. RIGHTS LAW §§ 48, 48-a (Consol. 2004) (prohibiting employment discrimination).

[65] N.J. STAT. §§ 10:5-5, 10:5-12 (2004) (prohibiting employment discrimination against "atypical hereditary cellular or blood trait").

[66] *See* MD. CODE ANN., Insurance § 27-208(a)(3) (2003) ("Unless there is actuarial justification, an insurer may not refuse to insure or make or allow a differential in ratings, premium payments, or dividends in connection with life insurance and annuity contracts solely because the applicant or policyholder has the sickle-cell trait, thalassemia-minor trait, hemoglobin C trait, Tay-Sachs trait, or a genetic trait that is harmless in itself.").

[67] *See* CAL. INS. CODE § 10143(a) (Deering supp. 2004).

Discrimination against unaffected carriers of recessive disorders surely is irrational. As argued by Professor Deborah Hellman, the problem of irrationality is at least partly addressed by existing non-genetic legal frameworks in the insurance setting. States already require that insurance rates be rationally calculated on the basis of actuarial data.[68] Charging higher premiums to unaffected carriers of recessive disorders runs counter to the most basic principle of insurance laws. Legal scholars employing a law and economics approach also allude to the supreme economics rule that market forces would punish and eventually eliminate irrational business behaviors in a competitive market, be it insurance or labor.[69] The presumption behind the stances is that since the problem results merely from an irrational misconception, it is practically correctible even without government intervention.

Once the goal is set to tackle irrational discrimination, the advocates for the antidiscrimination approach would agree that a specialized law prohibiting genetic discrimination against symptomatic individuals is itself irrational and a law prohibiting genetic discrimination against unaffected carriers of recessive disorders, though rational, is most likely unnecessary. Between these two poles remains the category of all

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[68] *See* Hellman, *supra* note 57, at 85 & n.33 (listing state insurance laws requiring rational rates setting).

[69] *See* Colin S. Diver & Jane Maslow Cohen, *Genophobia: What Is Wrong with Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1464 (2001) (citing GARY S. BECKER, THE ECONOMICS OF DISCRIMINATION 14-15 (Chicago: Univ.of Chicago Press, 2d ed., 1971)); RICHARD A. EPSTEIN, FORBIDDEN GROUNDS: A CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS 290-96 (Cambridge, MA: Harvard Univ. Press, 1992).

presymptomatic individuals with very diverse risk of becoming ill because of very different genotype-phenotype correlations of different genetic conditions. But, as long as they do not become symptomatic, the ardent advocates for the antidiscrimination approach would think their genetic risk, be it high or low, should not be used against them. That is, the advocates propose to see genetic information as a presumed irrational factor, just like race, sex, and religion, which should not become the basis of decisionmaking in either health insurance or employment. Employers or insurers should become "gene-blind" as they should be "color-blind" with regard to the issue of race.

5.2.2 Health Insurance

In response to the call to proscribe genetic discrimination against presymptomatic individuals genetically at risk, the HIPAA's insurance-related regulation, on the issue of preexisting condition exclusion, specifically put under legal protection people with a genetic condition "in the absence of a diagnosis of that condition."[70] The law restricts the extent to which employment-based group health plans or group health insurance[71] can

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[70] Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, §§ 101(a), 102(a), 110 Stat. 1936, 1939, 1955 (1996) (codified as amended as 29 U.S.C.A. § 1181(b)(1)(B) (2004), 42 U.S.C.A. § 300gg(b)(1)(B) (2004)) ("Genetic information shall not be treated as a [preexisting] condition...in the absence of a diagnosis of the condition related to such information."). Arguably, the language "in the absence of a diagnosis" may also cover unaffected carriers of recessive disorders. *See* 29 C.F.R. § 2590.701-2 (2003) (genetic information under the HIPAA includes information regarding carrier status).

[71] Unlike the HIPAA Privacy Rule, the HIPAA insurance-related regulation only applies to employment-based group health plans or insurance. *Compare* 42 U.S.C.A. § 1320d-1 (2004), *with* 29 U.S.C.A. § 1181, *and* 42 U.S.C.A. § 300gg. Excluding 40 million of the uninsured, the population of Americans under age 65 is around 210 million according to the 2001 data. *See* NATIONAL CTR. FOR

exclude coverage for "preexisting conditions," and prohibits them from treating affected people not yet manifesting the signs or symptoms of the disease as having a preexisting condition.

The HIPAA, in addition to its regulation of preexisting condition exclusion, also prohibits establishing rules for eligibility to group health insurance based on "genetic information."[72] Although it does not specify whether genetic information about a symptomatic individual is included or not, a further investigation of the law would suggest that the ambiguity is not grave since the law already prohibits discrimination based on other symptomatic "health factors," such as physical or mental medical conditions, medical history, and disability. In fact, to prevent a construction of the law that makes the restriction on the use of genetic information entirely redundant, it is reasonable to understand that the use of genetic information about a presymptomatic individual in determining eligibility is what the law intends to prohibit.

A more problematic question concerns the HIPAA's regulation of premiums. The

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HEALTH STATISTICS, HEALTH, UNITED STATES, 2003 at 95 tbl.1, 331 tbl.129 (Hyattsville, MD: National Center for Health Statistics, 2003) (population under age 65 is 250 million, nonelderly uninsured is 39.2 million). Among all insured population under age 65, only 163 million are covered through employment-based group health insurance. *See id.* at 326 tbl.127. The remaining 47 million are covered either through individually purchased private plans or through government-funded plans and thus are not protected by the HIPAA insurance-related regulation.

[72] Health Insurance Portability and Accountability Act, Pub. L. No. 104-191, §§ 101(a), 102(a), 110 Stat. 1936, 1945, 1961 (1996) (codified as amended as 29 U.S.C.A. § 1182(a) (2004), 42 U.S.C.A. § 300gg-1(a) (2004)) (defining genetic information as one of health factors that cannot be used for determining eligibility).

law prohibits discrimination in the premiums of group health insurance among “similarly situated individuals” based on health factors, including genetic information.[73] As a regulation regarding how people can be grouped as “similarly situated individuals,” it permits an employer to group employees only on any reasonable basis that does not involve a health factor, for instance, full time status, geographical location, date of hire, length of service, and type of occupation.[74] Accordingly, no group of people could be classified for premium setting on the basis of a presymptomatic genetic condition. But this is the result of a group health insurance that prohibits rating based on *individual* health factors or *individual* claim experience rather than the effect of a general prohibition of the *use* of genetic information in premium setting. As mentioned in the discussion of regulating genetic information flows, the HIPAA Privacy Rule does not prohibit health insurers from collecting genetic information. A group health insurer may obtain genetic information about an insured group to project the *group*’s actuarial risk without conflicting with the HIPAA’s premium regulation. That is, the HIPAA leaves open a possibility that all individuals within a group are charged higher premiums based on the *health status of the entire group* assessed by the genetic information about individuals of the group.[75] Unless the very unlikely precondition that an employer is

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[73] 29 U.S.C.A. § 1182(b), 42 U.S.C.A. § 300gg-1(b).

[74] *See* Roberta Casper Watson, *Employer-Sponsored Health Plans Under Non-Privacy Recent Health Provisions of HIPAA*, 2004 ALI-ABA COURSE STUDY 559, 584.

[75] *See Privacy, Confidentiality and Discrimination in Genetics: Hearing Before the House Comm. of Commerce*, 105th Cong. 17, 19 (1997) (prepared statement of Francis S. Collins, Dir., Nat’l Human Genome Research Inst.), *available at* http://www.genome.gov/10002352 (last reviewed April 2004);

willing to assume the higher insurance costs is satisfied, the HIPAA does nothing to relieve the most alarming danger that a presymptomatic individual genetically at risk would be rejected the benefits of health insurance altogether, not because his or her genetic status is wrongly considered as a preexisting condition, but because his or her access to a job, and therefore the employment-based group insurance, is largely curtailed by the fact that an employer would not hire someone whose genetic condition would eventually increase employer's insurance costs.[76]

In the market of individually purchased health insurance, where the HIPAA is not applicable, state laws play a more crucial role. Unlike indiscriminate laws that prohibit any use of genetic information in determining eligibility, premiums or coverage, a few states now have insurance laws prohibiting the use of genetic information unless there is actuarial justification.[77] The application of those laws is unequivocal to both symptomatic individuals and unaffected heterozygous carriers of recessive disorders: discrimination against symptomatic individuals is certainly permissible, whereas discrimination against unaffected carriers is clearly prohibited. What remains unclear is whether the protection

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Robert H. Jerry, II, *Health Insurers' Use of Genetic Information: A Missouri Perspective on a Changing Regulatory Landscape*, 64 MO. L. REV. 759, 778-79 (1999).

[76] As explained earlier, an employer can obtain, during the preplacement stage, genetic information about an employee even the information is not job-related.

[77] *See, e.g.*, VT. STAT. ANN. tit. 8, § 4724(7)(D) (2003) ("unfair discrimination…based on…the results of genetic testing, where there is not a relationship between the medical information and the cost of the insurance risk that the insurer would assume by insuring the proposed insured"); ARIZ. REV. STAT. § 20-448E (2004) ("unless the applicant's medical condition and history and either claims experience or actuarial projections establish that substantial differences in claims are likely to result from the genetic condition").

is applicable to presymptomatic individuals genetically at risk.

On October 14, 2003, the "Genetic Information Nondiscrimination Act of 2003" was passed by the United States Senate.[78] A similar House Bill 1910 was also introduced earlier in May 2003.[79] Both bills aim to close the loophole left by the HIPAA's premium regulation. Both bills explicitly prohibit setting discriminatory premiums of group health insurance based on information about presymptomatic genetic conditions of individuals in the group.[80] These provisions preclude the possibility that all individuals within a group are charged higher premiums according to the health status of the entire group assessed by the genetic information about individuals in the group. Moreover, both bills extend the protection to the individual market by prohibiting establishing rules for eligibility to enroll in individual health insurance coverage or setting premium rates based on genetic information.[81]

5.2.3 Employment

(1) ADA's "Regarded As" Prong and the Hurdle of the "Ability to Work" Analysis

Although people generally think that one's ability to do a job should be judged on

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[78] S. 1053, 108th Cong. (2003).

[79] H.R. 1910, 108th Cong. (2003) (Genetic Nondiscrimination in Health Insurance and Employment Act).

[80] *See* S. 1053 §§ 101(a)(3), 102(a)(3), 103(a)(2), 104(a); H.R. 1910 §§ 101(a)(2), 102(a)(1)(B), 103(a)(2), 104(a)(1).

[81] *See* S. 1053, 108th Cong. § 102(b); H.R. 1910, 108th Cong. § 102(b).

just one's ability, there is no general legal requirement of nondiscrimination in employment practices. Only when the discrimination is based on factors—such as sex, race, religion, national origin, age, and disability—proscribed by specialized laws is it prohibited.[82] No federal law currently speaks directly to the issue of genetic discrimination in employment. The closest link is to go through the mandate of Title I of the ADA against disability discrimination in workplace.

Given the common understanding that, before becoming symptomatic, presymptomatic individuals have not suffered a "physical or mental impairment substantially limiting a major life activity"—which is the most common definition of a disability,[83] genetic discrimination against presymptomatic individuals genetically at risk might not fall snugly within the ADA's coverage. The EEOC, however, issued a now much debated guideline in 1995,[84] interpreting the ADA as to apply to presymptomatic individuals through ADA's "regarded as" prong of the definition of a disability.[85] The "regarded as" prong covers the situations in which (1) an impairment that is not

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[82] *See* The Civil Rights Act of 1964 §§ 701-716(c), 42 U.S.C.A. §§ 2000e-2000e-15 (2004); The Age Discrimination in Employment Act of 1967 §§ 1-16, 29 U.S.C.A. §§ 621-634 (2004). *See also* Hellman, *supra* note 57, at 85-86.

[83] *See* 42 U.S.C.A. § 12102(2)(A) (2004).

[84] U.S. Equal Employment Opportunity Comm'n, 2 EEOC Compliance Manual 902.8 (2000). *See also* Mark S. Dichter & Sarah E. Sutor, *The New Genetic Age: Do Our Genes Make Us Disabled Individuals Under the Americans with Disabilities Act?*, 42 VILL. L. REV. 613 (1997).

[85] There are three prongs of the definition of a disability in the ADA: (A) individuals with a physical or mental impairment that substantially limits one or more major life activities; (B) individuals with a record of such an impairment; and (C) who are regarded as by others as having such an impairment. 42 U.S.C.A. § 12101(2).

substantially limiting is treated as so, (2) the substantial limitation of an impairment on major life activities is only the result of the attitudes of others toward such an impairment, or (3) an individual has none of the impairments but is treated as having one.[86]

Given the unfortunate history of eugenics, it is not surprising that the "regarded as" prong of the definition of a disability, which is intended by Congress to combat erroneous but widespread cultural assumptions about people with disabilities and "discrimination based on the myths, fears, and stereotypes associated with disability,"[87] would be handily summoned to tackle the issue of genetic discrimination in employment.

The difficulty of applying the EEOC's sympathetic guideline to people genetically at risk, however, lies in a general problem originating from current jurisprudence of the ADA concerning the first prong of the definition of a disability. The ADA's first prong provides that, in order to be categorized as a disability, an impairment under consideration has to substantially limit one or more major life activities. The EEOC has opined that "major life activities" refer to a wide-ranging list of activities including but not limited to caring for oneself, performing manual tasks, walking, seeing, hearing, speaking, breathing, learning, and working.[88] It has been commonplace in ADA litigation of employment discrimination that courts analyze only whether a plaintiff is substantially limited in the single major life activity of *working*, even when the plaintiff's impairment

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[86] 29 C.F.R. § 1630.2(l) (2003).

[87] 29 C.F.R. app. 1630.2(1) (2003) (EEOC's Interpretive Guidance).

[88] *See* 29 C.F.R. §1630.2(i) (2003).

should be logically understood as limiting some major life activities other than working. To establish that an impairment substantially limits the major life activity of working, the plaintiff has to prove that the impairment restricts him or her from performing not only the job at issue but also a class of jobs or a broad range of jobs in various classes.[89] That is, the plaintiff is required to demonstrate to the court that he or she is *totally incapacitated* in the ability to work in the entire labor market in which he or she could expect to participate.

As a result, a plaintiff's case is not allowed to rely on a more sensible claim that an impairment, though substantially limiting the life activity *other than* working, does not prevent him or her from performing the job at issue provided that some reasonable accommodation is made. The plaintiff is awkwardly required to prove that the impairment incapacitates his or her ability to work in all relevant labor markets, and, at the same time, that he or she is still fully qualified for the position that he or she just claimed to be substantially restricted in the ability to perform.[90] Professor Feldblum has pointed out that such jurisprudence is the product of a long mistaken "image of a 'disabled person' as a person who is unable to work," a view that rules out any person

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[89] *See, e.g.*, Broussard v. University of Cal. Berkeley, 192 F.3d 1252 (9th Cir. 1999); Muller v. Costello, 187 F.3d 298 (2d Cir. 1999); Redlich v. Albany Law Sch. of Union Univ., 899 F. Supp. 100, 106 (N.D.N.Y. 1995) (citing 29 C.F.R. § 1630.2(j)(3)(i) (1995)).

[90] *See* Chai R. Feldblum, *Definition of Disability Under Federal Anti-Discrimination Law: What Happened? Why? And What Can We Do About It?*, 21 BERKELEY J. EMP. & LAB. L. 91, 145 (2000). *See also* Robert L. Burgdorf, Jr., *Substantially Limited Protection from Disability Discrimination: The Special Treatment Model and Misconstructions of the Definition of Disability*, 42 VILL. L. REV. 409, 439-68 (1997).

still capable of working from the category of disability contemplated in the ADA. Ironically, the ADA is in fact designed to protect exactly people with disabilities who can still work.[91]

Jurisprudence of the first prong has a spillover effect on the "regarded as" prong of the definition. While one needs to have an impairment that substantially limits major life activities to qualify as a disabled person in the first prong, no such objective elements are required in the "regarded as" prong. Instead, the subjective state of the employee is the crux here. Viewing the "regarded as" prong as a mirror image of the first prong short of the objective element of impairment or limitation on major life activities of the person being discriminated against, courts regularly demand the plaintiffs to demonstrate that an employer holds an erroneous subjective perception about not only the existence of the impairment but also the substantial limitation on major life activities.[92]

When determining whether an employer perceives an employee as having a substantial limitation in life activity in an action against the employer, the mistaken image of "a disabled person as a person who is unable to work" again governs the courts. To be regarded as disabled in employment, a plaintiff is required to prove that the employer regarded him or her as being substantially limited in the major life activity of *working*. The "ability to work analysis" then again calls upon the concept of "a broad

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[91] *See* Feldblum, *supra* note 90, at 143.

[92] *See, e.g.*, Kelly v. Drexel Univ., 94 F.3d 102, 109 (3d Cir. 1996) ("The mere fact that an employer is aware of an employee's impairment is insufficient to demonstrate either that the employer regarded the employee as disabled or that perception caused the adverse employment action.").

range of jobs" as the proper standard to determine the severity of the limitation on the life activity of working.[93]

This reading of the "regarded as" prong unfortunately precludes a group that needs ADA's protection most in the employment context, such as neurofibromatosis, a cosmetic disfigurement, who are capable of working but are limited in life activities solely because of the unjustified fear and aversion of others to their impairments. The shrinking coverage of the ADA's "regarded as" prong greatly diminishes the potential of the EEOC's sympathetic guideline of 1995. However, the cause of the problem has nothing to do with the status of presymptomatic individuals with genetic conditions, nor does the problem limit to them.

(2) *Bragdon* and Presymptomatic Impairment

Recently, advocates for genetic antidiscrimination in employment were cheered by a Supreme Court decision, *Bragdon v. Abbott*,[94] whose holding seems to provide a new avenue for presymptomatic individuals genetically at risk to be considered as disabled under the first prong of the ADA.[95]

The Court in *Bragdon* held that an asymptomatic HIV positive individual is

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[93] *See* Sutton v. United Air Lines, Inc., 527 U.S. 471, 489 (1999).

[94] 524 U.S. 624 (1998) (5-4 decision).

[95] *See, e.g.*, Eugenia Liu, *Bragdon v. Abbott: Extending the Americans with Disabilities Act to Asymptomatic Individuals*, 3 J. HEALTH CARE L. & POL'Y 382, 393-99 (2000); Lawrence O. Gostin et al., *Disability Discrimination in America: HIV/AIDS and Other Health Conditions*, 281 JAMA 745, 748 (1999).

disabled within the meaning of the ADA because she has a physical impairment that substantially limits major life activity of reproduction. Although it is often argued that *Bragdon* agrees in principle that a physical condition in its asymptomatic phase can be considered as an impairment within the meaning of the ADA,[96] the Court indeed found that "clinical features of HIV infection—such as, lymphadenopathy, dermatological disorders, oral lesions, and bacterial infections—persist throughout the asymptomatic phase even though they might manifest themselves only to a relatively minor degree.[97]

If those clinical features are what made the Court recognize asymptomatic HIV infection as a physical impairment, it is reasonable to suspect that the ruling of *Bragdon* would not extend to a genetic condition in a person who has an increased risk of becoming ill but currently does not have clinical signs or symptoms. The concept of "clinical feature," however, is not a constant plain fact. It bears a close relation to the ever-progressing medical knowledge about what is "normal functioning" of human species and correspondingly what is an adverse departure from it.[98]

It may be unlikely that a concept of "normal functioning" based purely on the genotypic status would someday totally replace one based on observable phenotypic traits.

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[96] *See, e.g.*, Silvers & Stein, *supra* note 26, at 1365; Gostin et al., *supra* note 95, at 748. *See also* Bragdon, 524 U.S. at 637 (finding that the Rehabilitation Act "protects symptomatic and asymptomatic HIV-infected individuals against discrimination in any covered program").

[97] Bragdon, 524 U.S. at 635-36.

[98] *Cf. id*. at 636 ("It *was once thought* the virus became inactive during this period, but it *is now known* that the relative lack of symptoms is attributable to the virus' migration from the circulatory system into the lymph nodes.") (emphasis added).

There is a real possibility that the advance in human genomics would inform a concept of "normal functioning" independent of the more conventional understanding of the term. Traditionally, what matters in conceiving "normal functioning" is the fitness of a phenotypic trait.[99] Yet, the line between genotype and phenotype is increasingly dissolving.[100] Knowledge about the function of genes at a higher and higher developmental level is obtained as the paradigm in biomedical research shifts from identifying mutation as disease etiology to understanding the pathogenetic pathways of disease development.[101] We are indeed not far away to conceive a concept of "normal functioning" recognizing that a particular segment or segments of human genome function to produce certain gene product, such as proteins, in the appropriate amounts or to regulate a specific physiological condition. An altered gene departs from that "normal functioning" even without causing abnormality at a higher developmental level.[102] For example, in the case of sickle cell trait, even its deleterious effect is masked by the healthy copy of the gene, one copy of HbS mutation gene is a departure from its "normal

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[99] *See* Ron Amundson & George V. Lauder, *Function Without Purpose: The Uses of Causal Role Function in Evolutionary Biology*, 9 BIOLOGY & PHIL. 443 (1993-4), *reprinted in* THE PHILOSOPHY OF BIOLOGY 227 (David L. Hull & Michael Ruse eds., 1998) (discussing two accounts of normal functioning, one based on evolutionary goals, the other on anatomical criteria).

[100] *See* Richard C. Lewontin, *Genotype and Phenotype, in* KEYWORDS IN EVOLUTIONARY BIOLOGY 137, 143 (Evelyn Fox Keller & Elisabeth A. Lloyd eds., Cambridge, MA: Harvard Univ. Press, 1992) ("At the lowest level the DNA sequence of the genes itself is a phenotype, and a complete description of the DNA sequence is identical with a complete specification of the genotype.").

[101] *See supra* text accompanying notes 66-72 of Chapter 4.

[102] *See, e.g.*, Joseph S. Alper, *Does the ADA Provide Protection Against Discrimination on the Basis of Genotype?*, 23 J.L. MED. & ETHICS 167, 168-69 (1995).

functioning” of producing healthy hemoglobin.

The potential difficulty of this fresh understanding of “normal functioning” defined at the genic level[103] is that we do not have full knowledge about the function of every disease-related gene. The association study itself, a methodology now widely used to discover genes associated with diseases,[104] do not provide information about gene function. A mere association between the disease and the alteration or variation in the DNA sequence at a specific location of the genome—the substitution, deletion, or insertion of one or more base pairs—, without more, does not establish what is the “normal functioning” of the DNA sequence at that location of the genome. It is possible that the gene found to be associated with the disease indeed only inherits together with the real cause, whose function of producing normal genetic products is what really went wrong.

Without further information about the gene function, presence of a gene associated with a disease, at most, is a proxy of something that went wrong with the “normal functioning” at the genic level. But the fact that the proxy status of this gene is given by its association with a departure from “normal functioning” at a higher developmental level, for instance, a physiological disease, thwarts the very claim that it can be an indicator of a departure from “normal functioning” independently defined at the genic

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[103] Whereas the term *genetic* refers generally to the state of being hereditary, *genic* denotes something of or relating to or produced by or being a gene.

[104] *See supra* text accompanying notes 25-32 of Chapter 1.

level. In cases devoid of knowledge about the gene function, even the commonly invoked concept of *penetrance*—the strength of the association between a disease-related gene and the disease—would not lend support to the construction of the concept of genic "normal functioning" without referring to the concept of "normal functioning" at a higher developmental level.

The changing concept of "normal functioning" certainly would have cultural impacts on how people generally think of "impairment" and hence their grasp of who are the people with impairments. If, however, the gauge of "normal functioning" embraced in the definition of "impairment" of the ADA remains to be set at a higher developmental level, such as at the level of the "body systems" specified by the EEOC,[105] no amount of evidence proving the link between a genotype and the *future* appearance of the malfunctioning at that developmental level is sufficient to establish that adverse departures from the "normal functioning" at that developmental level now actually occur. That is, disease-related genotypes with different penetrance—the likelihood of expression—would not fare differently with regard to whether they are impairments in that sense. A disease-related genotype with a complete penetrance, for example, Huntington's Disease gene (HD), without more,[106] would not be considered as an impairment as much as a

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[105] 29 C.F.R. § 1630.2(h) (2003) ("Physical impairment means any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following the body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genito-urinary, hemic and lymphatic, skin, and endocrine.").

[106] Eugenia Liu suggested that, as more and more studies show that there are pre-clinical signs of Huntington's disease, such as neuronal loss or cognitive deficit, it becomes more and more likely to

disease-related genotype with an incomplete penetrance, such as BRCA1 and BRCA2 genes.

(3) *Bragdon* and Impaired Reproductive Function

Even if the asymptomatic status of HIV infection does not provide enough basis of a successful analogy for presymptomatic genetic conditions, the closer implication of *Bragdon* might lie in its theory that reproduction is a major life activity.[107] Finding that the available antiretroviral therapy can only reduce the risk of passing the disease to offspring from about 25% to roughly 8%,[108] the Court ruled that HIV infection substantially limits one's major life activity of reproduction, and that discrimination in public accommodation based on the status of asymptomatic HIV infection violates the ADA.

Along this line, it seems plausible to argue in the case of a presymptomatic genetic condition that a person's reproductive function is equally impaired because there is also a risk of transmission of his or her genetic condition to the offspring. Admittedly, such an

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categorize the disease as an ADA-defined impairment. *See* Liu, *supra* note 95, at 394-95 (citing Andrew D. Lawrence et al., *Evidence for Specific Cognitive Deficit in Pre-Clinical Huntington's Disease*, 12 BRAIN 1329, 1333-34 (1998), and Jean Paul G. Vonsattel & Marian DiFiglia, *Huntington Disease*, 57 J. NEUROPATHOLOGY & EXPERIMENTAL NEUROLOGY 369, 370 (1998)). Strictly speaking, the "pre-clinical" signs that Liu mentioned are still "clinical" signs other than that of chorea—the abnormal body movement characteristic of Huntington's disease.

[107] *See* Bragdon, 524 U.S. at 625 ("Reproduction and the sexual dynamics surrounding it are central to the life process itself.").

[108] *Id*. at 626, 640.

argument conflates the analysis of impairment with that of major life activities substantially limited by the impairment: the *Bragdon* Court first recognized asymptomatic HIV infection as affecting immune and lymphatic systems and then engaged in the analysis of major life activity of reproduction. The flaw is not fatal because it is perfectly logical that the major life activity limited could be the same as the body function impaired. The requirement of the analysis of major life activity separated from that of impairment is only to make clear that it is certain social environments, in which major life activities are defined, that makes an impairment disability.

The more serious problem of this application of *Bragdon*, however, comes from the nearly unlimited scope of the impaired reproduction the application could render. There is always a 50% chance of passing on one of the two copies of one's gene to the child, be it normal or abnormal, dominant or recessive, highly penetrant or incompletely penetrant. Just like the reproductive function of an asymptomatic HIV infected woman is impaired because there is a 8~25% risk that she transmits the disease to the child, one's reproductive function is also impaired if *any* of the two copies is altered because there then is either a 50% or 100% chance that one passes on *altered genes*, and thus *an impaired reproductive function*, to the direct offspring.[109] The reproductive function of the offspring inherited the altered genes are impaired because, once again, there is either

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[109] *See* Alper, *supra* note 102, at 168-69 ("Because it is the function of the reproductive system of an organism to produce healthy offspring, the reproductive system in the carrier has been affected."); Liu, *supra* note 95, at 397 ("[A] 50% chance of passing a gene alteration for a dread and fatal cancer to a child should also lead a court to find that a person with BRCA1or 2 is substantially limited in her ability to reproduce.").

a 50% or 100% chance that they further pass on altered genes and the impaired reproductive function to the next offspring.

Accordingly, the questions of how many copies of the altered gene is the sufficient dosage for the disease—the question of the mode of inheritance: dominant, recessive, or X-linked—and how likely the altered gene(s) would develop into actual disease—the question of penetrance—are not the concern here. What matters in the analysis of the impaired reproductive transmission from an individual to the offspring is not the disease affected by the altered gene, but the altered gene and the impaired reproductive function.[110]

There are, however, three reasons why such an application of *Bragdon* might not prevail. First, the broad coverage rendered by this application of *Bragdon* most likely would be rejected by the courts given the unwillingness of the Supreme Court to turn from the Congress' original estimation of some 43 millions who have one or more physical or mental disabilities and to expand too radically the ADA coverage.[111] Second, an anomalous legal situation may also arise in which, while a disease is not considered to

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[110] *But see* Laura F. Rothstein, *Genetic Discrimination: Why Bragdon Does Not Ensure Protection*, 3 J. HEALTH CARE L. & POL'Y 330, 345 (2000) (arguing that the risk of transmission depend on the mode of inheritance); *Protecting Against Genetic Discrimination: The Limits of Existing Laws*, *Hearing Before the Senate Comm. on Health, Educ., Labor, and Pensions*, 107th Cong. 6, 8 (2002) (paper prepared for Hon. Edward Kennedy by Chai R. Feldblum, Director, Federal Legislation Clinic, Georgetown University Law Center) [hereinafter Feldblum, *Prepared Paper*] (arguing that genetic conditions with higher penetrance, such as Huntington's disease gene, is more likely to be covered by *Bragdon*'s theory than those with lower penetrance, such as BRCA1 for breast cancer).

[111] *See* Sutton v. United Air Lines, Inc., 527 U.S. 471, 484-488 (1999).

be an impairment substantially limiting a major life activity, people with a genetic condition susceptible to that disease could still be considered to have an impaired reproductive function.[112] Moreover, by holding that the plaintiff's impaired major life activity is *reproduction* in the *public accommodation* context, *Bragdon* seems to break the nexus traditionally held by the courts between the allegedly impaired major life activity and the life activity in which the impaired person was actually discriminated against.[113] Whether *Bragdon*'s theory would survive the "ability to work" analysis in the employment context remains uncertain.[114]

(4) Workers' Compensation Claims

Another issue in the employment context is workers' compensation claims. Our earlier discussion of *Burlington* has shown that the EEOC's stance is to prohibit employers from requesting genetic information regarding the injured employee for the purpose of determining if the alleged injuries are really "work-related."[115] But if such genetic information is otherwise available, can decisions of workers' compensation be

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[112] *See* Feldblum, *Prepared Paper*, *supra* note 110, at 8.

[113] *See* Quick v. Tripp, 43 F. Supp. 2d 1357, 1367 (S.D. Fla. 1999) ("[*Bragdon*] dispels the traditional notion that there be a nexus between the allegedly impaired employee's workplace ability and the allegedly impaired major life activity.").

[114] *See also* Jennifer S. Geetter, *Coding for Change: The Power of the Human Genome to Transform the American Health Insurance System*, 28 AM. J.L. & MED. 1, 40 (2002).

[115] *See supra* notes 29-31 and accompanying text.

based on it? In *Virden v. Board of Trustees of Firefighters Pension Fund*,[116] a state appellate court ruled negatively.

Virden is about a line-of-duty disability pension claim filed by a firefighter based on his debilitating hypertension and severe anxiety aggravating the hypertension. The plaintiff claimed that his disability was caused by specific acts of duty as a fireman. It was revealed outside the proceeding that the plaintiff's father died of a heart attack at an early age and the plaintiff's brother also suffered from hypertension. Based on such information and the testimony of expert witnesses, the pension board of trustees concluded that, because the plaintiff's disability has strong genetic factors and tends to run in families, such genetic factors subsist as a preexisting condition that precludes the possibility that the disability was solely caused by the performance of firefighting duties. Without challenging the factual issue of whether the plaintiff's hypertension really has genetic roots, state district[117] and appellate courts, however, reversed the Board's decision on the ground that a line-of-duty disability pension can be awarded if the claimant proves that some condition of his employment exacerbated or aggravated a preexisting condition.[118]

Admittedly, *Virden* is not a genetically-conscious decision. Its ruling is more about whether a preexisting condition, be it genetic or not, would affect a worker's

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[116] Virden v. Bd. of Trustees of Firefighters Pension Fund, 709 N.E.2d 986 (Ill. App. Ct. 1999).

[117] The district court is named the "Circuit Court" in Illinois.

[118] *Id.* at 989.

compensation claim. However, the effect of *Virden* is indisputably relevant to the admissibility of genetic information in determining whether injuries are “work-related.” So far as the injury/disability at issue involves the interplay between genetic factors and non-genetic environmental influences, i.e., so-called multifactorial disorder, *Virden* amounts to a prohibition of taking genetic information into account in workers’ compensation claims if the compounding environmental influences originate from the workplace.

Virden may be viewed as a victory of the protection of employees. It impels employers to maintain a safer work environment. But *Virden* may also have unintended result of further deterring employers from hiring someone with genetic susceptibility to workplace hazards since employers are to be held responsible for an employee’s incompletely penetrant genetic conditions likely to be triggered by certain factors in work environment. Like presymptomatic impairment, if genetic susceptibility to workplace hazards, affecting at most only *future* ability to work, is to be covered by the ADA, it must resort to the concept of “regarded as disability” of the ADA or *Bragdon*’s “present reproductive function” analysis. However, it is beyond the reach of the ADA’s protection when employers can demonstrate that removing or reducing workplace hazards to a level safe to the affected employee would amount to imposing an “undue hardship” on the employers,[119] or that the compounding factor inheres in the work at issue, as stress is the characteristic of firefighting duties.

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[119] *See* 29 C.F.R. 1630.15(d) (2004).

(5) Specialized Legislation

Since the EEOC's guideline and *Bragdon* do not clearly ensure that presymptomatic genetic conditions are covered by the ADA and that the information about genetic susceptibility to workplace hazards will be used only in employees' favor, calls to enact specialized law prohibiting genetic discrimination in employment are enduring.[120]

Many states now have laws prohibiting employers from taking an individual's genetic status into account in addition to laws prohibiting disability discrimination.[121] The aforementioned executive order signed by former U.S. President Clinton regulating genetic information flows in the context of employment also prohibits federal employers from using genetic information to classify employees in a manner that would deprive them of opportunities or otherwise adversely affect their status.[122] Similarly, the "Genetic Information Nondiscrimination Act of 2003" engrossed by the United State Senate[123] and House Bill 1910 introduced in 2003[124] all sought to provide a much straightforward protection against genetic discrimination in the workplace without wading through the nasty issue of the definition of disability. Both bills explicitly prohibit employment

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[120] *See*, e.g., Rothstein, *supra* note 110, at 331, 351.

[121] *See, e.g.*, N.H. REV. STAT. ANN. § 141-H:3(I)(b) (2003); N.Y. EXEC. § 296(1) (Consol. 2004).

[122] *See* Exec. Order No. 13,145, 3 C.F.R. 235, 236 (2001).

[123] S. 1053, 108th Cong. (2003).

[124] H.R. 1910, 108th Cong. (2003) (Genetic Nondiscrimination in Health Insurance and Employment Act).

practices that fail or refuse to hire or that discharge any employee, or that otherwise discriminate against any employee with respect to the compensation, terms, conditions, or privileges of employment of the employee, because of genetic information regarding that employee.[125]

Moreover, both bills aim to address the issue of genetic susceptibility to environmental factors in workplace. “In order to identify, evaluate, and respond to the effects of or control adverse environmental exposures in the workplace,”[126] both bill authorize employers, with the procedural protection of employees’ written informed consent, to periodically examine employees to evaluate acquired modifications to their genetic material, that may have developed in the course of employment due to exposure to toxic substances in the workplace.[127] Notwithstanding this authorization, the information resulting from the “genetic monitoring” is to be used only in employees’ favor. While individual employees are informed of their individual monitoring results, the results are available to employers only in aggregate terms.[128] The prohibition of using genetic information in making adverse employment decisions still governs the case of genetic monitoring.[129] It is expected that such an asymmetrical regulation of genetic information flow will ensure a win-win situation, in which employers are able to

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[125] *See* S. 1053 tit. II; H.R. 1910 tit. II.

[126] S. 1053 § 201(5); H.R. 1910 § 201(3).

[127] *See* S. 1053 § 202(b)(5); H.R. 1910 § 202(a)(3)(A).

[128] *See* S. 1053 §§ 202(b)(5)(C), 202(b)(5)(E); H.R. 1910 §§ 202(a)(3)(A)(ii), 202(a)(3)(A)(iv).

[129] *See* S. 1053 § 202(c); H.R. 1910 § 202(b).

determine how to improve the condition of the workplace while employees are given autonomy to determine whether to stay in an environment that may pose a threat to their health. Whether such an ideal can be realized, however, remains to be seen since many employees are not in a position that affords them much autonomy to change their jobs. The problem would become pressing if one day we are used to the "self-responsible" idea that an informed employee's continuing stay in a work environment that is potentially detrimental to his health should be deprived of benefits in worker's compensation claims. This problem will expectantly be the lingering focus of continuous debates.

5.3 Combating Prejudice as a Matter of Increasing Rationality

The third strategy of tackling the possible adverse consequences occasioned by the unveiling power of human genomics is to boost the rationality of using genetic information in decisionmaking. One lingering concern about the consequences of human genomics has been focused on the irrationality arising as a result of meager "genetic literacy" in the society about the true meaning of the predictive power of the new science.[130]

The cause of this irrationality is twofold. On the one hand, the complexity of human genomics often confounds the predictive power of the new science. We are often

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[130] One of the aims of the ELSI Program of the HGP is to assure that professionals and the public become more "genetically literate." *See* Muin J. Khoury et al., *Genetics and Public Health: A Framework for the Integration of Human Genetics into Public Health Practice, in* GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY 3, 16 (Muin J. Khoury et al. eds., New York: Oxford Univ. Press, 2000).

faced with a scenario in which no sooner was an association between a disease and the suspect gene reported in the scientific journals than it was refuted by later studies.[131] Telling true science from snake oil becomes imperative. On the other hand, even with consensus within the scientific community, the unveiling power of human genomics might easily, though unwittingly, bring about erroneous public perception of risk as a result of the gap between what is known in the scientific community and what is conveyed or advertised to the public. As discussed earlier, discrimination against carriers of recessive disorders or non-carriers from families with members affected by the disorders occurs purely out of such public irrationality and prejudice. Cases of such a clear scientific boundary between risk and non-risk are after all rare. Most of the time, presymptomatic individuals, depending on the genotype-phenotype correlation of the genetic condition they are affected with, are at various risk of really becoming ill. This characteristic gives rise to another possible scenario of erroneous perception of risk. Some people, although not entirely free from a specific genetic risk, may indeed be at extremely low risk of really becoming ill. Treating them as if they are at high risk certainly is irrational. Guiding the public to engage only in rational and proportional risk assessment based on true science seems to help in combating unfounded prejudice.

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[131] For example, based on a survey conducted by Professor Neil Holtzman in 2000, among 100 most recent papers about bipolar affective disorder, twelve new associations was found or old associations confirmed, while fifteen old associations was refuted. Among 100 most recent papers about schizophrenia, eight new associations was found or old associations confirmed, while nine old associations was refuted. *See* Neil A. Holtzman, *Putting the Search for Genes in Perspective,* 31 INT'L J. HEALTH SERVICES 445, 451 tbl.1 (2001).

5.3.1 Ensuring Accuracy and Precision of Risk Prediction

It is now widely held that a systematic, evidence-based approach to assess the value of genetic testing is necessary in response to the problem of irrational risk assessment.[132] To formulate a model for potential regulatory purpose, the NIH-DOE Task Force on Genetic Testing in 1997 identified three broad criteria for evaluating genetic testing before it can be released for practical uses: Analytic validity, clinical validity, and clinical utility.[133]

"Analytic validity" refers to the capacity of a genetic test to detect the existence of a certain genotype. Ever since the notion of hereditary was understood, people have been interested in discovering the laws of heredity and eager to identify the individuals with those traits. The Mendelian theory provided a means to calculate the probability of having a certain genotype for an individual. Given that Mendelian calculation is based on the population recurrence rate, it yields four possible scenarios, 0%, 25%, 50%, and 100%, providing poor prediction for individuals.[134] There were huge uncertainties of the existence of the genotype. Also, Mendelian calculation is unable to identify

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[132] *See, e.g.*, Benjamin S. Wilfond & Elizabeth J. Thomson, *Models of Public Health Genetic Policy Development*, *in* GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY: USING GENETIC INFORMATION TO IMPROVE HEALTH AND PREVENT DISEASE, *supra* note 130, at 61, 73-79.

[133] TASK FORCE ON GENETIC TESTING, NATIONAL INST. OF HEALTH, PROMOTING SAFE AND EFFECTIVE GENETIC TESTING IN THE UNITED STATES 24-29 (Neil A. Holtzman & Michael S. Watson eds., Baltimore, MD: Johns Hopkins Univ. Press, 1998) [hereinafter TASK FORCE FINAL REPORT].

[134] *See* PETER J. BRIDGE, THE CALCULATION OF GENETIC RISKS: WORKED EXAMPLES IN DNA DIAGNOSIS 1, 2 (2nd ed. 1997).

heterozygotes for recessive disorders. This is probably one of the reasons that old eugenic movements would still fail to achieve the goal of improving the overall quality of the gene pool even without strong public resistance.[135] By contrast, knowledge of human genomics gives hope of greater predictive accuracy. Benefited from the advance in human genomics, new genetic tests are designed to detect either a simple presence or absence of a specific genotype—a 0% or 100% chance.

But even though analytic validity ensures that a genetic test can precisely detect the presence of a specific genotype, it does not automatically amount to affirming the presence of the disease. In the evaluation of "clinical validity," the concepts of penetrance and expressivity are offered to assess the genotype-phenotype correlations. The notion of "penetrance" indicates the proportion of individuals with a specific genotype who will express that corresponding character in the phenotype. Because all human disease is the result of the interactions between genes and the environment broadly defined as everything non-genetic, except in very rare cases, penetrance of genotypes is almost always incomplete.[136] "Expressivity" represents the expression consistency of a genotype. Sometimes, it is difficult to tell between these two notions. For instance, one may have the gene for PKU and on an abnormal enzyme level be clinically normal. Is this a varied expression or lack of penetrance? We need not resolve

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[135] *See* Neil A. Holtzman, *Eugenics and Genetic Testing*, 11 SCI. CONTEXT 397, 398, 402 (1998).

[136] *See* Muin J. Khoury, *Relationship Between Medical Genetics and Public Health: Changing the Paradigm of Disease Prevention and the Definition of a Genetic Disease*, 71 AM. J. MED. GENETICS 289, 290 (1997).

this difficulty here. A simple notion of risk, the risk that an individual with a certain genotype will develop a certain disease over a defined time period,[137] will suffice to encompass both notions of penetrance and expressivity for regulatory purpose.

The clarification of genotype-phenotype correlations helps to differentiate among different degrees of genetic risk. For example, with penetrance ranging from 0.26 to 0.85, depending on the relevant population,[138] BRCA1 and BRCA2 genotypes confer relatively low risk for inherited breast cancer since there is conversely a 15-74% of chance that people with BRCA1 or BRCA2 will not develop breast cancer. Even in patients who have signs or symptoms of breast cancer, genetic testing for BRCA1 and BRCA2 presents only suggestive rather than conclusive evidence of the possible etiology. By contrast, fully penetrant HbSS mutation presents a very high risk for sickle cell anemia. The manifestation of the disease is almost certain when no effective intervention is available to interrupt the pathogenesis of the disease.

From a public health viewpoint, however, a disease-related gene with a high genotype-phenotype correlation does not necessarily render genetic testing for that condition a worthwhile practice. The prevalence of the genotype in the population, the

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[137] This is actually the notion of "absolute risk." *See* Robert W. Jeffery, *Risk Behaviors and Health: Contrasting Individual and Population Perspectives,* AM. PSYCHOLOGIST, Sept. 1989, at 1194.

[138] *See* Jeffery P. Struewing et al., *The Risk of Cancer Associated with Specific Mutations of BRCA1 and BRCA2 among Ashkenazi Jews*, 336 NEW ENG. J. MED. 1401 (1997); *Prevalence and Penetrance of BRCA1 and BRCA2 Mutations in a Population-Based Series of Breast Cancer Cases*, 83 BRIT. J. CANCER 1301 (2000); D. Ford et al., *Genetic Heterogeneity and Penetrance Analysis of the BRCA1 and BRCA2 Genes in Breast Cancer Families*, 62 AM. J. HUM. GENETICS 676 (1998).

background risk of acquiring the disease in the population (absolute risk of disease), and the increased risk of having the disease conferred by that disease-related gene (relative risk of disease) all affect the probability that a person with a positive test result will manifest the disease.[139] On the other hand, the proportion of cases of a common disease that can be attributed to the disease-related gene also affects the probability that the disease will not develop in person with a negative test result. When the proportion attributable to the disease-related gene is small, it means that some factors other than the gene can have a substantial role in the development of the disease. As a result, people would gain little assurance that a negative test result means that they will remain free of becoming ill.[140] By making out only tests with high predictive value, the criteria of "clinical validity" helps to ensure that only people with real genetic risk will be screened out.

Whereas "clinical validity" and "analytic validity" together determine the accuracy of a genetic test, the third criterion, "clinical utility"—the third evaluating criterion—refers to whether information from the test can be put to beneficial use to improve an individual's health in a clinical context. It is believed that the danger of discrimination is most substantial when the unveiling power of human genomics is not accompanied with

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[139] *See, e.g.,* Alan E. Guttmacher & Francis S. Collins, *Genomic Medicine—A Primer*, 347 NEW ENG. J. MED. 1512, 1518 (2002). *Cf.* Mary E. Northridge, *Annotation: Public Health Methods—Attributable Risk as a Link Between Causality and Public Health Action*, 85 Am. J. Pub. Health 1201-4 (1995).

[140] *See* Neil A. Holtzman, *Will Genetic Revolutionize Medicine?*, 343 NEW ENG. J. MED 141, 142 (2000).

effective treatment to save people genetically at risk from that social risk.

The Secretary's Advisory Committee on Genetic Testing (SACGT) adopted the criteria developed by the Task Force and recommended to devise an oversight mechanism that incorporates the three criteria in assessing the benefits and risks of genetic tests and accordingly categorizing different tests for oversight purposes.[141] Although no simple, linear review template was in the end developed by the SACGT,[142] and both the FDA and Clinical Laboratory Improvement Amendment of 1988 (CLIA)[143]—the current regulatory frameworks for genetic tests—are thought not even suitable for the review of "clinical utility,"[144] at least the criteria of "analytic validity" and "clinical validity" are widely accepted in principle to be the appropriate regulatory

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[141] SECRETARY'S ADVISORY COMM. ON GENETIC TESTING, ENHANCING THE OVERSIGHT OF GENETIC TESTS: RECOMMENDATIONS OF THE SACGT 15-19, 20-22, 22 fig.1 (Bethesda, MD: National Institutes of Health, 2000), *available at* http://www4.od.nih.gov/oba/sacgt/reports/oversight_report.pdf.

[142] *See* SECRETARY'S ADVISORY COMM. ON GENETIC TESTING, DEVELOPMENT OF A CLASSIFICATION METHODOLOGY FOR GENETIC TESTS: CONCLUSIONS AND RECOMMENDATIONS 7 (Bethesda, MD: National Institutes of Health, 2001), *available at* http://www4.od.nih.gov/oba/sacgt/reports/Addendum_final.pdf.

[143] Clinical Laboratory Improvement Amendment of 1988, Pub. L. 100-578, 102 Stat. 2903 (1988) (codified as amended at 42 U.S.C.A. §§ 201, 263(a) (2004)). *See also* 42 C.F.R. pt. 493 (2003).

[144] The alleged rationale is a long embraced position that FDA is not empowered to regulate medical practice. If the safety and effectiveness of a medical device has been established and confirmed by FDA, it is a doctor's prerogative to assess and communicate with the patient about the utility of the medical device within the settings of doctor-patient relationship. *See* Food and Drug Administration Modernization Act of 1997 § 214, 21 U.S.C. 396 (1997) ("Nothing in this chapter shall be construed to limit or interfere with the authority of a health care practitioner to prescribe or administer any legally marketed device to a patient for any condition or disease within a legitimate health care practitioner-patient relationship.").

standard.[145]

5.3.2 A Hidden Tension

A regulatory scheme that ensures the accuracy and precision of risk prediction surely reduces the danger of irrational discrimination against people who are indeed not at risk. If served as a strategy in addition to a ban on the use of genetic information against people genetically at risk, it compliments the comprehensive protection against genetic discrimination.

However, separating out those who are indeed not at risk and claiming that they should not be subject to irrational discrimination seems at the same time to give the implication that treating those who are still identified as at risk is not irrational since they now, unlike those who has been separated out, are at very real risk. Similarly, sorting people by their different degrees of risk tempts us to think that treating them accordingly is justifiable. Such implication and temptation threatens to thwart the “gene-blind” framework of the original antidiscrimination approach asserting that, as long as one remains asymptomatic, one’s genetic risk, be it high or low, should not be used against them. Some advocates for the antidiscrimination approach are now inclined to accept that indiscriminate protection of all people genetically at risk against discrimination without

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[145] The only issue left to be addressed is how to fill the gap between different regulatory frameworks applied to genetic tests marketed as kits and those marketed as service offered in a laboratory. *See, e.g.*, Neil A. Holtzman, *FDA and the Regulation of Genetic Tests*, 41 JURIMETRICS J. 53 (2000). *But see* Richard A. Merrill, *Genetic Testing: A Role for FDA?*, 41 JURIMETRICS J. 63 (2000) (questioning the FDA jurisdiction over regulating genetic tests marketed as service).

differentiating the severity of their risk is unwarranted.[146]

The tension between the two possible applications of increased rationality in risk prediction leads us to the debate over whether and why treating people based on their individualized genetic risk is indeed a bad thing. I shall discuss this issue in the next chapter.

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[146] *See, e.g.*, Silvers & Stein, *supra* note 26, at 1392-93.

6/ FAILED ATTEMPTS TO TACKLE THE REAL EVIL

In the previous chapter, I investigated how mainstream approaches attempt to counter the potential menace of human genomics by shoring up a “veil of ignorance” against the use of genetic criteria for distinguishing among people presumably on an antidiscrimination-equality rationale. But is the “veil of ignorance” in employment and health insurance actually justifiable on the equality ground? Or is it even justifiable at all? The answers to these questions indeed hinge upon what kind of inequality we think human genomics might bring forth and what is bad about human genomics more generally.

Equality is an elusive concept. It contains two separate but interrelated lines of thinking: one bears upon the unjust distribution of goods and services; the other reflects a broader concern of exclusionary politics. The debate over genetic antidiscrimination law in employment and health insurance has commonly been suggested to implicate the first line of the concept of equality. Such an approach relies on an analysis of what counts as a just distribution of goods and services presumed in current equal protection jurisprudence and positive antidiscrimination law. The legal criteria of just distribution then serve as a touchstone for determining the existence of the unjust distribution of goods and services in the genetic context. The outcome of such an investigation is either that the “veil of ignorance” in employment and health insurance is necessary to eliminate the remaining evil of human genomics while the danger of involuntary eugenics is adequately bridled by the rhetoric of choice, or that, because distributive justice is not breached, no inequality exists at all. Once the concern of the unjust distribution of goods and services is either tamed or disenchanted, it is believed that making the power of human genomics available for voluntary individual choices should no longer raise great moral concerns. But if human genomics indeed implicates the concern of inequality as exclusionary politics, the concept of distributive justice may not be able to account for the real culprit. To combat this real evil may require us not only to unfurl a more comprehensive “veil of ignorance” beyond the domain of distributing goods and services but also to examine more critically the (unveiling, predictive, classifying) power of human genomics that incessantly, though perhaps unwittingly, fosters moral exclusion by producing an endless list of human classifications.

In what follows, I will first demonstrate that unveiling genetic endowments and classifying people based on their genetic risk in distributing goods and services do not seem to meet the conditions that are needed to trigger the concern of justice as equal opportunity recognized and embodied in current equal protection jurisprudence—irrationality defying logic of established institutions and bad intent in existing subordination. The fear that making the power of human genomics widely available without at the same time constructing a “veil of ignorance” would lead to an unjust distribution of goods and services seems at best uncorroborated under the analysis of distributive justice. But, as I will subsequently demonstrate, focusing on how the power of human genomics could harm or conversely contribute to distributive justice has connived at the real evil of human genomics. The real culprit subsists at the juncture when instrumental rationality is unable to account for the *externality cost* of summoning the power of human genomics to satisfy the demand for classifying people in the labor market, and the private insurance industry, when what the classifying power of human genomics advances is not message *denigrating others* but identity *ossifying selfhood*. All of these do not result from *existing* subordination but foster *emerging* exclusionary politics. Such an understanding calls for an alternative paradigm to combat the evil accompanying the emerging nature of exclusionary politics of human genomics.

6.1 Inequality as the Unjust Distribution of Goods and Services

6.1.1 The Case Against Antidiscrimination Law—Allocative Efficiency

The debate over the impact of human genomics on equality has commonly been suggested to implicate the issue of distributive justice. The pursuit of equality in this sense often intersects with the idea of efficiency.

In an ideal market of perfectly competitive equilibrium, where rational behavior is presumed as the norm and competition is thought to be the most effective corrective for unthinking prejudice, state intervention in the name of pursuing equality seems to only introduce both inefficiency and inefficacy. Except in the cases of "market failure," state intervention is at fault for diminishing allocative efficiency and causing welfare losses. Along this line of argument, it is charged that laws prohibiting genetic discrimination in employment and health insurance, although extolled with public support and academic acclamation, introduce unjustified and unwarranted inefficiency.[1]

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[1] *See, e.g.*, Richard A. Epstein, *The Legal Regulation of Genetic Discrimination: Old Responses to New* Technology, 74 B.U. L. REV 1 (1994); Colin S. Diver & Jane Maslow Cohen, *Genophobia: What is Wrong with Genetic Discrimination?*, 149 U. PA. L. REV. 1439, 1475-75 (2001).

In labor markets, such inefficiency is said to occur in two circumstances. First, state intervention prevents employers from selecting the most productive employees in the market. In an ideally competitive market, rational employers are expected to hire workers with the greatest net productivity regardless of their other personal characteristics unrelated to productivity.[2] The implication of this presumption is twofold. On the one hand, forgoing otherwise productive workers because of unrelated characteristics would be punished by other firms acquiring equally productive workforce at the lower price. Supposedly, no productive worker would be discriminated against. On the other hand, those who are left out are most likely undeserving workers because choosing under-qualified or under-performing workers over productive workers is an equally inefficient practice from the viewpoint of employers. Distinguishing productive workers from unproductive ones becomes imperative to successful business.

Given the replacement costs, which sometimes may be intimidating, hiring decisions very often rely on *ex ante* review of information about the potential productivity of the prospective employees. *Ex ante* determinations of productivity are predictive in nature; all information used in making such determinations—for example, past job performance and personality—is invariably probabilistic with varying degrees of confidence.[3] In this sense, genetic information about a potential employee is no different

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[2] Kenneth J. Arrow, *The Theory of Discrimination, in* DISCRIMINATION IN LABOR MARKETS 3, 3 (Orley Ashenfelter & Albert Rees eds., Princeton, NJ: Princeton Univ. Press, 1973).

[3] *See* Diver & Cohen, *supra* note 1, at 1461-62.

from other information that employers use to predict productivity. They are all "facts about the ability of a person." In this light, preventing an employer from *knowing* the full aspects of an potential employee, although some people may praise it as protecting privacy, amounts to giving the employee a "right to misrepresent [him]self to the rest of the world."[4] Restraining an employer from *using* genetic information about a potential employee in making employment decisions is tantamount to compelling private employers to bear the costs of an inefficient social policy.[5]

Second, a law prohibiting access to or use of information about an employee's susceptibility to workplace hazards in investigating workers compensation claims and, at the same time, requiring that that information be used only in the employee's favor or only at his/her discretion[6] considerably curtails employers' options of choosing the most cost-effective measure to ensure worker safety. When the defense of "undue hardship" is unavailable,[7] such a law compels employers to incur the expense of changing a production process or work environment even though there might be more cost-effective

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[4] Richard A. Epstein, *Privacy, Property Rights, and Misrepresentations*, 12 GA. L. REV. 455 (1978); Richard A. Posner, *The Right of Privacy*, 12 GA. L. REV. 393, 393-554 (1978).

[5] *See* RICHARD A. EPSTEIN, FORBIDDEN GROUNDS: THE CASE AGAINST EMPLOYMENT DISCRIMINATION LAWS 76-77 (Cambridge, MA: Harvard Univ. Press, 1992).

[6] *See supra* section 5.1.2 of Chapter 5.

[7] *See* 29 C.F.R. § 1630.15(d) (2003) ("It may be a defense to a charge of discrimination…that a requested or necessary accommodation would impose an undue hardship on the operation of the covered entity's business.").

measures to ensure worker safety, such as personnel reassignments.[8]

Likewise, in the context of private health insurance, state intervention also produces inefficiency and unfairness. It is the backbone principle of private insurance to pool together people with similar risk for risk sharing. To maintain this basic functioning requires symmetry in information about risk between insurers and insureds. Laws prohibiting insurers' access to genetic information annihilate the symmetry in information, increase the dangers from strategic behaviors of the insureds, and may eventually bring about the age-old problem of adverse selection. When genetic information is asymmetrically available only to insureds, they are in a better position to assess their own insurance risk than insurers. People who know they are at higher genetic risk are inclined to increase coverage to cover their expected high expenses, whereas those who know they are at lower genetic risk would choose to opt out when their expected expenses are lower than the premium.[9] The inefficient dynamics will eventually lead to the breakdown of the entire insurance market. Moreover, when undertaking of genetic testing is not universal, asymmetry in strategic behaviors occurs even among insureds. As a result, those who do not know that they are actually at lower risks are, indeed, unfairly compelled to subsidize those at higher risks.[10]

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[8] *See* Diver & Cohen, *supra* note 1, at 1463.

[9] *See id.* at 1466; Robert J. Pokorski, *Use of Genetic Information by Private Insurers, in* JUSTICE AND THE HUMAN GENOME PROJECT 91, 91 (Thomas F. Murphy & Marc A. Lappé eds., Berkeley: Univ. of California Press, 1994).

[10] *See, e.g.*, Pokorski, *supra* note 9, at 97.

Viewed from the above light, genetic information in both employment and insurance is stripped of its moral sacredness and treated instrumentally as a commodity with the calculable demand and the supply. Each party to the transaction wants to make use of it to increase his stake of the deal. The question of "who owns the secret" becomes a matter of how to efficiently allocate property rights among relevant parties.[11] When conferring property rights to the individual amounts to benefiting the dishonest at the expense of the honest,[12] what is required is not genetic privacy but "genetic transparency."[13] When enlisting people with "good genes" to support people with "bad genes" is no different from "coerced altruism," what is justifiable is not genetic antidiscrimination but different treatment based on genetic quality.

6.1.2 Factors that Lead to the Unjust Distribution of Goods and Services

The neoclassical economic argument for allocative efficiency leads to a rather conservative concept of justice as equal opportunity that chooses "desert" or "contribution" over "equality" as its governing principle of distribution. Unless there are legal or certain extra-legal barriers of discrimination for persons of similar natural assets,[14] the room for state intervention in the name of justice is generally limited under

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[11] *See* Richard A. Posner, *An Economic Theory of Privacy*, REGULATION, May/June 1978, at 19, 20-23.

[12] *See* Epstein, *supra* note 1, at 8-13.

[13] *See* Diver & Cohen, *supra* note 1, at 1482.

[14] For example, it is generally held that equal protection in employment rests on a particular concept of equal opportunity as "careers open to talents." This conception of equality as merit only assures

this view. This view may seem extremely unpalatable to many advocates of genetic antidiscrimination law who prefer an egalitarian or a need-based principle of distributive justice and who believe that people's life prospect and opportunity should not be adversely affected because of factors over which they have no control.

I do not here wish to engage in a theoretical debate over the appropriate value that should govern the distribution of goods and services in the genetic context. I will instead investigate the grounds that are generally considered to trigger the concern of distributive justice in current equal protection jurisprudence and positive antidiscrimination laws. Those grounds serve as a touchstone for determining the existence of the unjust distribution in the genetic context. At the risk of oversimplification, those grounds can be categorized along two main lines: instrumental irrationality defying the logic of established institutions and bad intent in existing subordination.

(1) Instrumental Irrationality and Genetic Determinism

One familiar argument in equal protection cases is that the merit of the individual should be evaluated on just his/her own real characteristics and not be tainted with misconceptions or inferred from the perception about the characteristics of the group to which the individual belongs. Thus, cases involving gender discrimination now proceed

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individuals the "right to compete based on their existing abilities as determined by their natural endowments as augmented by education and experience." *See* GEORGE RUTHERGLEN, EMPLOYMENT DISCRIMINATION LAW: VISIONS OF EQUALITY IN THEORY AND DOCTRINE 19 (New York: Foundation Press, 2001).

under the presumption that women as a class are as competent as men, notwithstanding that there might be subcategory of women who indeed is not competent to perform some of the tasks that most men can do.[15] Individual woman is to be gauged only on her real competency. The premise behind this argument is that discrimination based on erroneous judgment of facts is instrumentally irrational, or "means-end irrational" as Professor Owen Fiss would call it, because it is inherently impossible that the erroneous judgment could serve the stated objective.[16]

Along the same line, a plausible ground for denouncing the use of genetic criteria for distinguishing among people is that it generates misconceptions about the individuals and therefore is instrumentally irrational. There are stereotypic beliefs about people genetically at risk. Perhaps owing to the mistaken impression that takes the cases of fully penetrant single-gene disorders such as Huntington's disease as typical to all disease-related genes,[17] the blunder of *genetic determinism* has long bewildered the mind of the public. Viewing genes as having decisive causal potency regardless, perceptions caused by genetic determinism often do not represent accurately the real genotype-phenotype correlations. People with low penetrant disease-related genes may be wrongly judged as being doomed to develop the disease.

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[15] *See* Anita Silvers & Michael Ashley Stein, *The Americans with Disabilities Act: Disability, Equal Protection, and the Supreme Court: Standing at the Crossroads of Progressive and Retrogressive Logic in Constitutional Classification*, 35 U. MICH. L.J. REFORM 81, 82-83 (2002).

[16] *See* Owen M. Fiss, *Groups and the Equal Protection Clause*, 5 PHIL. & PUB. AFF. 107, 111 (1976).

[17] *See* Eric T. Juengst, *The Ethics of Prediction: Genetic Risk and the Physician-Patient Relationship*, 1 GENOME SCI. & TECH. 21, 30 (1995).

To the extent that such empirically unjustified generalization leads to erroneous perceptions of reality, instrumental irrationality is a genuine concern, and, as discussed in Chapter 5, it has motivated the regulatory scheme that aims to increase rationality in using genetic information.[18] And, as Professors Anita Silvers and Michael Stein argued, the principle that people with genetic risk as a class should not be treated with less favorable presumption surely would also be the cure to instrumental irrationality. Cases involving genetic anomalies, like cases involving gender discrimination, should now proceed from the presumption that people with genetic risk as a class remain as viable, healthy and productive as normal people and that those who discriminate bear the burden to produce empirical evidence to prove otherwise.[19]

But how about decisions based on empirically accurate understanding of genotype-phenotype correlations? It is practically possible that, even without complete knowledge of the underlying pathogenesis of genetic conditions, the information about the risk of each and every genetic condition be made available to the public in a legible table. The table of this kind may contain information of not only the penetrance of a genetic condition in the general population but also the penetrance of the genetic condition in several different subpopulations. The assessment of risk of a certain genetic condition can infinitely be carried out until countless classifications—for example, gender, race, ethnic

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[18] *See supra* section 5.3 of Chapter 5.

[19] *See* Anita Silvers & Michael Ashley Stein, *An Equality Paradigm for Preventing Genetic Discrimination*, 55 VAND. L. REV. 1341, 1392-93 (2002).

group, residence, diet, frequency of exercise, smoking or not, length of exposure to sun, and etc.—come together to make the assessment finally "individualized."[20] People genetically at risk therefore are indeed not treated as a homogeneous class. Their risk is individually gauged. Do distributive decisions based on such a table still commit the fault of instrumental irrationality that justifies the invocation of antidiscrimination laws to rectify erroneous judgment of reality?

Standard economic accounts of discrimination use the concept of statistical discrimination to explain the discriminatory practices resulting from a statistically valid generalization about people.[21] Considering that the cost of undertaking a more individualized investigation to determine the true characteristic of the commodity in a transaction is usually far greater than the use of some surrogate predictor, imperfect information is almost always the norm in the market.[22] Sometimes the surrogate predictor is some information about the *group* to which the individual belongs on the ground that an individual member of the group may statistically share a relevant average characteristic of that group. For example, an employer may use the information of

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[20] *See supra* section 4.2.2 of Chapter 4.

[21] *See* Arrow, *supra* note 2, at 23-25; Stewart Schwab, *Is Statistical Discrimination Efficient?*, 76 AM. ECON. REV. 228, 228 (1986).

[22] The famous "lemon theory" of George Akerlof, who won the 2001 Nobel prize for economics, is to explain how a market, say, the market for used cars as in Akerlof's example, will behave when a disparity in knowledge between buyers and sellers prevents buyers from differentiating superior from average products. *See, e.g.*, J. Barkley Rosser, Jr., *A Nobel Prize for Asymmetric Information: The Economic Contributions of George Akerlof, Michael Spence and Joseph Stiglitz*, 15 REV. POL. ECON. 3 (2003).

whether the prospective employees regularly attend church to generalize about employees with good mental health.[23] Sometimes information about some *individual-based* characteristic other than the relevant characteristic itself is used as the surrogate predictor on the ground that the surrogate characteristic is statistically correlated with the true characteristic and the administrative cost is much lower. For example, although writing samples may provide a more accurate measure, grades are commonly used in law firms to pick out promising lawyers because good grades are statistically associated with good legal ability.[24]

Whether statistical discrimination is instrumentally rational, to a large extent, turns on the operational logic of the institution that makes use of the generalized information. If the logic of the private health insurance industry is that people with good health do not have the obligation to share the burdens of those who are at higher risk, using a statistically valid generalization about a certain genetic condition to make risk predictions and to classify accordingly each individual's future medical expenses seems to be a practice that cannot be more rational. If the logic of the labor market is to employ the most cost-effective measure to project the net present value of the productivity a prospective employee can contribute within the period of predicted job tenure, drawing

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[23] *See* John Maltby, *Personality Dimensions of Religious Orientation*, 133 J. PSYCHOLOGY 631 (1999) (finding that psychosis shared a significant negative association with the frequency of church attendance); Christopher Alan Lewis, *Cultural Stereotype of the Effects of Religion on Mental Health*, 74 BRIT. J. MED. PSYCHOLOGY 359 (2001) (same).

[24] *See* Deborah Hellman, *What Makes Genetic Discrimination Exceptional?*, 29 AM. J.L. & MED. 77, 84 (2003).

on the individualized assessment of genetic risk to determine the future job performance is no less rational than using a writing sample as a measure to identify promising lawyers. But if this is the case, instrumental irrationality would prove to be an inappropriate ground for the charge of the unjust distribution of goods and services in genetic context.

(2) Bad Intent and Aversion

Another persistent reason for invoking an equal protection claim is to condemn the actor's bad intent embedded in the discriminatory practice. The invidious discrimination or so-called animus-based discrimination arises when a discriminatory practice originates from a mental state that is disapproved by the society. For instance, racial and gender discrimination are denounced when the aversion to a certain race or sex is the reason behind disparate treatments.

From the law and economics perspective, so long as the aversion or distaste remains widespread, discrimination persists even in a competitive market.[25] The general corrective effect of the market competition fails to rectify the pervasive biased preference, and the pursuit of efficiency, at best, gives rise to a "separate but equal" equilibrium.[26] The "market failure," not in the sense that the market is necessarily inefficient but in the

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[25] *See* GARY BECKER, THE ECONOMICS OF DISCRIMINATION 14-15, 39-54 (Chicago: Univ. of Chicago Press, 2nd. ed. 1971).

[26] *See* Arrow, *supra* note 2, at 6-20 (proving with neoclassical economic analysis that "the long-run equilibrium [of discriminatory tastes towards a certain race in a competitive labor market] is one of perfect segregation and equal wages").

sense that the widespread distaste cannot be weeded out, justifies state intervention in the name of creating an equal society.

Bad intent clearly affects the distribution of goods and services. However, the standard of bad intent is not self-implementing. People do not have a general legal obligation to like each other. Having a distaste of people who drive red cars can be a product of a bias or prejudice. It does not, absent more, violate the legal mandate of equality. One needs to rely on something other than the descriptive state of mind to determine its normative badness. Without articulating the underlying normative value, focusing on a particular descriptive dimension of mental state—aversion—provides no special clue for the judgment of the morality of disparate treatments based on one's genetic risk.

One commonly-sought approach that is claimed to dodge the hurdle of an extra normative question is to take the wrongness of racial and gender discrimination as given and to find the analogy strong enough between genetic and racial/gender discrimination to support the appropriation of the normative basis of the latter. Two such analogies are offered frequently.

First, one could argue that, since racial and gender discrimination are, after all, based on genetic differences, genetic discrimination should be condemned at least to the same extent as racial and gender discrimination for whatever normative reason that condemns the latter.[27] The problem with this argument is that, while genetic differences are necessarily involved in racial and gender discrimination, they do not automatically become the sufficient condition of condemnable discrimination. It is true that certain genetic conditions may especially affect identifiable racial or ethnic groups. For example, the prevalence of the HbSS (homozygous) mutation that causes sickled shape hemoglobin is much higher among African Americans (1 in 346) than in other ethnic groups (1 in 58,140 in White, and 1 in 13,141 in Asian) in the United States.[28] In these cases, it may be difficult to tell the aversion to the especially affected racial group from the aversion to the genetic condition. But most of the time, the distribution of the genetic conditions does not show clear disparity among different racial or ethnic groups, and the association between race and genetic differences is tenuous or at best contingent.

Second, it could also be argued that the factor of *immutability* forms the common basis for prohibiting discrimination based on race, gender, and genetic condition. The aversion to a certain genetic condition picks on an immutable characteristic as much as the aversion to a certain race or sex does. The problem with this seemingly intuitive argument is that immutability has never been the criterion for determining the immorality

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[27] *See, e.g.*, Lawrence O. Gostin, *Genetic Discrimination: The Use of Genetically Based Diagnostic and Prognostic Tests by Employers and Insurers*, 17 AM. J.L. & MED. 109, 111 (1991); Janet L. Dolgin, *Personhood, Discrimination and the New Genetics*, 66 BROOK. L. REV. 755, 786-87 (2000-2001).

[28] *See* Richard S. Olney, *Newborn Screening for Sickle Cell Disease: Public Health Impact and Evaluation, in* GENETICS AND PUBLIC HEALTH IN THE 21ST CENTURY 431, 442 tbl.2 (Muin J. Khoury et al. eds., New York: Oxford Univ. Press, 2000). *See also* Allison Ashley-Koch1 et al, *Sickle Hemoglobin (Hb S) Allele and Sickle Cell Disease*, 151 AM. J. EPIDEMIOLOGY 839, 840 (2000).

of disparate treatments. To the contrary, people often accept social norms that assign certain goods according to one's immutable characteristic. For example, the use of intelligence measures in education and the use of height and natural talent in basketball have long been regarded as acceptable practices.

If the analogous approach is unpromising, the moral basis for condemnation of the aversion based on race and gender must further be articulated. One plausible answer is the existence of long-standing subordination and oppression of blacks and women in the American society. Similarly, the prohibition of discriminatory aversion to disability is based on a Congressional finding that "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination ... continue to be a serious and pervasive social problem."[29] Overall, it is the fact of long-standing subordination and its lingering effect that make the aversion morally troublesome.[30]

Does subordination or oppression of people genetically at risk presently exists in the society? For some, the too recent lessons of history of eugenics attest to a positive answer.[31] For others, there is no systematic evidence showing that people have a

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[29] 42 U. S. C. §12101(a)(2).

[30] *See, e.g.,* Diver & Cohen, *supra* note 1, at 1476.

[31] *See, e.g.,* Susan M. Wolf, *Beyond "Genetic Discrimination": Toward the Broader Harm of Geneticism,* 23 J.L. MED. & ETHICS 345, 349 (1995).

widespread aversion to most genetic disease or other conditions.[32] Only anecdotal reports are available to estimate the existence of subordination of people genetically at risk. Two legal scholars recently found that there are almost no well-documented cases of health insurers asking for or using presymptomatic genetic test results to make underwriting decisions, either before or after the passage of the state laws. They concluded that the laws address a problem that does not exist and offer protection that is probably not needed.[33] Without the existing subordination and oppression that distorts the function of markets, the mere aversion would not be a basis for questioning the justice of distribution of goods and services.

6.1.3 Distributive Justice and Unaccounted-For External Effects

Despite the worry about the impact that the power of human genomics would have on distributive justice, the preliminary scan of the issue seems to suggest that the fear is at best uncorroborated. Under the current legal paradigm, unveiling genetic endowments and classifying people based on their genetic risk in employment and health insurance would not be considered to meet the conditions that are needed to trigger the concern of justice as equal opportunity: They do not rest on apparent instrumental irrationality that defies the logic of established institutions; nor can they be claimed to be the product of bad intent in existing subordination.

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[32] *See* Diver and Cohen, *supra* note 1, at 1465.

[33] *See* Mark A. Hall & Stephen S. Rich, *The Impact of Genetic Discrimination on Law Restricting Health Insurer's Use of Genetic Information*, 66 AM. J. HUM. GENETICS 293-307 (2000).

Arguably, in default of any substantive theory about value, the analysis that stakes the normative judgment of distributive justice on the agreement between a specific distribution practice and the logic of the established institutions very often privileges the norms of market economy since it uncritically takes as given the legitimacy of the logic of the established institutions and therefore the value such institutions endorse.[34] In societies where the primary or default distributive system is most often based on voluntary markets, such as the labor market,[35] the distribution is usually perceived as just under the analysis of means-end nexus so long as the distribution outcome achieved in the market is well-suited for the goal of maximizing utility or productivity[36] or distribution follows acquisitions or exchanges rules deemed just in the market.[37] This descriptive fact has led many to attach a presumed normative legitimacy to the voluntary markets as the only prototype of a just cooperative relation in the society.

But the analysis of means-end nexus may yield alternative results when distribution occurs in different institutions with different cooperative relations. To counteract the overgrowth of economic values into all social life, theorists of distributive justice have

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[34] *See, e.g.*, Michael Ashley Stein, *Labor Markets, Rationality, and Workers with Disabilities*, 21 BERKELEY J. EMP. & LAB. L. 314, 314 (2000) (examining generally the flaws of the neoclassical economic assumptions of the labor market).

[35] *See* DEBORAH A. STONE, THE DISABLED STATE 15-17 (Philadelphia: Temple Univ. Press, 1984).

[36] The "desert-based principle"—a principle posits that outcomes, or distributions, should be proportional to inputs, or contributions.

[37] This is the libertarian principles. *See, e.g.*, ROBERT NOZICK, ANARCHY, STATE AND UTOPIA 150-53 (Oxford: Blackwell, 1974).

come up with an alternative approach to determine contextually the allocation rules for different cooperative systems based on their distinct interaction goals or patterned modes of social relations. Three such goals or patterned relations are most commonly identified: economic productivity, the fostering or maintenance of enjoyable social relations, and the fostering of personal development and personal welfare.[38] Thus, whereas the desert-based principle may rein in the economic domain because it is most suitable for the purpose of increasing productivity or profits, the egalitarian principle or a need-based principle may be more appropriate in other cooperative relations. It is presumably under such a contextualized concept of justice that classifying people based on their genetic risk seems most defensible in economic cooperative systems, including both employment and private health insurance, whereas it could still be argued that genetic criteria be prohibited in other cooperative relations where need or equality should be the governing value.

However, the real problem of staking the evil of inequality that human genomics might cause on the analysis of distributive justice, which investigates merely the agreement between a specific distribution practice and the interaction goals of the cooperative system, is not that the norms of market economy might unwittingly dominate the outcome of the analysis. The real problem with such an analysis is that it proves to be unsuitable for the task of grasping, to use the terminology of economics, the externality

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[38] *See* MORTON DEUTSCH, DISTRIBUTIVE JUSTICE: A SOCIAL-PSYCHOLOGICAL PERSPECTIVE 38 (New Haven: Yale Univ. Press, 1985).

costs an otherwise rational practice might impose on the society.[39]

When scholarly wisdom now has it that the underlying cause of potential genetic discrimination in health insurance can largely be attributed to the logic of competitive risk-rating inhering in the profit-seeking private insurance,[40] to the ears of those who oppose the egalitarian or need-based principle in the economic domain the finding seems only to suggest that, *unless* we are to relinquish entirely the institution of private health insurance and replace it with state-funded universal coverage for all so that we do not need to rely so much on the premise of classifying people based on their individual risk, the cooperative system of private health insurance should not be coerced to practice altruism or to fulfill the responsibility that the society as a whole or other cooperative

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[39] For instance, to say that statistical discrimination is rational does not really answer the question of whether using a particular kind of statistically valid generalization to serve the operational logic of an institution is morally problematic or not. *See* David A. Strauss, *"Groups Rights" and the Problem of Statistical Discrimination*, ISSUES IN LEGAL SCHOLARSHIP, Symposium, *The Origins and Fate of Antisubordination Theory*, Article 17, at 2-4 (2003), *at* http://www.bepress.com/ils/iss2/art17 (inaugurated Aug. 2002). It could well be that the rational use of a statistically valid generalization infringes some value that people hold dear. *See, e.g.*, Los Angeles Dep't of Water & Power v. Manhart, 435 U.S. 702 (1978) (invalidating a city pension plan that required, on the basis of actuarial justification that women live longer than men, female employees to contribute more than male employees each month). *See also id.* at 708 ("Even a true generalization about the class is an insufficient reason for disqualifying an individual to whom the generalization does not apply.").

[40] *See* Paul A. Lombardo, *Genetic Confidentiality: What's the Big Secret?*, 3 U. CHI. L. SCH. ROUNDTABLE 589, 613 (1996). *See also* Henry T. Greely, *Health Insurance, Employment Discrimination, and the Genetics Revolution*, *in* THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT 264, 278-80 (Daniel J. Kevles & Leroy Hood eds., Cambridge, MA: Harvard Univ. Press, 1992).

systems must assume.[41] And to the extent that we are to keep the institution of private health insurance, whether or not a cooperative system providing universal access to healthcare is also in place, classifying people based on their genetic risks in private health insurance is not by itself impeachable.

The public debate of health policy over "who should get care and at what cost"[42] surely is imminently necessary in the face of the current health crisis with 43.3 million Americans uninsured. But the debate over whether the supply of the classifying power of human genomics dovetails nicely (rationally) with the demand of a specific cooperative relation and therefore its allocation rules do not really confront the question of what is bad about the otherwise rational means. Without capturing the evil first, the prospect is indeed grim that even the health policy debate—a political quagmire always entangled with the question of "Why should *I* bear the burden of assuming the risk of *others*?"—can escape the temptation of locating the source of problems on certain individuals when human genomics conveniently provides the classifying categories for us to differentiate between "people like us" and "those who swamp us." The supply of the classifying power alone is capable of creating new demand of moral exclusion.

The use of human genomics deemed most compatible with the allocation rules in one cooperative relation may actually have adverse external effects on other cooperative systems. The potential external effects have eluded the normative analysis of distributive

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[41] *See, e.g.*, Diver & Cohen, *supra* note 1, at 1473-75.

[42] Lombardo, *supra* note 40, at 612.

justice, although they may greatly influence how allocation rules are empirically determined in real life. Scholars from the discipline of social psychology have pointed out that the perceived relationship between the people involved is a more critical element in the actual choice of allocation rules than the interaction goal or the patterned mode of social relations.[43] People usually are more willing to apply generous standards of morality, justice, and fairness to "ingroup" members than to "outgroup" members.[44] Allocation rules chosen by participants of a cooperative system who consider each other as competing *others* may be less lenient than rules chosen by participants who consider each other as members of a solidaritic community or as one of the *we*.[45]

Admittedly, such empirical findings of different subjective responses to distributive allocations report only a descriptive *is*, or at best a descriptive *ought*, with regard to the issue of distributive justice.[46] But to the extent that the power of human genomics,

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[43] *See* MORTON DEUTSCH, *Interdependence and Psychological Orientation*, *in* DEUTSCH, *supra* note 38, at 74, 85-86, 87-88, 90 (arguing that the extent of different social relations between participants to the interaction influences choice of distribution rule); Gerold Mikula et al., *What People Regard as Unjust: Types and Structures of Everyday Experiences of Injustice*, 20 EUR. J. SOC. PSYCHOL. 133, 143-45 (1990) (suggesting that relationship type matters more than interaction goal); Edith Barrett-Howard & Tom R. Tyler, *Procedural Justice as a Criterion in Allocation Decisions*, 50 J. PERSONALITY AND SOC. PSYCHOL. 296, 300 (1986) (finding that the interrelationship of the participants influences the definition and importance of fair procedures and that the importance of distributive and procedural justice are positively related).

[44] *See* Susan Opotow, *Moral Exclusion and Injustice: An Introduction*, 46 J. SOC. ISSUE 1, 3-6 (1990).

[45] *See* DEUTSCH, *supra* note 38, at 37.

[46] *See* DAVID MILLER, PRINCIPLES OF SOCIAL JUSTICE 42-60 (Cambridge, MA: Harvard Univ. Press, 1999) (exploring the relationship between descriptive accounts of people's beliefs about fairness and entitlement and normative theories of justice).

whether it conforms to a specific normative concept of distributive justice or not, may negatively influence people’s willingness to choose the egalitarian or need-based principle as allocation rules in cooperative systems that are supposed to foster solidarity or even their willingness to form such kinds of cooperative systems at all, we need an alternative paradigm other than that of distributive justice to account for the real implication of human genomics on equality.

6.2 Inequality as Emerging Exclusionary Politics

If the green light that the analysis of distributive justice gives to human genomics on the issue of equality might be the product of an incomplete scrutiny because it fails to account for some major external effects, what could be the real implication of human genomics on equality? In contrast to a posterior concern of distributive justice, common recourse to the concept of equality may indeed reflect a more primitive uneasiness about exclusionary politics. A few scholars who invoke the language of genetic antidiscrimination indeed are asserting that we should look beyond the issues of distributive justice in employment and health insurance and tackle the broader harm that human genomics might engender.[47]

What those scholars worry might be understood as the concern that the concept of justice/injustice does not take much effect in relations with others who are perceived to be outside the boundary in which one’s moral values, rules, and considerations of fairness

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[47] *See, e.g.*, Wolf, *supra* note 31.

apply.[48] People who abuse, humiliate, torture or murder those “nonentities” that are perceived to be outside one’s moral community may believe that what they do is like killing a mosquito—destructive but acceptable, filthy but not unjust.[49]

The uneasiness about the potential for moral exclusion seems to better explain the evil of classifying people based on their genetic risk in employment and health insurance, and thus provides an alternative ground for holding a “veil of ignorance” against employers and insurers. However, the emerging nature of exclusionary politics of human genomics has made the effort of employing the equal protection approach to combat burgeoning moral exclusion a mission not overly viable. But before explaining why this is so, I will first deal with the claim that human genomics serves to realize the morality of inclusion—a rejoinder that stands in stark contrast to the charge of moral exclusion.

6.2.1 Human Genomics and the Contested Morality of Inclusion

One of the public promises of human genomics is its capability to offset the effects of bad luck in the natural lottery. For those who believe in the resource-based principle of distributive justice, justice as equal opportunity even requires that such a capability be affirmatively employed to compensate for opportunity-limiting effects caused by factors beyond one’s control so as to remove natural barriers that prevent an individual from

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[48] *See* Opotow, *supra* note 44, at 1.

[49] *See* Morton Deutsch, *Psychological Roots of Moral Exclusion*, 46 J. SOC. ISSUES 21, 21 (1990).

being a normal competitor in any given cooperative systems.[50]

(1) The Morality of Inclusion and the Critique of Disability Rights

Classic theories of justice tend to hold an assumption that natural inequalities are not a concern of justice.[51] Justice as equal opportunity, at most, requires counteracting the effects that bad luck in the social lottery would have on opportunities of those with similar natural assets.[52] It ensures that competition in social institutions tests only for relevant abilities.[53] Not until lately do contemporary theories of justice start to place natural inequalities in the domain of justice on the ground that fairness requires combating opportunity-limiting effects caused by factors that are nevertheless "beyond one's control."[54] Whether they are social assets or natural assets does not matter much anymore.[55]

However, even in these theories, the distinction between natural assets and social

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[50] *See* ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 65-67 (New York: Cambridge Univ. Press, 2000).

[51] *See id*. at 63.

[52] Natural assets generally refer to characters such as intelligence, strength, and more generally genetic endowments, which are thought to be biologically given, whereas social assets, on the other hand, refer to those endowments given apparently without biological origin, such as one's wealth and social class.

[53] Thomas Scanlon calls this the "relevant competition" concept of equal opportunity. Thomas J. Scanlon, *A Good Start-Comments on Roemer*, 20 BOSTON REV. 8, 8 (1995).

[54] *See* John Roemer, *Equality and Responsibility*, 20 BOSTON REV. 3 (1995); JOHN RAWLS, A THEORY OF JUSTICE 54-80 (Cambridge, MA: Belknap Press of Harvard Univ. Press, 1971).

[55] *See* RAWLS, *supra* note 54, at 54-80.

assets still carries some weight. Opportunity-limiting effects caused by natural assets are most likely the ground for redistributing the *result* of the distribution. They are seldom, unlike opportunity-limiting effects originating in unjust social structures, the ground for combating directly the *source* of inequalities. For example, John Rawls only suggests his principle of equal opportunity to redress social inequality, and leaves the effects of natural inequality to be mitigated by the Difference Principle, a principle commanding the redistribution of goods and services.[56] On this view, people genetically at risk may call for *re*distribution of goods and services. But that does not in itself become the reason to prohibit the use of genetic criteria for distinguishing among people on equal opportunity terms. Professor Allen Buchanan and his colleagues argued that this thinking is primarily the result of the belief that natural assets are not only something biologically given to individuals but also something beyond anybody's control, so that natural inequalities can only be socially compensated by means subject to human control.[57]

The foundation of this presumption is shaken along with the development of human genomics. The technique of genetic testing makes it possible to uncover the composition of one's natural assets; the advance in genomic medicine helps to formulate effective strategies to counteract the effects of natural misfortune. Growing understanding and knowledge of genes has enhanced human's ability to take control over what once regarded as natural. Human genomics seems to promise a prospect of an equal

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[56] *See id*. at 65.

[57] *See* BUCHANAN ET AL., *supra* note 50, at 82, 83.

distribution of natural assets.

To people who argue for a moral right to health care, such as Professor Norman Daniels, the power of human genomics is most welcome since justice as equal opportunity requires efforts to be made to ensure individuals' natural assets meet the threshold of "normal functioning" necessary for them to participate in the dominant cooperative framework. Given that people with physical or mental conditions that are adverse departures from "normal functioning" of human species may have limited or constrained opportunities for being a normal participant in the dominant cooperative framework, health care in general and human genomics in particular promotes the "morality of inclusion" by removing natural barriers that prevent an individual from being a normal competitor.[58]

However, even the apparently well-intended vision of human genomics as a means to fostering such a kind of "morality of inclusion" may reflect the troubling potential of moral exclusion. Employing human genomics to bring people up to the threshold of "normal species functioning" is inherently exclusionary because its thinking nevertheless implies a negative judgment that devalues people with certain genotypes.[59] Such a

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[58] *See generally* NORMAN DANIELS, JUST HEALTH CARE 36-56 (1985); Norman Daniels, *Mental Disabilities, Equal Opportunity, and the ADA*, *in* MENTAL DISORDER, WORK DISABILITY, AND THE LAW 281, 282 (Richard J. Bonnie & John Monahan eds., 1997).

[59] *See generally* ERIK PARENS & ADRIENNE ASCH, PRENATAL TESTING AND DISABILITY RIGHTS (Washington, D.C.: Georgetown Univ. Press, 2000); Joy Hinson Penticuff, *Ethical Dimensions in Genetic Screening: A Look Into the Future*, 25 J. OBSTETRIC, GYNECOLOGIC, NEONATAL NURSING 785 (1996).

critique of exclusionary politics finds its currency among members of the disability-rights movements concerned about people with genetic risks not being treated with equal worth, likely being neglected and abused, if not exterminated.[60] Just as a society relegates women as a second sex, blacks as second-tier citizens, and gays as the aberrant,[61] to value only those traits approved by the dominant culture and to devalue those not so approved runs completely against the idea of moral inclusion.

To expose exclusionary politics that inheres in the definition of disability, the supporters of the disability-rights movement tell the often-ignored stories about the benefits and the values of those depreciated genetic traits.[62] For instance, those who identify with "Deaf culture" argue that the deaf community has provided exceptional solidarity and developed a rich culture based on their special way of linguistic expression—American Sign Language.[63] They wish to suggest that having certain genotypes does not in itself amount to disabilities; they are disabling traits only because

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[60] *See* BUCHANAN ET AL., *supra* note 50, at 272.

[61] *See id.* at 283.

[62] The Cx26 mutation accounts for about 50 percent of hereditary nonsyndromic hearing loss. *See* R. F. Mueller et al., *Congenital Non-syndromal Sensorineural Hearing Impairment Due to Connexin26 Gene Mutation: Molecular and Audiological Findings*, 50 INT'L J. PEDIATRIC OTORHINOLARYNGOLOGY 3-13 (1999).

[63] *See* Bonnie Poitras Tucker, *Deaf Culture, Cochlear Implants, and Elective Disability*, 28 HASTINGS CENTER. REP. 6 (1998). *But see* Dena S. Davis, *Groups, Communities, and Contested Identities in Genetic Research*, 30 HASTINGS CENTER REP. 38, 41, 42 (2000) (describing the conflict among the deaf community).

of social construction.[64]

(2) Normal Species Functioning

The social constructivist critique of exclusionary politics provokes strong opposition from advocates who propose to use human genomics as a means to foster moral inclusion. To them, human genomics does not construct genetic diseases out of nothing; the critique of exclusionary politics ignores a very important fact that genetic diseases impose real constraints or limitations on opportunities.[65] The values those genetic traits bring do not change this opportunity-limiting nature. Even though people in deaf communities may enjoy "Deaf culture," "the limitations imposed by being without hearing in a world in which most people hear are quite severe."[66] These opportunity-limiting effects are primarily, if not exclusively, the direct outcome of those physical, mental or genetic conditions that are adverse departures from "species-typical functioning." This character makes genetic diseases qualitatively different from the cases of discrimination against people of certain gender, racial, or sexual preference. The latter are the result of social injustice, while the genetic diseases are inherently opportunity-limiting. People with those impaired traits would "continue to suffer limited opportunities

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[64] *See generally*, Christopher Newell, *The Social Nature of Disability, Disease and Genetics: A Response to Gillam, Persson, Holtug, Draper and Chadwick*, 25 J. MED. ETHICS 172, 173 (1999).

[65] *See generally* ERIK PARENS & ADRIENNE ASCH, *supra* note 59; Adrienne Asch, *Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy*, 89 AM. J. PUB. HEALTH 1649, 1651 (1999).

[66] *See* BUCHANAN ET AL., *supra* note 50, at 282.

even if there were no discrimination against them."[67] The opportunity-limiting effects of genetic diseases are real.

Interestingly, the critique of exclusionary politics indeed has pushed the optimistic advocates of human genomics to accept a limited version of social constructivism. Based on the work of Norman Daniels and Christopher Boorse, Professor Buchanan and his colleagues call for a distinction between impairments and disabilities. For them, while "impairments" or "diseases" are the *descriptive* notions of adverse departures from "species-typical functioning," they may not necessarily result in "disabilities," a *normative* judgment which is sometimes contingent on social or historical environments.[68] This is because only when the social environment demands certain abilities would lack of those abilities become a disability. Dyslexia, a condition in which an individual with normal vision is unable to properly interpret written language,[69] results in no disability in a pre-literate hunting and gathering society.

It is in this light that Buchanan and his colleagues could both argue that "disabilities" could be prevented by modifying social arrangements, and, at the same time, retain the legitimacy of the mission of human genomics to fight against "impairments." In

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[67] *Id*. at 283, 284.

[68] See DANIELS, *supra* note 58, at 29, 30, for a discussion of the distinction between "disease" and "illness." See BUCHANAN ET AL., *supra* note 50, at 285-87, for a discussion of the distinction between "impairments" and "disabilities."

[69] *See* The On-line Medical Dictionary, http://www.graylab.ac.uk/cgi-bin/omd?query=dyslexia (last modified Sep. 27, 1997).

other words, they can, on the one hand, advocate the "morality of inclusion" that encourages change of social environment to allow more people to participate in the social cooperative scheme.[70] The claim that physical or mental impairments possess *non-normative* nature, on the other hand, averts the accusation that the public health genetics is a form of social oppression.

(3) Rethinking the Morality of Inclusion

Do the responses of those who advocate using human genomics to foster moral inclusion dismiss the challenge of exclusionary politics? Does their limited version of social constructivism alleviate the tension between disability as a given and disability as social construction?

Under the limited version of social constructivism, "impairments" are not sufficient for "disabilities," but "disabilities" must at least be constructed on some sorts of "impairments." The only exception is discrimination caused by *artificial* injustices, such as racial discrimination: The opportunity-limiting effects are not based on any solid notion of "impairments." Admittedly, modifying social arrangements can prevent impairments from resulting in disabilities. Only when there is real *artificial* injustice will those in the dominant cooperative scheme have a strong *obligation* to do so, such as the case of racial discrimination. In most of the cases, the "morality of inclusion," as

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[70] *See* BUCHANAN ET AL., *supra* note 50, at 284-87. *See also* Allen Buchanan, *The Morality of Inclusion*, 10 SOC. PHIL. POL'Y 233-57 (1993).

constructed by Professor Buchanan and his colleagues, has to be balanced by an opposing interest that ensures each individual participation in the most productive and rewarding form of interaction. In contrast to the interest in inclusion of people without normal functioning, people with normal or better functioning have an interest in gaining advantage from making use of it.[71]

The difficulty is that we can never repose too much confidence in standing beyond our social paradigm to form an external critique on the practices of our social paradigm. The judgment of *artificial* injustice is always hindsight during or after the transformation of social paradigms. Within a paradigm, it provides little or no opportunity for self-examination. The limited version of social constructivism will inadvertently have demobilizing effects on the advocacy of changing social arrangements. Because, most of the time, it is *their* impairments that cause the problem, fixing *their* impairments to qualify *our* demands is no less permissible than changing social arrangements and sacrificing *our* interests to accommodate *them*. To see people with certain genotypes as "*others*" is probably the most troubling ideology that theoretically exclusionary criticisms oppose. The "morality of inclusion" constructed on this limited version of social constructivism does not solve the problem.

This difficulty cannot be alleviated even when resorting to the notion of "normal species functioning." First, it is widely recognized that statistical normality does not itself

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[71] *See* BUCHANAN ET AL., *supra* note 50, at 292, 293.

constitute the notion of “normal functioning,” since some diseases such as tooth decay are nearly universal. Nor does the fact of deviation from the statistical norm automatically amount to adverse departures from “normal functioning.”[72] A function of organisms is a contribution to a goal in a certain context.[73] Determining “normal functioning” for human species needs to specify the range of environments taken as “natural” for the purpose of revealing dysfunction.[74] Given that human is a species living in both natural and social environments, it is difficult to draw the line between purely natural and purely social. Just as Professor Daniels has pointed out, if we allow too much of the social environment, then “drapetomania,” the condition believed to make slaves run away, would be a disease; if we disallow all socially created environments, then “dyslexia” wouldn’t be an impairment in the first place, let alone disability.[75] Daniels did not tell us how to draw this line in his work. Indeed, he could accept quite uncritically the notion of “normal functioning” without touching these hard issues of philosophy of biology, for his whole objective was merely to find a baseline to make the distinction between uses of health-care services to prevent and treat diseases and uses which meet other social goals, such as aesthetics.[76] However, when we come to the challenge of social constructivism, we need to take these philosophy-of-biology issues more seriously.

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[72] *See* Christopher Boorse, *On the Distinction Between Disease and Illness*, 5 PHIL. PUB. AFF. 49, 50 (1975).

[73] *See* Christopher Boorse, *Wright on Functions*, 85 PHIL. REV. 70-85 (1976).

[74] *See* DANIELS, *supra* note 58, at 30.

[75] *See id*. at 29, 30.

[76] *See id*. at 30, 31.

Second, to suggest a social constructivist notion of "normal functioning" is not to claim that "normal functioning" is "unreal" or that it necessarily involves normative or value judgments on the function. That some neurological organisms function to develop reading skills is surely a *descriptive* reality. Whether one's neurological conditions function in accordance with this design involves no value judgments, either. But the point is that the biological goals that human species pursue can never be decided without recognizing the fact that human species pursue them as social animals.[77]

Indeed, the central flaw in the "morality of inclusion" adopted by Professor Buchanan and his colleagues, the same drawback of much traditional moral philosophy identified by Richard Rorty, is the myth of a fixed notion of self as nonrelational, as capable of existing independently of any concern for others.[78] In the West, traditional moral philosophy tended to think of moral progress as consisting of a growing awareness of our common humanity. This common humanity constitutes the basis of our moral obligations, and this view of morality places an encumbrance on our selves. The struggle to abolish slavery and racial segregation is believed to be informed by the recognition that slaves and people of different races were the same human beings, too.[79] They possess, at least, rationality and the same "normal functioning" for human species. Discrimination

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[77] For this reason, we need not directly encounter Christopher Boorse's critique of what he called *normativism*, a view that denies descriptive notions of diseases. *See* Christopher Boorse, *supra* note 72, at 50-56.

[78] *See* Richard Rorty, *Ethics Without Principle*, *in* PHILOSOPHY AND SOCIAL HOPE 73, 79 (1999) (1994).

[79] *See* BUCHANAN ET AL., *supra* note 50, at 94.

against them is purely a form of artificial injustice. But this is only because *they* possess the same characters as *we* do.

Likewise, the "morality of inclusion" adopted by Professor Buchanan and his colleagues is limited in the sense that it does not go beyond this thinking. For Rorty, the source of moral obligations is not common humanity but a sense of "solidarity" with all other human beings.[80] The sense of solidarity derives from our willingness to extend the boundary of *our selfhood* to encompass *others*. This is a process of expanding the notion of *selfhood* and also a process of recreating *we*.[81] Moral progress is not a matter of an increase of rationality, but a matter of increasing *sensitivity*, "increasing responsiveness to the needs of a larger and larger variety of people and things."[82] In this light, the real "morality of inclusion" is not to hold a fixed notion of *we* and to adjudicate who qualifies this notion, or to normalize *them* so as to conform to the *we* category. Instead, the "morality of inclusion" demands us to imagine a better society with more flexible boundaries of our selfhood.

6.2.2 The Consequences of Exclusionary Politics and Legal Theories

Bearing this in mind, it is easy to see why the power of human genomics implicates the concern of exclusionary politics. As discussed in Chapter 4, the identity that human

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[80] *See* RICHARD RORTY, CONTINGENCY, IRONY, AND SOLIDARITY 190, 192 (1989).

[81] *See* Rorty, *supra* note 78, at 77, 78.

[82] *Id*. at 81.

genomics depicts for us tends to ossify our selfhood. It confines our imagination and makes the efforts of solidarity more difficult.

In response to the concern of inequality as exclusionary politics, legal scholars have tried to locate the potential consequences of exclusionary politics in three different conceptual realms: subordination in the *material realm*, psychological stigma in the *subjective realm* of the heads of victims/readers/listeners, and the denigrating message in the *social realm*.[83] However, the emerging nature of exclusionary politics of human genomics barely fits these consequence-based approaches.

(1) Subordination in the *Material* Realm

Admittedly, the language of exclusionary politics is reminiscent of Professor Owen Fiss's "group-disadvantaging principle" of equal protection proposed over a quarter century ago.[84] Professor Fiss argued that the evil of discrimination is that it aggravates or perpetuates the subordination of specially disadvantaged groups rather than that it causes the unfair treatment of individuals.[85] He believed that the stress of "disadvantaged groups" and the harm to their social positioning would enable the courts to more consistently invalidate facially neutral laws that have the effect of disadvantaging a subordinate group and also enable them to uphold facially group-based laws aimed at

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[83] The concept of the three realms is articulated by Professor Edwin Baker. *See* C. Edwin Baker, *Injustice and the Normative Nature of Meaning*, 60 MD. L. REV. 578, 583-86 (2001).

[84] *See* Fiss, *supra* note 16.

[85] *See id*. at 157.

ameliorating the condition of a subordinate group.

Fiss's "group-disadvantaging principle" and the proposition of "group rights" are attractive insofar as the moral exclusion of traditionally disadvantaged groups, such as blacks and women, is concerned. However, the "group-disadvantaging principle" and "group rights" may not be well suited for the current case of exclusionary politics of human genomics. In a sense, the exclusionary politics of human genomics certainly has "group implications." It involves groups of people defined not by their citizenship but by a common tie of a particular heredity or disease,[86] or more generally by their status of being genetically at risk. Some have criticized the concept of group in the genetic context as elusive. They charge that sharing certain genetic characteristics does not automatically confer membership to a homogenous community with shared values and concerns.[87]

Perhaps, Professor Fiss's use of the language of "group rights" is somewhat awkward since it has been an individual's right not to be unfairly or irrationally treated that is at issue. The language of "group rights" makes the "anti-subordination" claim that he was really proposing sounds more radical than it is.[88] But what makes the group disadvantaging or anti-subordination principle ill-fitted for exclusionary politics of human genomics is a current lack of collective memory of oppression that is nevertheless

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[86] *See* Henry T. Greely, *The Control of Genetic Research: Involving the "Groups Between"*, 33 HOUS. L. REV. 1397, 1399 (1997).

[87] *See* Davis, *supra* note 63, at 40-42.

[88] *See* Strauss, *supra* note 39, at 7.

present in cases of racial and gender discrimination. Long-standing subordination of blacks and women in American society creates the necessary collective memory for these groups of people over their biological characteristics. By contrast, the subordinate effect of exclusionary politics of human genomics is still in its infancy. Despite the shared concern between anti-subordination principle and the uneasiness about exclusionary politics, the emerging nature makes the claim of anti-subordination or group rights currently inapt for addressing exclusionary politics of human genomics.

(2) Psychological Stigma in the *Subjective* Realm

A familiar ground for opposing exclusionary politics is that it causes stigmatic harm. Ever since the early days of constitutional equal protection jurisprudence, the theme of "stigma" has persisted. From *Strauder v. West Virginia* of 1879,[89] to modern day cases such as *Brown v. Board of Education,*[90] and *City of Richmond v. J.A. Croson Co.,*[91] the concept of stigma has been again and again invoked to address the construction of inferiority in a certain class of people. Despite its fame, the concept of stigma is not so coherently used in legal theories that critics sometimes accuse it of being protean and

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[89] 100 U.S. 303, 308 (1879) ("The very fact that colored people are singled out and expressly denied by a statute all right to participate in the administration of the law, as jurors, because of their color…is practically a brand upon them, affixed by the law, an assertion of their inferiority….").

[90] 347 U.S. 483, 494 (1954) (condemning the school segregation of black students as "generat[ing] a feeling of inferiority as to their status in the community that may affect their hearts and minds in a way unlikely ever to be undone").

[91] 488 U.S. 469, 493 (1989) ("Classification based upon race carry [sic] a danger of stigmatic harm.").

confusing.[92] It contains at least two accounts that characterize the detrimental consequences of exclusionary politics in the subjective realm and the social realm respectively.

Psychological stigma refers to psychological injury inflicted on the victims of discrimination. The psychological stigma theory sees exclusionary politics as inflicting detrimental consequences on victims through their heads.[93] Because stigma in this sense is concerned with the understanding of the victims/readers/listeners about exclusionary politics, it is sometimes confused with the concept of bad intent involving another subjective realm though in the opposite side of the communication—heads of the actors/authors/speakers.[94] It is possible in practice that the "understanding" is identical with the "intent," but the two are different concepts implicating very different understandings about what is wrong with exclusionary politics.

Advocates of the psychological stigma theory often allude to the customary view that the *Brown* Court relied on social science studies in footnote eleven showing that public school segregation caused social and psychological harm to black schoolchildren

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[92] *See, e.g.*, Diver & Cohen, *supra* note 1, at 1477.

[93] *See* ANDREW KOPPELMAN, ANTIDISCRIMINATION LAW AND SOCIAL EQUALITY 76 (New Haven: Yale Univ. Press, 1996).

[94] See, Diver & Cohen, *supra* note 1, at 1477, for an example that commits the fault of confusing stigma with aversion. In their criticism of using public polls as the evidence for the existence of stigma, Professors Diver and Cohen use instead the existence of "aversion" as the touchstone. *See id*. ("Still others cite the results of public opinion polls expressing popular concern about invasions of genetic privacy, as though fear of misuses of information necessarily reflected *aversion* to the underlying condition revealed by such information.") (emphasis added).

as a ground to hold segregation unconstitutional.[95] Just like racial discrimination may "generate a feeling of inferiority," exclusionary politics of human genomics, argued the advocates of antidiscrimination law, is wrong because of the similarly harmful psychological injury inflicted on the person denied the social membership owing to his/her genetic trait. Minds of those genetically at risk are traumatized for possessing "bad" or "inferior" genes because they may be viewed as "less desirable as customers, as employees or as marriage partners."[96]

A lack of rigorous empirical investigation of the existence and the scope of "the inferior feeling" in the potential victims of genetic discrimination, however, undermines the strength of the psychological stigma theory.[97] But another challenge comes from the objection to having the determination of wrongful exclusionary politics rest on the contingent mental state of the victims.[98] The now dominant view is that psychological

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[95] *See* KOPPELMAN, *supra* note 93, at 57. *But see* Sanjay Mody, Note, *Brown Footnote Eleven in Historical Context: Social Science and the Supreme Court's Quest for Legitimacy*, 54 STAN. L. REV. 793 (2002) (arguing that *Brown* Court's actually did not rely on social science in deciding that public school segregation was unconstitutional).

[96] Hellman, *supra* note 24, at 89.

[97] Most studies of "psychological harms" associated with genetic testing deal with the anxiety about the development of the disease rather than the "feeling of inferiority." *See*, *e.g.*, Theresa M. Marteau, *Effects of Genetic Screening on Perceptions of Health: A Pilot Study*, 29 J. MED. GENETICS 24 (1992); Janet K. Williams & Debra L. Schutte, *Benefits and Burdens of Genetic Carrier Identification*, 19 W.J. NURSING RES. 71 (1997).

[98] *See, e.g.*, Deborah Hellman, *The Expressive Dimension of Equal Protection*, 85 MINN. L. REV. 1, 10 (2000) (arguing that the psychological stigma theory would not condemn racial segregation of facilities for infants or those in a permanent vegetative state); Edmond Cahn, *Jurisprudence*, 30 N.Y.U. L. Rev. 150, 157-58 (1955) (criticizing *Brown*'s approach that rested the constitutional rights on the "flimsy foundation

injury or benefit is entirely irrelevant to the question of why exclusionary politics is wrong.[99]

(3) Expressive Stigma in the *Social* Realm

Unlike the psychological stigma theory that purports to locate the detrimental consequences of exclusionary politics in the subjective realm of the victims, the expressive stigma theory captures the harm of exclusionary politics in the cultural meaning of inferiority expressed in exclusionary politics in the social realm where the basis for understanding texts and other objects created by humans is supplied.[100]

Advocates of the expressive stigma theory charge that the expression of denigrating cultural message, linguistic or not,[101] is what is really wrong with exclusionary politics.[102]

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as some of the scientific demonstrations in these records").

[99] *Cf.* Catherine A. MacKinnon, *Concurring in the Judgment*, *in* WHAT *BROWN V. BOARD OF EDUCATION* SHOULD HAVE SAID 143, 146-47 (Jack M. Balkin ed., New York: New York Univ. Press, 2001) (arguing that the psychological feeling of inferiority measured by the social scientists was only the traces of the greater injury. It is as if one identified blood that flows from a cut as the injury rather than the cut itself).

[100] *See* Baker, *supra* note 83, at 585.

[101] Meaning can refer either to linguistic meaning or to nonlinguistic meaning. Linguistic meaning comes from the communication of a linguistic sentence by authors/speakers, whereas nonlinguistic meaning can exist in an action, event, or state of affairs if it evidences, indicates or signals something. *See* H. PAUL GRICE, *Meaning*, *in* STUDIES IN THE WAY OF WORDS 213, 213-15 (Cambridge, MA: Harvard Univ. Press, 1989). Professor Matthew Adler, a harsh critic of the expressive stigma theory, understood at first that only linguistic meaning of a law, for example, "Only white male persons who are twenty-one years of age and who are citizens of the State shall be liable to serve as jurors…," could communicate the cultural meaning of black inferiority. Matthew D. Adler, *Expressive Theories of Law: A Skeptical Overview*, 148 U. PA. L. REV. 1363, 1386 n.77, 1404, 1429-30 (2000) [hereinafter Adler, *A Skeptical Overview*]. Professor Adler later admitted that the expressive stigma theory concerns both linguistic and nonlinguistic meaning.

The cultural meaning of an expression relies on common linguistic practices and conventions to give it flesh. For this reason, neither the subjective intent of authors/speakers nor the subjective understanding of readers/listeners is able to command the objective social meaning of a discriminatory practice.[103]

Why does the message of inferiority matter? It could be argued that, whereas denigrating messages and the tangible cultural impacts of status harm are only contingently linked,[104] the connection between the two could be stably strong in certain cultural contexts.[105] Using denigrating messages as a proxy, in those cases, to track the culture impacts seems more sensible in terms of doctrinal feasibility.[106] But if serving as a proxy for tangible harm in the material realm were what the expressive stigma theory meant to suggest, it would have lost all its appeal when there is no immediate adverse impact on the social positioning. The expressive stigma theory needs to explain why the denigrating message is harmful without alluding to tangible injuries.

Matthew D. Adler, *Linguistic Meaning, Nonlinguistic "Expression," and the Multiple Variants of Expressivism: A Reply Response to Professors Anderson and Pildes*, 148 U. PA. L. Rev. 1577, 1577, 1585 (2000) [hereinafter Adler, *A Reply*].

[102] *See, e.g.*, Charles R. Lawrence III, *The Id, the Ego, and Equal Protection: Reckoning with Unconscious Racism*, 39 STAN. L. REV. 317, 356-62 (1987); Hellman, *supra* note 98, at 13-14, 28-37.

[103] *See* C. Edwin Baker, *Outcome Equality or Equality of Respect: The Substantive Content of Equal Protection*, 131 U. PA. L. REV. 933, 973 (1983).

[104] *See* Adler, *A Skeptical Overview*, *supra* note 101, at 1434, 1436; Adler, *A Reply*, *supra* note 101, at 1591-93.

[105] *See* Andrew Koppelman, *On the Moral Foundations of Legal Expressivism*, 60 MD. L. REV 777, 779-80 (2001).

[106] *See* Adler, *A Skeptical Overview*, *supra* note 101, at 1437.

The best answer thus far seems to be the one proffered by Professor Edwin Baker. He argued that the denigrating message of a political decision is wrong in itself because, in a Rawlsian original position, no individual would “find acceptable a political order that ‘disparages’ her as a person or that ‘expresses’ disrespect for her inherent worth.”[107] Professor Baker’s account seems convincing insofar as the denigrating message of *law* is concerned. But his theory does not provide better clue for the question why the denigrating message, if any, of a *private decisionmaking* is equally, if not more, problematic. This surely is a theoretical snag to the expressive stigma theory in answering why classifying people based on their genetic risks in private decisionmaking is wrong. But a moment’s reflection will show that, although to ferret out the real evil of exclusionary politics of human genomics in the social realm rather than material or subjective realm seems a right direction, capturing messages that *denigrate others* probably misses again the real quarry.

Expression of a message *denigrating others* certainly is the symptom of existing moral exclusion in which common linguistic practices and conventions could readily provide the basis for comprehending denigrating meaning. In cases of the emerging exclusionary politics of human genomics, the cultural implication in the social realm is instead its potential to set up an ideal body image that ossifies *selfhood* and fosters moral exclusion anew. This understanding makes the rejoinder that most genetic conditions

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[107] Baker, *supra* note 83, at 581-82.

"elicit reactions of sympathy and solicitude far more than fear and aversion"[108] ineffective.

6.2.3 Limited Capacity of Equality Paradigm

The emerging nature of exclusionary politics engendered by human genomics has proved to be elusive even for legal scholars who understand inequality as reflecting a broader concern of exclusionary politics rather than the squabble over the unjust distribution of goods and services. But the practical difficulty for employing any consequence-based legal theory to address exclusionary politics of human genomics is that current equal protection jurisprudence has since the 1970s, at every turn, rejected anything other than the intent—the subjective realm of the actors/authors/speakers—as a proper domain to entertain wrong of discrimination.[109]

Despite Professor Fiss's contention that the group-disadvantaging principle could better account for egalitarian jurisprudence, the Court has since chosen "intent" over the "disparate impact" analysis.[110] Similarly, stigma, psychological or expressive, has never

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[108] Diver & Cohen, *supra* note 1, at 108.

[109] *See* Washington v. Davis, 426 U.S. 229 (1976) (holding that facially neutral laws that disparately impact minorities do not, absent more, trigger heightened scrutiny).

[110] *See* Griggs v. Duke Power Co., 401 U.S. 424 (1971) (recognizing disparate impact not as a freestanding standard in addition to discriminatory intent but as a presumptive inference of discriminatory intent when the actors provide no justification for such an impact). *See also* Robin West, *Groups, Equal Protection and Law*, ISSUES IN LEGAL SCHOLARSHIP, Symposium, *The Origins and Fate of Antisubordination Theory*, Article 8, (2002), *at* http://www.bepress.com/ils/iss2/art8 (inaugurated Aug. 2002) (analyzing the conceptual missteps of the group-disadvantaging principle that caused the court's

been accepted as a freestanding standard to account for what is bad about discrimination.[111] Many commentators have criticized such jurisprudence for putting more emphasis on expediency of institutional capacity than on principle of equality.[112] Such expedient considerations remain vibrant in current equal protection jurisprudence and positive antidiscrimination laws.[113] For instance, without intending to combat every and all discrimination attributable to impairments,[114] the design of the coverage of the Americans with Disabilities Act also embodies the consideration of the capacity of a

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rejection). *But see* Michael C. Dorf, *A Partial Defense of an Anti-Discrimination Principle*, ISSUES IN LEGAL SCHOLARSHIP, Symposium, *The Origins and Fate of Antisubordination Theory*, Article 2, (2002), *at* http://www.bepress.com/ils/iss2/art2 (inaugurated Aug. 2002) (arguing that both the approach adopted by courts and Fiss's "group-disadvantaging principle" are sufficiently open-ended conceptions of equality capable of producing a variety of morally attractive and not-so-attractive outcomes).

[111] In *Cleburne v. Cleburne Living Center, Inc.*, a case involving an equal protection challenge to a city ordinance requiring a special use permit for the operation of a group home for the mentally retarded, the Supreme Court refused to treat the mental retardation as a "quasi-suspect" classification even though the Court admitted that the mentally retarded may indeed suffer from varied degree of "public prejudice." Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. 432 (1985). The challenged city ordinance was struck down at the end not because of any type of the stigma theory but because of the inconsistent treatments between several similarly situated facilities in the zoning proceeding. *See id*. at 448.

[112] *See, e.g.*, David A. Strauss, *Discriminatory Intent and the Taming of Brown*, 56 U. CHI. L. REV. 935, 951-54 (1989).

[113] *See* Washington v. Davis, 426 U.S. at 248 (apprehending the consequences of a disparate impact analysis as raising "serious questions about, and perhaps invalidate, a whole range of tax, welfare, public service, regulatory, and licensing statutes that may be more burdensome to the poor and to the average black than to the more affluent white"). One rationale behind the decision of *Cleburne* is that "if the…class of the mentally retarded were deemed quasi-suspect," the Court would have been forced to set out on a difficult course "to find a principled way to distinguish a variety of other groups who have perhaps immutable disabilities…and who can claim some degree of prejudice from at least part of the public at large." *See* Cleburne v. Cleburne Living Ctr., Inc., 473 U.S. at 445-46.

[114] 42 U.S.C.A. § 12102(2) (2004).

remedial justice scheme.[115] The dissent of Chief Justice Rehnquist in *Bragdon v. Abbott*—"[an] argument [for protection of those who are physically impaired but not presently limited in major life activities], taken to its logical extreme, would render every individual with a genetic marker for some debilitating disease "disabled" here and now because of some possible future effects"[116]—implicitly invoked the same rationale.

It may be true that, as Professor Deborah Hellman said in arguing against the effect-based anti-subordination approach to equality, "we weaken [Equal Protection's] power and dilute its special appeal to deep and shared moral intuitions if we interpret it as a general guarantee of distributional fairness."[117] Interestingly, while Professor Hellman proposed instead an expressive stigma theory as a conceptual middle course between the poles of "intent" and "consequence,"[118] she did not demonstrate that the criterion that she just put forth is satisfied, i.e., whether the institutional demand of her expressive stigma theory is actually less than that of a consequence-based approach.

Perhaps, a better way to answer for the concern of emerging exclusionary politics of human genomics is not through its consequences but a return to the subjective realm of the actors/authors/speakers. After all, the fixed selfhood that eventually gives rise to moral exclusion exists right there in the heads of the actors/authors/speakers. But the

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[115] *See* RUTHERGLEN, *supra* note 14, at 222.

[116] 524 U.S. 624, 661 (1998) (Rehnquist, C.J., concurring in the judgment in part and dissenting in part).

[117] Hellman, *supra* note 98, at 5.

[118] *See id*.

definition of intent currently adopted in equal protection jurisprudence thwarts such a possibility.

Hence, we have, on the one hand, the analysis of distributive justice that discredits the charge of inequality, even though the assurance is inconclusive because such an analysis fails to account for major external effects. On the other hand, we have the analysis of exclusionary politics that has a better grip on the implication of human genomics on equality. Yet, current equal protection jurisprudence does not afford to combat the emerging nature of exclusionary politics of human genomics. This incapacity calls for an alternative paradigm.

7/ AN ALTERNATIVE SCIENCE REGULATORY SCHEME

7.1 Challenges of Liberal Pluralism

7.2 Toward a Possible Substantive Standard

7.3 Reinterpreting Privacy as a Compelling Government Interest

If the most portentous harm posed by human genomics in the current socio-cultural ambience is its potential to form inflexible identities and in the end its threats to social solidarity, and if rules for confidentiality and anti-discrimination laws, at the end of the pipeline, poorly control the symptoms of social and ethical injury without attacking the source of the injury, it seems plausible to look upward at the front of the pipeline for the ultimate solution. (See Figure 7-1) This realization brings us to the challenge of formulating a possible approach to regulating science in general and human genomics in particular.

It is not an entirely new topic to talk about the regulation of the scientific enterprise owing to the ethical, social and cultural implications science may engender. Both legal scholars and social scientists have from time to time urged scientists to be more socially responsible and scientific inquiry be more publicly accountable.[1] Experience from several past research controversies, however, shows that the attention of instrumental rationality, prominently the safety issue, has more often than not dominated the agenda of the regulation of the scientific enterprise. Concerns of ethical, social and cultural impacts

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[1] *See*, *e.g.*, Dorothy Nelkin, *Threats and Promises: Negotiating the Control of Research*, 107 DAEDALUS 191 (1978); Halsted R. Holman & Diana B. Dutton, *A Case for Public Participation in Science Policy Formation and Practice*, 51 S. CAL. L. REV. 1505 (1978); Kelly Moore, *Organizing Integrity: American Science and the Creation of Public Interest Organizations, 1975-1995*, 101 AM. J. SOC. 1592 (1996) (detailing the scientific responsibility movement); Bentley Glass, *The Ethical Basis of Science*, *in* THE ETHICAL DIMENSIONS OF THE BIOLOGICAL SCIENCES 43, 43-55 (Ruth Ellen Bulger et al. eds., New York: Cambridge Univ. Press, 1993) (identifying three ethical and social responsibilities of scientists: to proclaim science's benefits, to warn of risks, and to discuss quandaries).

were very often marginalized. Much criticism has been leveled against this lack of ethical

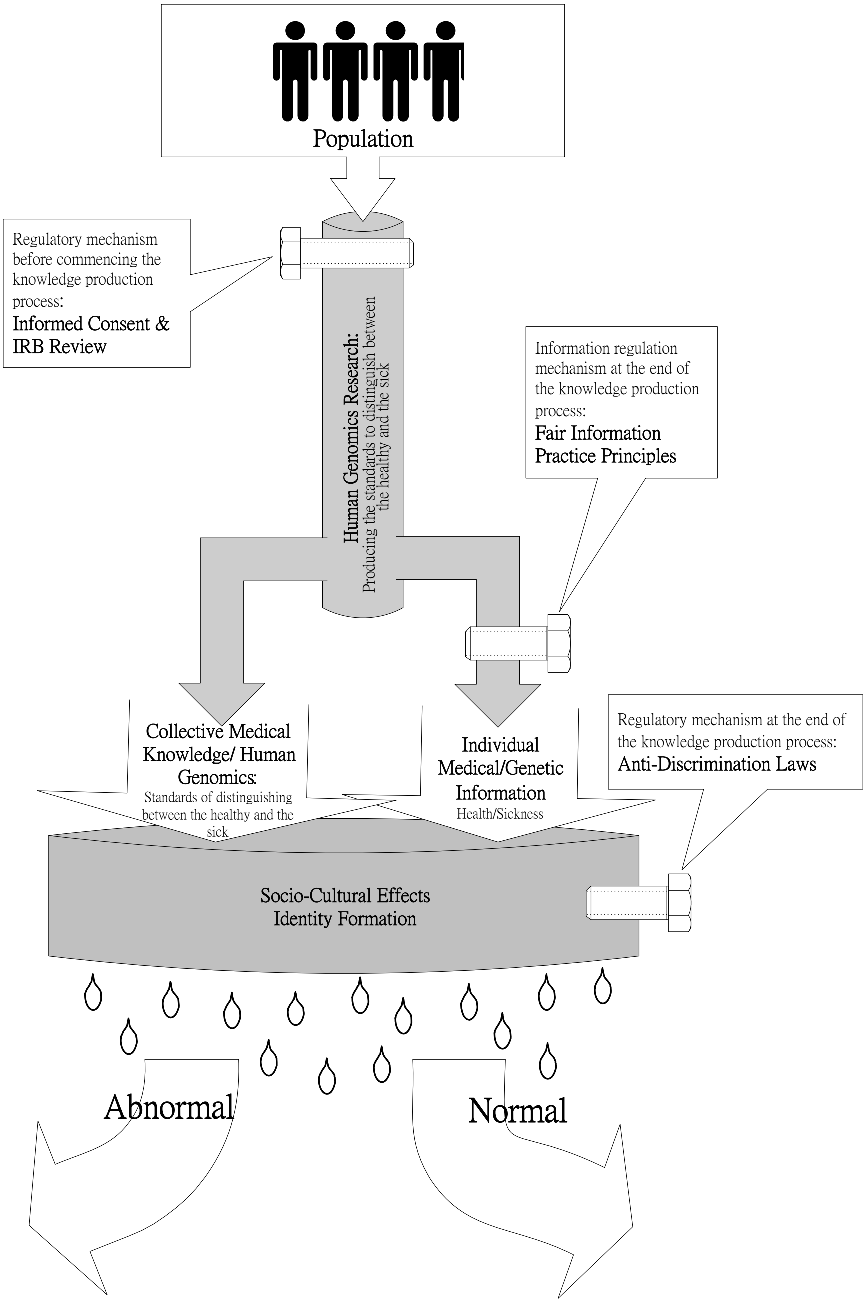

Figure 7-1 Production of Human Genomics and the Current Regulatory Scheme

depth in the practice of science regulation.[2] To the extent that ethical, social, and cultural concerns enter the realm of regulatory scheme, only issues of micro-ethics are actually considered.

Although recognizing the shortcoming, scholars have so far failed to devise a more sophisticated conceptual apparatus to effectively deliver the idea of a richer bioethics that takes into account the broader social and cultural implications without tumbling in front of the neutrality demand in a liberal pluralistic society. Familiar claims for such a richer bioethics oftentimes frame the ethical, social, and cultural implications of human genomics in a fashion less amenable to public deliberation and easily lose the edge against a libertarian market alternative that advocates leaving decisions privately up to individual consumer hands.

To formulate a successful approach to regulating the production of human genomics, we must first overcome such conceptual barriers and put forward substantive norms of science regulation that are both sympathetic to the concerns of identity formation effects of knowledge and compatible with the idea of liberal pluralism. Only

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[2] *See* JOHN H. EVANS, PLAYING GOD: HUMAN GENETIC ENGINEERING AND THE RATIONALIZATION OF PUBLIC BIOETHICAL DEBATE (Chicago: Univ. of Chicago Press, 2002); DANIEL CALLAHAN, WHAT PRICE BETTER HEALTH?: HAZARDS OF THE RESEARCH IMPERATIVE 165-200 (Berkeley: Univ. of California Press, 2003); LEON R. KASS ET AL., THE PRESIDENT'S COUNCIL ON BIOETHICS, BEYOND THERAPY: BIOTECHNOLOGY AND THE PURSUIT OF HAPPINESS 6 (Washington, DC: Pre-Publication Version, 2003); SHELDON KRIMSKY, GENETIC ALCHEMY: THE SOCIAL HISTORY OF THE RECOMBINANT DNA CONTROVERSY (Cambridge, MA: MIT Press, 1982); Emily Marden & Dorothy Nelkin, *Displaced Agendas: Current Regulatory Strategies for Germline Gene Therapy*, 45 MCGILL L.J. 461 (2000); Laurence H. Tribe, *Technology Assessment and the Fourth Discontinuity: The Limits of Instrumental Rationality*, 46 S. CAL. L. REV. 617 (1973).

after such substantive norms are developed can an instrumentalist approach be sensibly employed to determine, among possible options, the best design of procedural regulatory mechanisms or strategies based on the criteria of how well the substantive norms could be implemented.

7.1 Challenges of Liberal Pluralism

After reviewing an array of ethical, social, and cultural concerns about reprogenetics, Professor Gregory Stock declares that "no amount of [philosophical] debate about advanced reproductive technology will settle the question of whether human genetic enhancement is right or wrong. But in pluralistic societies, this situation is not new or even unusual."[3] "And endless debate over whether we should be "playing God" or whether advanced [germinal choice technology] will corrupt us spiritually will not get us far. Nor will arguing about the unknowable future consequences for children or parents or society. The areas that would most benefit from discussion right now are concrete matters: how to test these technologies, appraise their risks, monitor research, and minimize clinical abuse."[4] Such allegations are certainly not unusual in the discussion of science regulation. The similar debate among legal scholars over whether legal judgment should touch upon moral issues or be guided solely by an instrumentalist approach to law reflects the same intellectual tug-of-war, whose result Stock's comment wishes to

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[3] GREGORY STOCK, REDESIGNING HUMANS: OUR INEVITABLE GENETIC FUTURE 133 (Boston: Houghton Mifflin Company, 2002).

[4] *Id*. at 152.

influence toward one direction rather than the other.[5] Along with the successful development of modern science, substantive norms of public policy that are less amenable to objective measurement or instrumental analysis tend to be seen as inevitably subjective and arbitrary. Equating incalculability with subjectivity bred what Professor Laurence Tribe called an end-of-ideology view of the 1960s,[6] which held that "most of the problems, or at least many of them, that we now face are technical problems [calling for] … very sophisticated judgments which do not lend themselves to the great sort of 'passionate movements' which have stirred this country so often in the past…."[7]

Four decades later, that view apparently still exerted its influence when Congressman Ted Strickland of Ohio, during a Congressional debate on human cloning, insisted that we be guided solely by the best available science, and that "we should not allow theology, philosophy, or politics to interfere with the decision we make on this issue."[8] Unfortunately, the ethical, social, and cultural concerns of human genomics are indeed hardly ever subject to instrumental calculation. If, as per Stock or Strickland, such incalculable concerns merely reflect arbitrary and subjective preferences, they had better

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[5] Compare Ronald Dworkin, *Darwin's New Bulldog*, 111 HARV. L. REV. 1718 (1998) with Richard A. Posner, *The Problematics of Moral and Legal Theory*, 111 HARV. L. REV. 1637 (1998). *See also* Ronald Dworkin, *In Praise of Theory*, 29 ARIZ. ST. L.J. 353 (1997); Richard A. Posner, *Conceptions of Legal Theory: A Reply to Ronald Dworkin*, 29 ARIZ. ST. L.J. 377 (1997); Ronald Dworkin, *Reply*, 29 ARIZ. ST. L.J. 431 (1997).

[6] *See* Tribe, *supra* note 2, at 622 & n.18.

[7] *Id.* at 623 n.18 (quoting President Kennedy *in* ARTHUR M. SCHLESINGER, JR., A THOUSAND DAYS: JOHN F. KENNEDY IN THE WHITE HOUSE 644 (1965)).

[8] *See* Francis Fukuyama, *How to Regulate Science*, 146 PUBLIC INTEREST 20 (2002).

be left in the private sphere and not proffered as the substantive norms of science regulation that would have persecuted the ghost of Galileo.[9] That is, since disagreement about the morality of a certain line of genomics research will rest on incommensurable worldviews, we should in a pluralistic society respect freedom of scientific inquiry and leave the decision whether to engage or support the research up to the choice of individuals as the best idea is decided in a free marketplace.[10]

The end-of-ideology view and the instrumental-libertarian approach also exist lucidly in the present thinking of the science regulatory schemes or the regulation of the production of scientific knowledge. The current regulatory safeguards established around the making of scientific knowledge consist of ethical review by the Institutional Review Boards (IRBs) and the informed consent of human subjects. IRBs are local administrative bodies charged with protecting the rights and welfare of research participants. One of the mechanisms an IRB employs to implement its mandate is to weigh the risks the proposed research may pose to the research participants against the benefits the research may offer

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[9] *See*, *e.g.*, IRA H. CARMEN, CLONING AND THE CONSTITUTION 38 (Madison, WI: The Univ. of Wisconsin Press, 1985); STOCK, *supra* note 3, at 174; Richard Delgado & David R. Millen, *God, Galileo, and Government: Toward Constitutional Protection for Scientific Inquiry*, 53 WASH. L. REV. 349, 394-99 (1978); John B. Attanasio, *The Genetic Revolution: What Lawyers Don’t Know*, 63 N.Y.U. L. Rev. 662, 662 (1988); Glenn Harlan Reynolds, *Between Pilate and Galileo*, 35 Jurimetrics J. 349, 352 (1995) (reviewing STEVEN GOLDBERG, CULTURE CLASH: LAW AND SCIENCE IN AMERICA (New York: New York Univ. Press, 1994)). But it should be noted that, although Galileo was sentenced to life imprisonment, he was not tortured and never kept in a prison or a dungeon. Recent examination of Galileo’s case suggests that it was probably more a political clash between Galileo and the Jesuits than a real confrontation between religion and science.

[10] *See* Erik Parens & Lori P. Knowles, *Reprogenetics and Public Policy: Reflections and Recommendations,* HASTINGS CENTER REP., July-Aug. 2003, S3, S14; CALLAHAN, *supra* note 2, at 119.

to the patient and society. Such a risk-benefit analysis is embedded squarely with instrumentalist-libertarian thought. The risk-benefit analysis pays most, if not all, attention to possible tangible harms imposed by the physically unsafe research. Concerns of the risk of psychological injury, such as the feeling of stress, guilt, and loss of self-esteem occurring as a result of research involving methods such as deception, providing the subjects with unwelcome or disturbing information, and manipulating the subject's environment, are also considered.[11] Given its specified mandate of protecting rights and welfare of *individual* human subjects, IRBs do not usually reflect on the broader social and cultural impacts on the society that the proposed research may cause. Federal regulations explicitly exclude the "possible long-range effects of applying knowledge gained in the research" from the lists of what an IRB should consider the research risks that fall within the purview of its responsibility.[12] Experience from past history shows that such "possible long-range effects" may occur because of the socially volatile subject matters of the research or its possible findings, such as associations between race or gender and intelligence.[13] In spite of their possible impact on a society's ethical landscape, "possible long-range effects" are not literally a concern for IRBs. To the extent that

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[11] *See* ROBIN LEVIN PENSLAR ET AL., PROTECTING HUMAN RESEARCH SUBJECTS: INSTITUTIONAL REVIEW BOARD GUIDEBOOK 3-3–3-4 (Bethesda, MD: U.S. Dept. of Health and Human Services, Public Health Service, National Institutes of Health, Office of Extramural Research, Office for Protection from Research Risks, 2nd ed.1993).

[12] The Model Federal Policy for the Protection of Human Subjects, 45 C.F.R. § 46.111(a)(2) (2003). *See also* PENSLAR ET AL., *supra* note 11, at 3-3.

[13] *Cf.* Richard Delgado et al., *Can Science be Inopportune? Constitutional Validity of Governmental Restrictions on Race-IQ Research,* 31 UCLA L. REV. 128 (1983).

"social harms" are taken into account by IRBs, they have to either be translated into something directly affecting the individual human subjects, such as loss of employment or insurance because of stigmatization or discrimination, or in some cases be presented as information of background risks that individual human subjects may consider before giving out their informed consent. Not surprisingly, the instrumentalist approach of the IRB review eventually falls back on a libertarian solution without engaging in any serious deliberation about what I have called the macro-ethics of science.

This lack of ethical depth, however, should be attributed less to a limited purview of IRBs than to a pluralist thesis that supports more generally the laissez-faire of the scientific enterprise. A pluralist's lack of interest in ethical questions other than the technical safety of research designs and the voluntariness of individual choices in the production of scientific knowledge leads to destitution of regulatory schemes. The pluralist thesis explains why Saleem A. Shah, chief of the Center for Studies of Crime and Delinquency, which was involved in XYY research in the 1970s, when he was faced with the inquiry about the social and ethical concerns of XYY research, would think that once a research passes the established procedures for determining the scientific merits, for funding policies, and for the IRB review, and follows the guidelines for the protection of human subjects, "there is something fundamentally wrong with the notion that an individual or small group, whatever their ideology or interest, could or should decide that a certain line of research should be stopped."[14] Likewise, the pluralist thesis also explains

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[14] Statement of Saleem A. Shah, chief of the Center for Studies of Crime and Delinquency, National

why investigation of the controversy over a New York Psychiatric Institute's study on violence and antisocial behavior among youth of minority ethnic groups in 1993 would end up in debating only whether the use of fenfluramine, a chemical used to measure indirectly the brain serotonin level implicated in antisocial behavior, will cause cardiac damage to the young participants and whether the offer of financial incentive[15] would compromise the voluntariness of individual choices.[16]

One implication of employing such a pluralist end-of-ideology view to handle the ramifications of knowledge production is that its over-simplified way of framing the ethical issues very often pits privacy against research and individual interest against public good,[17] while the denotation of public good is never seriously deliberated. Professor David Korn once argued that "[s]ince every individual is a direct beneficiary of the historic medical knowledge base, the ethical principle of distributive justice would suggest that everyone should be obligated to contribute to that base."[18] Korn's

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Institute of Mental Health, at a conference on the XYY controversy held by the Hastings Center in 1978. *The XYY Controversy: Researching Violence and Genetics*, 10 HASTINGS CENTER REP. S1, S3 (1980).

[15] $100 was paid to parents for their children's participation in the study and $25 gift certificates to the 36 healthy black and Hispanic elementary school pupils agreeing to enroll in the study.

[16] *See Institutional Review Boards: A System in Jeopardy*: *Hearings Before the Subcomm. on Human Resources of the House Comm. on Gov't Reform and Oversight*, 105th Cong. 77-82, 154-59 (1998).

[17] *See* NATIONAL COMM. ON VITAL & HEALTH STATISTICS, HEALTH PRIVACY AND CONFIDENTIALITY RECOMMENDATIONS OF THE NATIONAL COMMITTEE ON VITAL AND HEALTH STATISTICS, Approved on June 25, 1997, *available at* http://www.mssm.edu/medicine/medical-informatics/ncvhs.html.

[18] *See, e.g.*, David Korn, *Genetic Privacy, Medical Information Privacy, and the Use of Human Tissue Specimens in Research*, *in* GENETIC TESTING AND THE USE OF INFORMATION 60-61 (Clarisa Long ed., Washington, DC: AEI Press, 1999).

enthusiasm, although it seems to be based so comfortably on an end-of-ideology view of science regulation, which clears the underbrush of nasty moral debates and leaves it to the neat instrumentalist risk-benefit analysis, is in fact premised on the notion of a "research imperative" that holds prima facie moral value in production of scientific knowledge.[19] It certainly is not a point-of-viewless pluralism.

So, is it really impossible to deliberate about the ethical, social, and cultural concerns of human genomics in a pluralistic society? What's wrong with the instrumental-libertarian approach to the regulation of the scientific enterprise? Do we have a third choice besides the pluralist laissez-faire and absolute moralism? Can any substantive norm, though instrumentally incalculable, be developed in a pluralistic society through public deliberation to anchor the ethical, social, and cultural concerns of human genomics? What would be the content of such substantive norms? The answers to those questions hinge both upon the recognition of the identity forming potential of human genomics and the understanding that instrumental incalculability does not necessarily amount to being arbitrary or subjective.

7.2 Toward a Possible Substantive Standard

A close analysis of the pluralist thesis supporting laissez-faire of the scientific enterprise would suggest that such a thesis is primarily based on two claims. The first

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[19] Bioethicist Daniel Callahan first articulated the concept of the "research imperative." *See* CALLAHAN, *supra* note 2, at 3-4, 57-84.

claim posits that the production of scientific findings and knowledge per se are of no ethical significance other than being the raw facts exterior to the choosing subject who is the one to determine the value of those facts. The second claim posits that, even if scientific findings and knowledge do produce some changes in the ethical landscape, we are unable to reach a consensus on the proper standard to judge publicly the value of such changes without damaging the foundation of a pluralistic society at the same time. The first claim is about the domain of ethical decision-making, while the second is about availability of the substantive standard for value judgment.

The first claim of the pluralist thesis is clearly derived from Mill's distinction between self-regarding and other-regarding actions.[20] It makes a similar distinction between the *production* and the *application* of scientific knowledge. Holding the notion that the self is prior to and unencumbered by scientific knowledge, the pluralist thesis assumes that the influence of scientific knowledge must be exterior to the self, and that any ethical impact of scientific knowledge on the exterior world, if any, would only be materialized through the application of knowledge. Production of scientific knowledge per se affects nobody. Professor Allen Buchanan and his colleagues talk about the colonization of the natural by human beings and the shift of the boundary between what is subject to human control and what is not. But in their mind, the sources that cause such

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[20] *See* JOHN STUART MILL, ON LIBERTY 52 (Edward Alexander ed., Peterborough, Ont: Broadview Press, 1999) (1869) ("The only part of the conduct of any one, for which he is amenable to society, is that which concerns others. In the part which merely concerns himself, his independence is, of right, absolute.").

ethical impacts are human technologies.[21] Similarly, Langdon Winner was concerned with the relation between science and society but only attempted to examine the power of technology in reconstructing social roles and relationships.[22] This understanding of the production of scientific knowledge as merely self-regarding allows the pluralist thesis to safely contain the conflict of diversified moral judgment of scientific knowledge within the domain of individual choices.

But the understanding that any ethical impact of scientific knowledge could only be materialized through application is problematic in view of our discussion in Part I of this dissertation. Indeed, the criticism of the concept of a choosing subject prior to its chosen objects was once made by Professor Tribe some thirty years ago. He argued that the notion of "choices as invariably the *products* rather than the *constituents* of human identity" must be replaced by one that recognizes the "formative influence" of our technologies on who and what we are.[23] Although literally Tribe still talked about the technologies rather than the production of scientific knowledge, his analysis is useful to our case here. Tribe made use of a distinction between the "self-forming type" of human behavior, which interest-maximizing offers no assistance, and the "operational" type of human behavior, as to which interest-maximizing is perfectly appropriate and fully

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[21] *See* ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS & JUSTICE 83 (New York: Cambridge Univ. Press, 2000).

[22] *See* LANGDON WINNER, THE WHALE AND THE REACTOR: A SEARCH FOR LIMITS IN AN AGE OF HIGH TECHNOLOGY 13 (Chicago: Univ. of California Press, 1986).

[23] Tribe, *supra* note 2, at 618, 650-55 (emphases in original).

adequate. He asserted that every human action is at once both operational (or instrumental) and self-forming (or constitutive).[24]

I suspect that the essence of Tribe's claim is correct, but what he asserted is indeed a factual question, which needs evidence to support its truth. We might imagine that some human actions are constitutive but some are non-constitutive or at least less constitutive. Similarly, the formative influence of some scientific investigation on identity is conspicuous and dominant, some remote and minor. For example, our discussion of the constitutive effects of human genomics shows that it has great influence on self-identity. On the other hand, significant as it is, quantum theory may have little or no bearing on the constitution of self-identity of the public. Tribe himself admitted this point in another place when he discussed the possible limit of the freedom of scientific inquiry: "[T]he *more* one links profound and irreversible shifts in basic conceptions or ideals to a specific area of research, and the less one can accept as realistic the vision of truly decentralized choice on the questions at stake, the stronger becomes the argument for a collective, society-wide decision (one that would indeed have to be world-wide in order to be effective) to suspend, or even to phase out altogether, an avenue of inquiry."[25] Although Tribe did not himself provide evidence to beef up his factual claim, nor did he identify and elucidate the possible mechanism through which a specific human action can constitute self identity, to the extent that such a factual claim is provable or at least

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[24] *See id.* at 635.

[25] LAURENCE H. TRIBE, AMERICAN CONSTITUTIONAL LAW 1321 (Mineola, NY: Foundation Press, 1988) (footnotes omitted) (emphasis added).

falsifiable, Tribe's account helps to explain why there might be a morally significant dimension to the production of scientific knowledge whose disposition should not be credulously delegated to the domain of individual choice.

This understanding suggests that we stop using the distinction between the production and the application of scientific knowledge in determining the existence of ethical impacts of science. It also suggests that the meaning of other-regarding actions not be confined exclusively to the notion of *external harm* to others, if the constitutive effect of the production of science and that of the application is to be equitably recognized. To reach the ethical depth of science regulation we need first to accept that only those human actions that do not pose external harm to others nor have great constitutive effect on identity formation can be safely termed as self-regarding, which summon no public scrutiny about their moral value. On the other hand, although traditionally reserved exclusively for individual choice, those human actions that pose great constitutive effects on self-identity are *formative projects*,[26] which should concern a society as a whole whether they are state-funded or not. Here we have a domain with shared jurisdiction of individuals and society.

The understanding that the moral value of the formative influence of scientific knowledge (both its production and its application) should not be liberally priced in the domain of individual choices, however, does not itself provide enough grounds to refute

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[26] For the notion of a "formative project," see *supra* note 2 of Chapter 3 and accompanying text.

the second claim of the pluralist thesis, which contradicts the possibility of a consensus on the substantive standard for value judgment in a pluralistic society. In other words, even if we can get people to agree on shared jurisdiction of individuals and a society over the morality of formative influence on self-identity, it seems the latter still lacks the necessary by-laws to run the parish. The understanding of the constitutive effects of scientific knowledge on identity surely illuminates the need to deliberate collectively the question of "what sort of people we want ourselves to become."

But what substantive standard can a society employ to judge the moral value of the sort of people particular scientific knowledge produces without damaging the foundation of a pluralistic society at the same time? Won't it become a pathetic situation in which Michael wants the sort of people to be constituted to have a preference for sports, while Laura wants it to be constituted to like reading more? Doesn't opening the door for public scrutiny of scientific knowledge risk inviting too many ideological quarrels into the public sphere? To avoid a similar dilemma, moral philosophers have tried to base their arguments for morality on something objective and universal, something that transcends subjective penchant. One such allegedly objective ground on which secular moral philosophers are especially fond to establish their value claims is the answer to the question "what it means to be a human being," that often is the notion of a universal human nature or humanity. As we have seen, many people who are not satisfied with the instrumental-libertarian approach to the morality of the human genetic engineering (HGE) are quick to resort to the notion of some essential human quality in various ways to back their cases.[27] It is not uncommon to find arguments such as that the technologies that human genomics makes possible threaten to change the "popular ways of viewing human nature," or to wreck so-called "human dignity," or to bring about the "eventual disappearance of human," or to disrupt "the unity or the continuity of human lineage." Setting aside their persistent failure to relinquish the distinction between the production and the application of scientific knowledge, their cases suggest that one might expect the concept of human nature to place constraints on formative projects once the constitutive effects of scientific knowledge are readily recognized.

But resorting to the notion of human essence for moral guidance is not without discontent. There are at least two programs challenging the relevancy of answering "what is our nature" to the question of morality. The first program is an age-old debate over the so-called "naturalistic fallacy." The theme of the naturalistic fallacy charges that one should not derive an "ought" argument from an "is" statement. Because the concept of human nature is merely a claim about facts, to derive normative ethics from it commits the naturalistic fallacy. Since G. E. Moore first used the term in 1903, it has drawn lots of academic energy in debating the validity of a naturalistic approach to ethics.[28] A now

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[27] *See, e.g.*, BUCHANAN ET AL., *supra* 21, at 93-94 ("[T]he possibility of fundamentally reengineering human beings presents a profound and disturbing challenge to the traditional idea that a theory of justice must be based on a (fixed) conception of human nature."); Thomas H. Murray, *Ethical Issues in Human Genome Research*, 5 FASEB J. 55 (1991); E. Donald Elliott, *The Genome and the Law: Should Increased Genetic Knowledge Change the Law?*, 25 HARV. J.L. & PUB. POL'Y 61 (2001); Edmund D. Pellegrino, *The Human Genome Project: The Central Ethical Challenge*, 13 ST. THOMAS L. REV. 815 (2001).

[28] "Naturalistic fallacy" refers to Moore's criticism in PRINCIPIA ETHICA of Herbert Spencer's evolutionary ethics, which generally refers to attempts to use the theory of evolution to study the questions

familiar counterargument to this charge is that the gap between the “is” and the “ought” is bridged by the goals and ends that human beings set for themselves and that are reflected in the intermediate concepts such as wanting, needing, desiring, pleasure, happiness, and health. Though knowledge about human nature never dictates the full content of morality in a logically a priori way, it nevertheless is relevant.[29] Unless one tries to deduce the full content of moral rules from human nature,[30] many people think the charge of naturalistic fallacy is itself fallacious and leaves intact the project of grounding morality on human nature.[31]

The second and fiercer program challenging the relevancy of human nature to morality does not attack the link between the two but questions the privileged status of human nature. This theme is motivated by the unmitigated success of modern human science, including human genomics. As more and more aspects of human life are accounted for by biomedical knowledge, it is not surprising that some see scientific

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of morality. Moore’s theme indeed had been made a century and a half earlier by David Hume in A TREATIE OF HUMAN NATURE. *See* PETER SINGER, A DARWINIAN LEFT: POLITICS, EVOLUTION AND COOPERATION 12-18 (London: Weidenfeld & Nicolson, 1999); Michel Ruse, *Evolutionary Ethics in the Twentieth Century: Julian Sorell Huxley and George Gaylord Simpson*, *in* BIOLOGY AND THE FOUNDATION OF ETHICS 198, 198-99 (Jane Maienschein & Michael Ruse eds., Cambridge, UK: Cambridge Univ. Press, 1999).

[29] *See* FRANCIS FUKUYAMA, OUR POSTHUMAN FUTURE 115 (New York: Farrar, Straus & Giroux, 2002).

[30] *See* PAUL EHRLICH, HUMAN NATURES: GENES, CULTURES, AND THE HUMAN PROSPECT 309 (Washington, DC: Island Press for Shearwater Books, 2000) (arguing that human nature gives no guidance as to what human values should be). *See also* BUCHANAN ET AL., *supra* note 21, 93.

[31] *But see* Peter G. Woolcock, *The Case Against Evolutionary Ethics Today*, *in* BIOLOGY AND THE FOUNDATION OF ETHICS, *supra* note 28, at 276.

investigation of the human body, such as the Human Genome Project's attempt to decode the three billion base pairs, as giving a *necessary* and *sufficient* answer to "what it means to be a human being." This now rather popular way of understanding human nature in purely biological and reductionist terms is largely the product of modern human science that has its roots in eighteenth-century scientism, which has given an inflated trust in the efficacy of the methods of natural science applied to all areas of human investigation.[32] Under this scientistic framework, the ultimate answer to "what it means to be a human being" lies in the reductionist methods of those disciplines such as molecular biology, biochemistry, biophysics and neuroscience.[33] Metaphysics, such as Kant's system of transcendental philosophy, which presumes "practical reason" as the true nature of human, and traditional utilitarian crude empiricism, which depicts a simple interest-seeking human nature, is at best pseudo-science and offers no real insight to the inquiry.

The attempt to view humanity through a reductionist lens does not stop at a lower primitive level. It goes with the stream of the traditional body/mind dualism, which tends to see a human soul as a necessary component of human nature, to touch on higher-order behaviors such as moral thinking that the human soul is thought to embody. The mind or soul is reduced to the brain and then to its reductionist parts, which are thought to be subject to the rules of natural sciences. Sociobiologist Edward O. Wilson, extrapolating

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[32] *See, e.g.*, EDWARD O. WILSON, ON HUMAN NATURE (Cambridge, MA: Harvard Univ. Press, 1978); Michael Ruse & Edward O. Wilson, *Moral Philosophy as Applied Science*, 61 PHIL. 173 (1986).

[33] *See, e.g.*, STEVEN PINKER, THE BLANK SLATE: THE MODERN DENIAL OF HUMAN NATURE (New York: Viking, 2002).

from the theory of evolutionary biology,[34] even tries to ground the answer to human nature on a biological understanding of human culture as a factor of gene/culture coevolution. For Wilson, natural selection determines the gene evolution, which in turns prescribes the regularities of sensory perception and mental development that animate and channel the acquisition of human culture. Culture, as a form of evolutionary pressure, further helps to determine which of the prescribing genes survive and multiply from one generation to the next.[35] Human nature so understood is not any ahistorical quality but the snapshot of human species taken in form of genome sequence at one particular moment out of prolonged evolutionary time spanning some 100,000 years. What came before and what comes after might be different. Human nature as such lacks the unchanging quality that makes it inherently good and worth protecting, and surely does not have special status as guidance to morality. We might say that the naturalistic/reductionist approach deprives human nature of its halo after the authority of metaphysics that conferred the eminence was usurped. If this is the case, the concept of human nature is incapable of imposing any constraint on how the HGE would manipulate the material basis of human beings, let alone the formative influence of scientific knowledge on self identify that we are concerned with here.

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[34] For a discussion about whether evolutionary theory is a scientific theory, see David L. Hull, *The Use and Abuse of Sir Karl Popper*, 14 BIOLOGY & PHIL. 481 (1999).

[35] *See* EDWARD O. WILSON, CONSILIENCE: THE UNITY OF KNOWLEDGE 157 (New YORK: Alfred A. Knopf, 1998). *See also* CHARLES J. LUMSDEN & EDWARD O. WILSON, GENES, MIND, AND CULTURE 343-62 (Cambridge, MA: Harvard Univ. Press, 1981).

The naturalistic/reductionist approach to human nature, however, has been criticized as mistaking method for reality. Reductionism as a methodological strategy is responsible for a great deal of the advancement of the natural sciences. It nonetheless should never be taken as the ontological reality itself.[36] Some seek to save the concept of human nature from a purely positivist view by suggesting that there is still something more than the aggregation of chemical materials to be a human being. Biological basis is a necessary part of human nature, but it is not sufficient to understand the essential human qualities in purely reductionist terms. One characteristic example of the band is Professor Francis Fukuyama's "Factor X" thesis. Fukuyama makes the distinction between simple parts and complex wholes, between what the reductionist approach is good at and when reductionist approach is of little help. He believes that human traits and behaviors that make up a human essence involve nonlinear complex systems that cannot be fully understood by analyzing their simpler composing parts. "There is no simple predictive model that allows us to move from the parts to the emergent behaviors of the wholes."[37] His investigation of biotechnological manipulation of human beings brings him to a conclusion that biotechnological alteration of the material basis of human beings may well move us into a "posthuman" stage of history. His posthumanity worry, however, touches on the potential impact of biotechnology on some ineffable human qualities that Fukuyama dubs "Factor X." Such human qualities are what remains underneath that are

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[36] *See* Hwa Yol Jung, *Edward O. Wilson's Theory of Consilience: A Hermeneutical Critique*, 25 INT'L J PUB. ADMIN. 1171, 1182 (2002).

[37] *See* FUKUYAMA, *supra* note 29, at 163.

worthy of a certain minimal level of respect "when we strip all of a person's contingent and accidental characteristics away," and "what gives us dignity and a moral status higher than that of other living creatures."[38] Fukuyama argues that his "Factor X" cannot be reduced to "the possession of moral choice, or reason, or language, or sociability, or sentience, or emotions, or consciousness, or any other quality that has been put forth as a ground for human dignity. It is all of these qualities coming together in a human whole that make up Factor X."[39] This "Factor X," rather than the material basis of human beings that Fukuyama terms "human nature," is what he really thinks of the answer to "what it means to be a human being." For Fukuyama, modern human science does have a say about what is a human being, but it does not provide a sufficient answer, nor does it make the notion of a human essence obsolete.

Is Professor Fukuyama's treatment of "Factor X" helpful in our quest of substantive norms of science regulation? Is human nature useful in our search for a substantive standard to judge the moral value of formative projects of human genomics and the HGE in constituting identity? Is the talk of "what it means to be a human being" really necessary in public deliberation of "what sort of people we want ourselves to become" if any substantive standard is to be set? Fukuyama himself firmly believes that the concept of a human essence is indispensable in an era when God no longer places constraints on those people who might accord their fellow humans less respect or treat their fellow

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[38] *See id*. at 149, 171.

[39] *Id*. at 171.

humans as they treat—cook, eat, torture, enslave, or render the carcass of—other species of animals. The concept of a human essence defines a boundary within which violation of equality of respect can be legitimately condemned as a "crime against humanity."[40] Forgoing the notion of a human essence risks losing the grip of embracing all members of human species in one moral community that accords everybody human dignity and equal respect. Without the notion of a human essence, Fukuyama fears, one wouldn't know why immigrants from southern Europe with smaller head sizes, blacks who used to be slaves, and gays with sexual orientation differing from heterosexual norms "are people too."

For Fukuyama, the direst threat of biotechnologies hence comes from the possible though speculative scenario in which some but not all people obtain the uses of the HGE to alter their material basis to a point that they break off from the rest of the human race to form a separate race.[41] From this perspective, what the emergence of a new genetic class portends is not just a widening gap between the haves and the have-nots that exacerbates the existing inequality, as already has been envisioned by many,[42] but the

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[40] *See id.* at 150, 155

[41] *See id.* at 154, 158-60.

[42] *See* LEE M. SILVER, REMAKING EDEN: CLONING AND BEYOND IN A BRAVE NEW WORLD 4-8 (New York: Avon Books, 2nd ed. 1998); KASS ET AL., *supra* note 2, 281-83; Audrey R. Chapman, *The Implications of Inheritable Genetic Modifications for Justice, in* DESIGNING OUR DESCENDANTS 130, 141-44 (Audrey R. Chapman & Mark S. Frankel eds., Baltimore, MD: The Johns Hopkins Univ. Press, 2003); Maxwell H. Mehlman, *Access to the Genome and Federal Entitlement Programs, in* THE HUMAN GENOME PROJECT AND THE FUTURE OF HEALTH CARE 113, 127 (Thomas H. Murray et al. eds., Bloomington, IN: Indiana Univ. Press, 1996).

complete loss of people’s ability to reason that “they are people too.” This gives the ground for Fukuyama to discriminate between those technological advances that promote human flourishing, and those that pose a threat to the human essence, or his “Factor X,” and justifies the claim that the state should be involved in the distribution of biotechnology resources to make sure that no one within the family of human species falls outside of it.

Arguably, Fukuyama’s thesis concerns more about equal access or equal application of biotechnology than about the permissibility of altering the human essence itself. Fukuyama does use the language “we want to protect the full range of our complex, evolved natures against attempts at *self-modification*. We do not want to disrupt either *the unity or the continuity of human nature*….”[43] But I cannot see how he is able to infer this assertion from his earlier reasoning. A more consistent analysis of Fukuyama’s own thesis only allows one to claim that even though biotechnology that threatens to alter “Factor X” signifies the need of public concerns, it is not the alteration of human essence per se but the unequal distribution of this alteration among current members of human species that causes the possible trouble of the deterioration of equality of respect that worries Fukuyama. The solution to this undesirable outcome lies in the proper implementation of distributive justice[44] rather than a commandment against humans’ attempts to seize control of their own evolutionary future. So, if integrity of Fukuyama’s

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[43] FUKUYAMA, *supra* note 29, at 172 (emphases added).

[44] *See also* BUCHANAN, *supra* note 21, at 61-82; Chapman, *supra* note 42, at 146-50.

"Factor X" does not on its own force determine the permissible range of biotechnological application, it does not on its own force constitute the limitation on formative projects of human genomics and the HGE constituting self identity either. If the only meaningful constraint on biotechnological manipulation of the human essence is the equal distribution of manipulation result, it offers absolutely no guidance to what sort of people (materially or not) we should not produce.

Fukuyama's case seems to be just another example of a failed attempt to derive from the notion of human nature moral constraints on formative influence of human genomics and the HGE on identity, or at least on biotechnological manipulation of the material basis of human beings. But the real problem with deriving moral constraints from "what it means to be a human being" in a pluralistic society is less about whether human nature has been deprived of a privileged status by modern science, or about the reservation that morality so derived might be the fruit of the naturalistic fallacy. The real problem is more that grounding the answer to "what do we want to become" on "what it means to be a human being" is not as politically useful as some, like Fukuyama, would like to think it is in achieving consensus that is necessary for social solidarity. And quite the reverse, it actually is detrimental to the very basis of liberal democracy.

The question "what it means to be a human being" brings invariably a closure to the open-ended imagination of "what do we want to become," but brings with it the sometimes arbitrary and sometimes violent exclusiveness.[45] Professor Daniel J. Kevles

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[45] People constantly disagree on the concepts of human nature. *See, e.g.*, Seth Eben Shapiro, *A Vote*

suggests in his comment on Fukuyama's posthumanity thesis that Fukuyama selects "sociobiological characteristics as constitutive of human nature that are consistent with democratic capitalism, whereas ignoring those—for example, tribalism, submissiveness to authority, and the subordination of women to reproduction—that seem to make large parts of the world decidedly resistant to the freedom and political structures of the West."[46] The selectivity involved in defining "what it means to be a human being," although it might not be arbitrary in theory, is always exclusive in practice. Such a practice of exclusion hinders consensus and social cooperation in a pluralistic society from being built. What is it to be a human being? To be smart? How about someone in coma? To be intelligent? How about newborns? To be bipedal and be able to survive in an ever changing environment? How about the disabled? To be able to do math and play chess? To be artistic and creative? To be humorous?[47] No matter how we define human beings, somebody is excluded from the classification. Fukuyama tries to avoid this obstacle by asserting that any boundary narrower than one that can cover the whole human race is suspicious of being erroneously or irrationally drawn. Setting aside a

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for "Posthumanity," N.Y. TIMES, April 9, 2002, F10 ("Dr. Fukuyama...seems to think that there is a definition of "human nature" so mystical that alteration must by definition be negative. I, having accepted years ago that his definition excludes me, propose that perhaps a little posthumanity may be just what earth needs to survive.").

[46] Daniel J. Kevles, *Meddling with Human Nature: The Political Outcomes of Biotechnology*, 286 SCI. AM. 99, 100 (2002) (book review).

[47] These questions were posed by Professor Anne Foerst in her presentation "Human and Non-Human Persons: A New Concept of Ethics for the Technological Age" in the colloquium "Technology and the Human Person" held by the University of Virginia's Institute for Advanced Studies in Culture in 2002.

possible inconsistence between this minimalist position and his all-encompassing "Factor X," knowledge of the human essence does not get those who think sodomy an abomination more likely to think that "there is [something] more essential to being a human being than displaying a proper abhorrence of 'unnatural acts'."[48] Nor does knowledge of the human essence make the idea of gay marriage less morally repugnant to those who think it ravages a sacred institution between a man and a woman.[49] Similarly, the belief that *all men* are endowed by their creator with certain inalienable rights did not prevent Thomas Jefferson from owning slaves, for the mind of blacks, like that of animals, "participates more of sensation than of reflection;"[50] Serbs do not think of themselves as committing a crime against humanity when they forced a Muslim to bite off the penis of a fellow-Muslim, since they do not think they are doing it to their fellow

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[48] Richard Rorty, *When Philosophy is Irrelevant*, 85 NEW LEADER, May-June 2002, at 19, 20 (reviewing FRANCIS FUKUYAMA, OUR POSTHUMAN FUTURE (New York: Farrar, Straus & Giroux, 2002)).

[49] *See* President's Statement on the Decision of the Massachusetts Supreme Judicial Court on Same-Sex Marriage, 40 WEEKLY COMP. PRES. DOC. PRES. DOC. 191 (FEB. 9, 2004) ("Marriage is a sacred institution between a man and a woman. If activist judges insist on redefining marriage by court order, the only alternative will be the constitutional process. We must do what is legally necessary to defend the sanctity of marriage.").

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> In general, their existence appears to participate more of sensation than reflection. To this must be ascribed their disposition to sleep when abstracted from their diversions, and unemployed in labor. An animal whose body is at rest, and who does not reflect must be disposed to sleep of course. Comparing them by their faculties of memory, reason, and imagination, it appears to me that in memory they are equal to the whites; in reason much inferior, as I think one could scarcely be found capable of tracing and comprehending the investigations of Euclid; and that in imagination they are dull, tasteless, and anomalous.

THOMAS JEFFERSON, NOTES ON VIRGINIA, *in* 2 THE WRITINGS OF THOMAS JEFFERSON 194 (Albert Ellery Bergh ed., Charlottesville, VA: Univ. of Virginia Library, 1993) (1853).

human beings, but to Muslims;[51] the airline hijackers who launched suicide attacks saw themselves waging a holy war against "the devil," and we probably do not think they are "people like us," either.[52]

Fukuyama's concerns about the impact of biotechnology on social solidarity is worthy of appreciation. He is worried that in "our posthuman future," a splitting-up of human race resulting from unequal alteration of human material basis among people would obliterate the knowledge of being a same biological species, which, he thinks, is the guarantee for equal membership in a moral community. But "in our human present" no aforementioned misfortune occurred because of lacking knowledge of some little commonalities between men and women, white and black, believers and heathens, straights and gays. They occurred rather as the result of a sort of self-identity that tells people "who they are not"—"*not* an infidel, *not* a queer, *not* a woman, *not* an untouchable."[53] For Fukuyama, a moral progress evolving from holding such an irrational sense to reasoning "they are people too" consists of a growing awareness of our common humanity. But how irrational could they be if their identity has been so constituted? And what is the use of the concept of a human essence to those who think it is too risky or insanely dangerous to let one's sense of moral community stretch beyond people like us

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[51] The story is cited by Richard Rorty from David Rieff, *Letters from Bosnia*, NEW YORKER, NOV. 23, 1992, at 82-95, in RICHARD RORTY, *Human Rights, Rationality, and Sentimentality*, *in* TRUTH AND PROGRESS 167, 167 (Cambridge, UK: Cambridge Univ. Press, 1998).

[52] *See* Edward Said, *Terror in America*, OBSERVER, Sep. 16, 2001, Spec. Supplement, at 27 (arguing that the banners of "Islam" and "the West" are imaginary threshold that separates people from each other).

[53] RORTY, *supra* note 51, at 178 (emphases original).

to cover people who we are not? Dwelling on the concept of human essence as the only adhesive force that binds people together in a moral community very often ends up in people wielding their own banner of identity as the proof of membership in the moral community, and indeed prevents them from taking up and formulating a response to the real challenge of "what sort of people we want to become." Insisting on discovering a human essence actually impairs our imaginative power, which is all that is needed to make the particular little things that divide "people like us" and "people who we are not" seem unimportant.[54]

If that is the case, the substantive standard that we are searching for to evaluate the formative influence of human genomics and the HGE on identity in a pluralistic society should not be supplied by any answer to "what it means to be a human being." Instead, we should only be worried about the danger of those formative projects constituting a less flexible identity, whose unwillingness to expand its boundary has been the source of human misfortunes in history. As far as the application of the HGE is concerned, this substantive standard is sympathetic to Professor Fukuyama's concern about the emergence of a genetic class and the deterioration of equality of respect as a result. It is so not because the disappearance of a common biological membership threatens the concept of a human essence, but because the formative influence of the HGE used in such a manner would render the constitution of a more flexible identity virtually impossible.

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[54] *See* RICHARD RORTY, *Ethics Without Principles, in* PHILOSOPHY AND SOCIAL HOPE 87 (New York: Penguin Books, 1999).

On the other hand, this substantive standard in the context of the production of human genomics would suggest that we reject all the other moral concerns similar to what would stem from a notion of human nature, such as “playing God” or the “sanctity of human genome,” and keep a minimalist stance on “what kind of people we should not constitute.” Such a minimalist stance would not only be consistent with the demand of liberal pluralism but also be protective of the very foundation of a pluralistic society in a postgenomics era.

Before we proceed to the next section, one final point should be made clear. Although similar in tone and appearance to legal moralism that would proscribe offenses to the public’s moral sentiments for the purpose of protecting “social cohesion,”[55] the substantive standard that I just elaborated is significantly different in quality from that position. Legal moralism is indeed indifferent to the substantive merit of morality involved,[56] whereas the minimalist stance would take that a more flexible identity is always better than a rigid one. The maintenance of “social cohesion” is a direct goal of legal moralism, whereas “social solidarity” is an incidental product of a more flexible identity. Such a distinction is crucial because legal moralism incurs controversial metaphysical claims, whereas the minimalist stance seeks as few answers to substantial

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[55] *See, e.g.*, PATRICK B DEVLIN, THE ENFORCEMENT OF MORALS 13-14 (New York: Oxford Univ. Press, 1965) (“There is disintegration when on common morality is observed…, so that society is justified in taking the same steps to preserve its moral code as it does to preserve its government and other essential institutions.”); Robert P. George, *The Concept of Public Morality* 45 AM. J. JURIS. 17 (2000).

[56] *See* DEVLIN, *supra* note 55, at 94 (“I have said that a sense of right and wrong is necessary for the life of community. It is not necessary that their appreciation of right and wrong…should be correct.”).

moral questions as possible. We can and should talk about the moral value of formative effects of human genomics because they inevitably affect our ethical environment. Our moral concerns of formative effects, however, could be consistent with liberal pluralism only to the extent that we adopt only a minimalist stance and no more.

7.3 Reinterpreting Privacy as a Compelling Government Interest

If we need to translate the idea of such substantive norms into real practice, we must further identify the legal rhetoric or doctrine that is capable of bearing the weight of the substantive norms that shore up the case of regulating the scientific enterprise in face of the allegation of violating freedom of scientific inquiry. That is, we need to address the question of how we are to translate the moral concern for identity formation into some kind of "compelling government interest" that justifies the regulation of the scientific enterprise. This way of orienting the question at first glance appears as though it is an overt First Amendment issue pertaining to freedom of scientific inquiry. A more promising approach to this task, however, hints at a less taken avenue toward a project of aligning the concept of privacy rights[57] with the moral concern of identity formation.

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[57] For quite a while, many scholars thought that "privacy" in its paradigmatic uses referring to restricted access to persons and personal information is not a proper synonym for "liberty as autonomy." *See*, *e.g.*, Ruth Gavison, *Privacy and the Limits of Law*, 89 YALE L.J. 421, 428, 438-39 (1980). It is now a common place to accept that the concept of privacy or, more specifically, decisional privacy covers the traditional areas concerning autonomy, liberty, and freedom. *See* ANITA ALLEN, UNEASY ACCESS: PRIVACY FOR WOMEN IN A FREE SOCIETY 33-34 (Totowa, NJ: Rowman & Littlefield, 1988). Some others also try to link the concern of informational privacy and that of decisional privacy under a united scheme, such as "the integrity of one's personhood or identity." *See*, *e.g.*, Jonathan Kahn, *Privacy as a Legal Principle of*

Aside from the debate over whether the privacy right first enunciated in *Griswold* and further expanded in *Roe* is now recognized as a fundamental right or a mere liberty interest to be weighed and balanced against the legitimate governmental interest,[58] the most articulate legal exposition of the concept of the (decisional) privacy right is now widely regarded to be expressed by Justices O'Connor, Kennedy and Souter in their joint opinion in *Planned Parenthood of Southeastern Pennsylvania v. Casey*.[59] Privacy rights, they said, "involv[e] the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy…. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of

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Identity Maintenance, 33 SETON HALL L. REV. 371, 386-88 (2003).

[58] The constitutional right to privacy was first found to "emanate" from the "penumbras" of the Bill of Rights. The language of "penumbras," instead of "liberty," was deliberately used to avoid the suspicion of judicial lawmaking historically associated with the substantive due process jurisprudence of *Lochnerism*. Privacy rights so constructed are thought not only to reflect the core value of the Bill of Rights but also to enjoy automatically the same fundamental status of those rights, the restrictions of which call for the most arduous standard of judicial review—strict scrutiny. The fundamental-right status of the privacy began to wane in the 1980s and died out eventually. *See* Bowers v. Hardwick, 478 U.S. 186, 191-93 (1986), *overruled by* Lawrence v. Texas, 123 S. Ct. 2472 (2003); Cruzan v. Director, Missouri Department of Health, 497 U.S. 261, 279 (1990); Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 874 (1992). The language of "penumbras" has become rarely used and been substituted with "liberty interests." *See* Anita L. Allen, *Autonomy's Magic Wand: Abortion and Constitutional Interpretation*, 72 B.U. L. REV. 683 (1992). Alternatively, substantive due process doctrine was again invoked to explicate the privacy right as personal "liberty" protected in the Due Process Clause of the Fourteenth Amendment. This development deprives the decisional privacy of its automatic "fundamental" status and makes possible the subjection of state interventions to less stringent standard of judicial review.

[59] 505 U.S. 833 (1992).

personhood were they formed under compulsion of the State."[60] This eloquent paragraph reflects exactly the philosophical thinking of what legal scholars usually term as the personhood thesis,[61] consisting of both a descriptive theory of selfhood and a normative judgment of the values justifying specific claims about privacy rights.[62]

The descriptive prong of the personhood thesis is a familiar voluntarist account of the selfhood, positing that selfhood or personal identity is something that persons are able to define for themselves in the absence of external interference with certain conducts, roles, values and relationships they choose to undertake, to play, to espouse and to enter. This factual proposition implies two separate but closely related dimensions of a person. The interior domain concerns the necessary condition for the full realization of one's distinct personhood. This necessary condition is thought to be associated with the

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[60] *Id*. at 851.

[61] *See* Jed Rubenfeld, *The Right of Privacy*, 102 HARV. L. REV. 737, 753 (1989). *See also* TRIBE, *supra* note 25, §15-3 (discussing "right of personhood"); J. Braxton Craven, Jr., *Personhood: The Right to Be Let Alone* 1976 DUKE L.J. 699, 706; Lois Shepherd, *Looking Forward with the Right of Privacy*, 49 U. KAN. L. REV. 251, 268 (2001).

[62] *Cf.* Robert C. Post, *Rereading Warren and Brandeis: Privacy, Property, and Appropriation*, 41 CASE W. RES. L. REV. 647, 650-53 (1991). In his analysis of Warren and Brandeis' article, Samuel D. Warren & Louis D. Brandeis, *The Right to Privacy*, 4 HARV. L. REV. 193 (1890), Professor Post makes a distinction between "descriptive privacy" and "normative privacy." Although his account of descriptive privacy offers a factual proposition about personality as "an amalgam of [some] empirically ascertainable states," his account also contains a prescriptive element. On the other hand, Post's normative privacy, in addition to its prescriptive element, also presupposes a descriptive theory about how a person is socialized to certain forms of respect. The difference between Post's descriptive privacy and normative privacy is actually at the level of justification. While the harm to Post's normative privacy is understood as to *morally* transgress "the forms of respect that we owe to each other as members of a common community," the harm to his descriptive privacy is to *empirically* cause "mental pain and distress."

maintenance of an unfettered domain, in which one can articulate and develop one's self-identity,[63] find meaning in one's life,[64] or pursue human flourishing and perfection.[65] By contrast, in the exterior domain, certain behaviors and activities are so intimately linked to one's selfhood that decisions about them are considered to fall within the realm, the intrusion of which would thwart the full realization of one's personhood.

It is true that, despite the fact that the legal concept of liberty deals primarily with the socially permissible boundary of exterior behaviors, the consideration of the interior domain has always been the focus of the liberal tradition. The distinction between "liberty as license" and "liberty as independence" made by Professor Ronald Dworkin and the essential status he accords to the latter in liberalism speak volumes for the point. Dworkin understands "liberty as license" as "the degree to which a person is free from social or legal constraint to *do* what he might wish to do."[66] "Liberty as independence" is less about the boundary of behaviors than about the condition of independent

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[63] *See* Jeffrey H. Reiman, *Privacy, Intimacy and Personhood*, 6 PHIL. & PUB. AFF. 26, 39 (1976) (considering a person's exclusive right to shape his or her own destiny to be necessary to the creation of selves out of human beings).

[64] *See* Shepherd, *supra* note 61, at 301-8 (arguing that at the heart of privacy right is the opportunity to find meaning in one's life to determine one's future rather than the self-expression of some static identity).

[65] *See* Aaron J. Rappaport, *Beyond Personhood and Autonomy: Moral Theory and the Premises of Privacy*, 2001 UTAH L. REV. 441, 454-59 (arguing that the moral premise of privacy right is the protection of individual's opportunities for perfection, defined as the pursuit of the ideal of the good life, flourishing, or simply happiness).

[66] RONALD DWORKIN, *Liberty and Liberalism, in* TAKING RIGHTS SERIOUSLY 259, 262 (Cambridge, MA: Harvard Univ. Press, 1977) (emphasis added).

personality—it is about "the status of a person as independent and equal rather than subservient."[67] The constraints on "liberty as license" occur whenever prescriptive law prevents people from engaging in an activity, be it walking or murdering. However, the constraints on "liberty as license" do not necessarily infringe on "liberty as independence," but sometimes serve as necessary protection of the latter. Dworkin believes that people do not have a general right to "liberty as license." For him, it is the concept of "liberty as independence" that Mill tried painstakingly to make available for the liberal political theory.[68] He ultimately makes the proposition that any given "right to liberty as license"—for example liberty of free speech and freedom of religion—is justifiable and its constraint objectionable only when the concept of "liberty as independence" can be shown to require such a right.[69] For Dworkin, the link to the interior domain is the most robust ground that justifies claims to liberty in the exterior domain.

But, at least in constitutional jurisprudence, no liberty right like privacy places so much emphasis on the interior domain and relies so explicitly on the interior domain to determine the substance of its exterior domain that some people would take privacy as indeed the concept of "liberty as independence" itself. If this is the case, privacy then becomes the common basis of all "liberties as license" and resides exactly in the

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[67] *Id*.

[68] *Id*. at 263-64.

[69] *See* RONALD DWORKIN, *What Rights Do We Have?, in* DWORKIN, *supra* note 66, at 266, 273-74.

"penumbras" of the Bill of Rights. It is less clear, however, how to determine what, in addition to those clearly enumerated, would "emanate" from such a concept of privacy with respect to the exterior domain. Justice Scalia's dissent in *Casey* points out this potential difficulty. He argues that the concept "central to personal dignity and autonomy" could just as easily have described "homosexual sodomy, polygamy, adult incest, and suicide, all of which are equally 'intimate' and 'deep[ly] personal' decisions involving 'personal autonomy and bodily integrity'…."[70] This seems to pose a great challenge to the task of making a consistent normative judgment of the values justifying specific "liberty as license" claims based on privacy as "liberty as independence." Why do privacy rights extend to interracial marriage[71] but not same-sex marriage or polygamy, to contraception[72] but not adultery, to the withdrawal of life-sustaining treatment,[73] but not to physician-assisted suicide?[74]

One result of this challenge is an increasingly popular stance in constitutional jurisprudence to reject the idea of deducing directly the claim to specific "liberty as

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[70] Planned Parenthood of Southeastern Pennsylvania v. Casey, 505 U.S. 833, 983-84 (1992) (Scalia, J., concurring in the judgment in part and dissenting in part) (alteration in original).

[71] *See* Loving v. Virginia, 388 U.S. 1 (1967).

[72] *See* Griswold v. Connecticut, 381 U.S. 479 (1965); Eisenstadt v. Baird, 405 U.S. 438 (1972); Carey v. Population Serv. Int'l., 431 U.S. 678 (1977).

[73] *See* Cruzan v. Dir., Missouri Dep't Of Health, 497 U.S. 261 (1990); *In re* Quinlan, 70 N.J. 10 (1976).

[74] *See* Washington v. Glucksberg, 521 U.S. 702 (1997).

license" from "liberty as independence."[75] If privacy is of any meaning in constitutional law, this stance believes, it must be a specific claim to "liberty as license" rather than an abstract ideal of "liberty as independence." The thinking explains at least partly the shift from privacy as a fundamental right (liberty as independence) to privacy as a mere liberty interest (liberty as license) to be weighed and balanced against the legitimate governmental interest. It also in the end collapses the two-prong approach of substantive due process doctrine to ascertaining the fundamental status of liberty interests—the autonomy approach and the traditional approach—into one.[76] Chief Justice Rehnquist in *Washington v. Glucksberg*, a case upholding a state law that prohibits physician-assisted suicide, argued that behind those rights and liberties sounding in "personal autonomy" is the fact that they are indeed so "deeply rooted in our Nation's history, legal traditions and practices" that they are protected by the Fourteenth Amendment.[77] Along this line of

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[75] *See, e.g., id.* at 725-27 (arguing that rights and liberties protected by the Due Process Clause were not simply deduced from abstract concepts of personal autonomy, but were instead grounded in the Nation's history and traditions). *See also* Casey, 505 U.S. at 852 (arguing that the considerations of personal autonomy begin the analysis of liberty interests, "but cannot end it, for this reason: though the abortion decision may originate within the zone of conscience and belief, it is more than a philosophic exercise").

[76] *See* Robert C. Post, *Fashioning the Legal Constitution: Culture, Courts, and Law*, 117 HARV. L. REV. 4, 88-93 (2003). Chief Justice Rehnquist calls this synthesized approach an "established method of substantive due process analysis," deeply rooted in "this Nation's history and tradition." *See* Glucksberg, 521 U.S. at 721. *See also* Seth F. Kreimer, *The Second Time as Tragedy: The Assisted Suicide Cases and the Heritage of Roe v. Wade*, 24 HASTINGS CONST. L.Q. 863, 869-75 (1997) (arguing that the "established method" is at odds with Court's another line of cases including *Eisenstadt, Loving, Cruzan,* and *Roe*).

[77] Glucksberg, 521 U.S. at 727 ("That many of the rights and liberties protected by the Due Process Clause sound in personal autonomy does not warrant the sweeping conclusion that any and all important, intimate, and personal decisions are so protected."). Although the language of "so fundamental to our

development, privacy as “liberty as license” is to be identified solely by answering a question of historical fact without engaging in any nasty normative argument. Privacy’s central concerns of the *necessary condition* for the full realization of one’s distinct personhood in the interior domain are thus far largely curtailed, leaving only a voluntarist claim that focuses on free *choices* of behaviors in the exterior.[78]

This development would not be that worrisome if, as generally presumed by the descriptive prong of the personhood thesis, being able to choose to do something in the exterior world were to suffice the necessary condition for the independent personality in the interior domain. It would also be unnecessary to grant the concerns of the interior domain an independent normative value if cutting away all (relevant) external obstacles were to amount to erasing all formative effects on self-identity. It is from the vantage point of recognizing such a discrepancy[79] that Professor Jed Rubenfeld’s anti-totalitarian

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concept of constitutionally ordered liberty” was also used in identifying fundamental rights, *see id*., this prong of the analysis has real meaning only when the right in question has not been consistently rejected throughout the Nation’s history. *See* Kreimer, *supra* note 76, at 875.

[78] *Cf.* Michael J. Sandel, *Moral Argument and Liberal Toleration: Abortion and Homosexuality*, 77 CALIF. L. REV 521, 526-28 (1989) (making a distinction between “normative privacy” that protects “space” and “voluntarist privacy” that protects “choice” and criticizing a shift from the former to the latter). Professor Sandel later elaborated the “new” privacy as protecting choice and “old” privacy as protecting “certain kinds of personal bonds that have played a critical role in the culture and traditions of the Nation by cultivating and transmitting shared ideals and beliefs.” MICHAEL SANDEL, DEMOCRACY’S DISCONTENT 93 (Cambridge, MA: Harvard Univ. Press, 1998) (1996). Sandel’s observation of a shift of emphasis from normative to voluntarist privacy is useful, although his notion of normative privacy is unnecessarily too narrowed.

[79] The discrepancy between the interior and exterior domain that I refer to here does not abide by the distinction between positive liberty and negative liberty Isaiah Berlin made, nor does it implicate the split between a higher (true) self and a lower (false) self. *See supra* text accompanying notes 87-90of Chapter 2.

thesis proposed to substitute the personhood thesis some fifteen years ago should be understood.[80] Drawing on Michel Foucault’s work, Rubenfeld put forward a normative attitude focusing not so much on what the individual is prohibited by state law from doing, not on what is being taken away. He suggested that we should instead focus on what kind of life or self-identity the law imposes upon the individual. For him, the true normative value of privacy is not to save for the individual an “abstract and chimerical” freedom of decision[81] but to prohibit the state from instilling its own preferred identities and to protect one’s life from being “too totally determined by a progressively more normalizing state.”[82]

Rubenfeld’s criticism of the personhood thesis is, however, somewhat ambiguous. He contended that to understand privacy as securing the possibility of engaging in homosexual sex for homosexuals to either express an existing or to develop in future a homosexual identity—an identity defined in opposition to heterosexuality—is to “reproduce the very constraints on identity that [privacy] purports to resist.”[83] Similarly, to understand the conduct of interracial marriage as defining the identity of those who marry out of their race is, he argued, to “repeat the same impulse toward rigid classification presupposing the discrimination sought to be undone.”[84] Focusing on the

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[80] *See* Rubenfeld, *supra* note 61, at 782-92.

[81] *Id*. at 794.

[82] *Id*. at 784.

[83] *Id*. at 779-81.

[84] *Id*. at 781.

danger that the personhood thesis could easily mistake reproducing an existing "repressive identity" in those who seek the protection of privacy for defining themselves, some read Rubenfeld's anti-totalitarian thesis as faulting an overemphasis on identity. They accused Rubenfeld of committing the same flaw when they found that his anti-totalitarian thesis indeed makes use of privacy as a tool to wage resistance in the exactly same identity politics.[85] If, however, Rubenfeld's deepest concern is that removing external constraints on behaviors does not necessarily bring about an interior domain free of formative effects,[86] the significance of self-identity in privacy can never be overemphasized. This latter reading would be more coherent in comprehending Rubenfeld's charge that even if bans on certain conducts—such as homosexual sex, interracial marriage, use of contraception, and abortion—were lifted, conceiving privacy in the way suggested by the personhood thesis, i.e., that freedom of decision secures the

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[85] *See* Shepherd, *supra* note 61, at 275 ("What the anti-totalitarian thesis appears to reject—the emphasis on identity—it instead adopts."). Shepherd accuses Rubenfeld of failing to empathize with the impact of the prohibitory laws on the individual when Rubenfeld advocated a shift of emphasis from "what is prohibited" to "what is forced upon individuals." *Id.* at 277 ("What is critical for the person who wishes to marry someone outside of his own race is not that he is then forced…into marrying within his own race, but that he cannot marry the one he truly desires to marry, the person he loves."). Shepherd's criticism, however, fails to appreciate that Rubenfeld's distinction indeed needs to be read under the light of the distinction between exterior and interior domain that I make here. What Rubenfeld really suggests to us is to explore the impact of "what is prohibited" from the angle of "what is forced upon," rather than a total ignorance of the impact of "what is prohibited." Shepherd's own "meaning thesis," arguing that privacy is to protect the opportunity to find meaning in our lives, *id.* at 301-8, does not really engage the argument that Rubenfeld puts forth here.

[86] Rubenfeld's own account of the difference between his and the personhood thesis is that "[t]he anti-totalitarian right to privacy…prevents the state from imposing on individuals a defined identity, whereas the personhood right to privacy ensures that individuals are free to define their own identities." Rubenfeld, *supra* note 61, at 794.

necessary condition for self-definition, is unable to attend to the real issue of what kind of life or self-identity individuals are constantly being prompted, forced, or encouraged to adopt.

The normative value that Rubenfeld thinks privacy can contribute to the concerns of identity formation needs to be seriously taken considering his descriptive account of the discrepancy between the exterior and the interior domain. His failure to speak unequivocally on whether his normative ideal of privacy expects an interior domain free of any formative effect on self-identity diminishes the contribution that his thesis could have made. Indeed, this ambiguity led him to derive from *Meyer v. Nebraska*[87] and *Pierce v. Society of Sisters*[88] a problematic hermeneutic attitude that opposes the undertaking of formative projects.

In *Meyer*, the Court struck down a state law that prohibited the teaching of “living” foreign languages to schoolchildren. The challenged law was the product of the virulent anti-German sentiment developed as a result of the First World War for fear that the priority of American ideals and interests would be undermined if the children of immigrants were inculcated first with “foreign thinking” and “foreign ideas.”[89] The Court found that the state in *Meyer* went too far in trying to “foster a *homogeneous* people.”[90]

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[87] 262 U.S. 390 (1923).

[88] 268 U.S. 510 (1925).

[89] Meyer, 262 U.S. at 398.

[90] *Id*. at 402 (emphasis added).

Similarly, at issue in *Pierce* was a state law requiring compulsory general attendance at public schools by normal children between the ages of eight and sixteen. Although primarily relying on the analysis resembling other liberty-of-contract cases of the *Lochner* era, Justice McReynolds, the same author of the Court opinion in *Meyer*, enunciated the essence of modern privacy right stating that "[t]he fundamental theory of liberty upon which all governments in this Union repose excludes any general power of the state to *standardize* its children…"[91] Rubenfeld praised *Meyer* and *Pierce* as the "true parents of the privacy doctrine"[92] and rested his case of anti-totalitarian right to privacy on the notion that a democratic polity as which we choose to constitute ourselves, by definition, rejects a totalitarian government that seeks to "inform[], shape[], direct[], and occup[y] the actual day-to-day activities of the persons concerned.[93] Privacy, he claimed, is to "prevent the state from taking over, or taking undue advantage of, those processes by which individuals are defined in order to produce overly standardized, functional citizens."[94]

The concept of anti-standardization that Rubenfeld derived from *Meyer* and *Pierce* does not, however, lead him to a stance advocating a total prohibition of the undertaking

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[91] Pierce, 268 U.S. at 535 (emphasis added).

[92] Rubenfeld, *supra* note 61, at 743. Many agree with Rubenfeld's reading of *Meyer* and *Pierce*. *See* TRIBE, *supra* note 25, at 1319; RICHARD C. TURKINGTON & ANITA L. ALLEN, PRIVACY LAW 757 (St. Paul, MN: West Group, 2nd ed., 2002).

[93] *Id*. at 794.

[94] *Id*.

of all formative projects. He instead asserts that "[privacy] is to be invoked only where the government threatens to take over or occupy our lives—to exert its power in some way over the totality of our lives."[95] It is at this point that Rubenfeld's anti-totalitarian thesis of privacy quietly diverges from the traditional focus of privacy on the protection of *individual* and becomes the tool of constraining and harnessing the *public authority* to prevent abuse. It also becomes clear that the distinction between the exterior and the interior domain implicitly held by Rubenfeld in his article indeed presents two practical ways to monitor and control state power.

But as Professor Richard Turkington and Professor Anita Allen point out, "curbing government" and "protecting autonomy" are indeed different goals.[96] If "curbing government" is the goal, what the mandate of anti-standardization renders seems to be the mere avoidance of the result of "too much sameness and too much conformity," which can easily, though not without challenge, be achieved by selectively preserving some degree of diversity.[97] If, however, "protecting autonomy," or protecting the necessary condition for the full realization of one's distinct personhood in the interior domain, is the normative goal of privacy, both the meaning of formative projects to self-identity and the concept of anti-standardization that *Meyer* and *Pierce* hint to us need to be carefully reexamined.

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[95] *Id*. at 787.

[96] *See* TURKINGTON & ALLEN, *supra* note 92, at 753.

[97] *See* Shepherd, *supra* note 61, at 276-77.

The normative goal of protecting the interior domain in the sense of maintaining the necessary condition for the full realization of one's distinct personhood brings us back to our earlier discussion of Lacanian theory of identity formation and the concept of imaginary domain in Chapter 3. To recap, under this theory, there is no such thing as identity formation independent of exterior formative effects. Nor is there such a thing as an interior domain free from the influence of formative projects. Self-identity invariably is the reflexive projection overdetermined by the "mirror image" that the Symbolic Other through formative projects has to offer individuals.[98] In this light, if what we care about is the condition of the interior domain, i.e., the removal of the internal barrier to freedom,[99] and if the formative influence is not something that we can live without, the only thing we are left to claim is to ask for the provision of those mirror images that allow more rather than less room for imagination.

Even when it is practically impossible to talk about a condition of identity formation "free" of influence, we are at least able to make a distinction between more reflective and less reflective, freer and less free people. Formative projects that accord a fixed body image as the source of imagination constitute a kind of identity that is less free, in the sense that it is less sensitive to the needs of a variety of people and things and is less willing to expand its selfhood to recreate the concept of *we*. It is less free also in the sense that people so constituted find it less possible to engage in social cooperation, a

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[98] *See supra* text accompanying notes 57-64 of Chapter 3.

[99] *See* Nancy J. Hirschmann, *Toward a Feminist Theory of Freedom*, 24 POLITICAL THEORY 46, 53-54 (1996) (discussing the notion of interior barrier to freedom).

condition necessary to the very possibility of a democratic polity. By contrast, formative projects that accord a more flexible body image would constitute a kind of people freer in the sense that their selfhood is flexible and more responsive to the needs of a larger and larger variety of people and things. They are freer also in the sense that they are more capable of "considering alternative scenarios for their personal futures, and for the future of their societies,"[100] and "more patient, tolerant, and imaginative, and so are better citizens of a democracy."[101] Thus, the harm of "standardization" that concerns *Meyer* and *Pierce*, viewed from this light, is not so much in that it produces "too much sameness and too much conformity," but as it renders our selfhood less flexible.

Rubenfeld's criterion of "total occupation of life" surely is a key index to such an inflexible identity. But as our discussion in Chapter 4 showed, we indeed already live a life "overly informed, shaped, directed and occupied" even without those prescriptive laws that Rubenfeld identified as infringing the anti-totalitarian concept of right to privacy. The problem seems to arise less from the fact that we are too "socially constructed" than the fact that we are constructed in a certain way. Privacy, if we are to maintain a "freer" condition for identity formation, is not a right against legislating morality in general, but a right against legislating those moralities that constitute less flexible selfhood; it is not a right sheltering oneself from state intrusion, but a right to claim more flexible identity being provided in any formative project. Such a concept of

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[100] Richard Rorty, *A Defense of Minimalist Liberalism, in* DEBATING DEMOCRACY'S DISCONTENT 119 (Anita L. Allen & Milton C. Regan, Jr., eds., New York: Oxford Univ. Press, 1998).

[101] *Id.*

privacy cannot be understood from the concept of "positive right"[102] because it is still not an "entitlement right" to basic governmental services.[103] It is, however, not an utter "negative right" because it does affirmatively demand a "freer" condition for identity formation.[104]

Constructing privacy as a right devoted exclusively to the maintenance of a "freer" interior domain for identity formation helps to distinguish the normative judgment

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[102] I shall here clarify a common case of language confusion in legal discourses. When denoting entitlement rights, the term "positive rights" is often used, for it implies a claim on others to provide positive helps, services or resources. Sometime, lawyers even use the term "positive liberty" to stand for "entitlement rights." *See*, *e.g.*, Steven J. Heyman, *The First Duty of Government: Protection, Liberty and the Fourteenth Amendment*, 41 Duke L.J. 507 (1991). However, these "positive rights" or "positive liberties" as entitlement are conceptually different from "positive liberty" in the Berlinian sense. The concept of "positive rights/liberties" as entitlement is not designed to answer the questions of 'How can one obtain self-mastery?' as is "positive liberty." Entitlement rights, to Berlin, can at best be seen as rights to securing the *conditions of liberty*, rather than liberty itself. *See* ISAIAH BERLIN, *Introduction to Four Essays on Liberty*, *in* LIBERTY: INCORPORATING FOUR ESSAYS ON LIBERTY 38, 39, 45-47 (Henry Hardy ed., Oxford: Oxford Univ. Press, 2002) (1969).

[103] In rejecting any individual's entitlements to government assistance, basic services or resources necessary to exercise of a right, contemporary constitutional case law deliberately and ceaselessly stresses that only negative liberty rights are constitutionally recognized. *See*, *e.g.*, Dandridge v. Williams, 397 U.S. 471 (1970) (upholding a state law imposing a maximum family AFDC grant regardless of family size on the ground that there is no fundamental right to subsistence); Harris v. McRae, 448 U.S. 297 (1980) (arguing that the freedom of a woman to choose to terminate her pregnancy does not carry with it a constitutional entitlement to the financial resources to avail herself of the full range or protected choices); DeShaney v. Winnebago County Dep't of Soc. Serv., 489 U.S. 189 (1989) (rejecting general affirmative duties of state to protect the life, liberty and property of the citizens). For a further discussion of the concept of "positive right," see, for example, Seth Kreimer, *Allocational Sanctions: The Problem of Negative Rights in a Positive State*, 132 U. PA. L. REV. 1293 (1984); Frank B. Cross, *The Error of Positive Rights*, 48 UCLA L. REV. 857. (2001).

[104] *Cf.* Kahn, *supra* note 57, at 385 (suggesting an affirmative concept of privacy); Ruth Gavison, *Too Early for a Requiem*, 43 S.C. L. REV. 437, 461-62 (1992).

between those constraints on exterior behaviors that, though involving “important” personal matters, do not constitute less tolerant identity and those external constraints that engender and exert a bad influence on the interior domain. Constraints in the first category implicate “liberty interests” whose weight against competing value is contingent on how deep their roots are in the “Nation’s history, legal traditions, and practices,” whereas constraints in the second category directly assault “privacy,” which should automatically be accorded a fundamental-right status. For example, although prohibition of physician-assisted suicide is commonly considered involving very important personal decisions and even self-definition of personhood, it does not, at least in the current socio-culture milieu, legislate a kind of morality that constitutes intolerant people or less flexible identity detrimental to social solidarity.[105] To recognize a right to physician-assisted suicide thus needs to take into account several competing value, such as the symbolic and aspirational interest in the preservation of human life, and the public health concern for protecting the lives of those who are depressed or otherwise vulnerable.[106] On

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[105] The empirical judgment of whether a particular constraint engenders less flexible identity is necessarily contingent on the cultural condition of a society. This means that it is perfectly possible that the same constraint in a different socio-cultural context would have different meaning to the interior domain. For example, if a society generally regards people who commit physician-assisted suicide as cowards or weak in personality, prohibition on physician-assisted suicide may have different significance.

[106] *But see* Brief for Ronald Dworkin, Thomas Nagel, Robert Nozick, John Rawls, Thomas Scanlon, and Judith Jarvis Thomason at 5-7, *Glucksberg* (No. 95-110) and Vacco v. Quill, 117 S. Ct. 2293 (No. 96-1858) (arguing for a constitutionally protected interest in making moral, ethical, or religious judgments for an individual about how one should approach or confront one’s death or about when it is ethically appropriate to hasten one's own death, out of one’s own faith, conscience and convictions, free from the imposition of any religious or philosophical orthodoxy by court or legislature). The authors of the amicus curiae brief still adopt the personhood thesis and seem to hold that an interior domain free of state-

the contrary, bans on homosexual sex or same-sex marriage, in the current socio-cultural context, not only impinge on very important personal decisions but also legislate a kind of morality that constitutes less flexible and imaginative identity and less patient and tolerant citizens of a democracy. They therefore raise the real privacy concern of a less free interior domain.

Table 7-1 Liberty Interests v. Privacy

Types of Rights	Liberty Interests	Privacy
Mode of Infringement	External constraints on exterior behaviors that, though involving "important" personal matters, do not constitute less tolerant identity.	External constraints that engender and exert a bad influence on the interior domain.
Weight of Rights	Depending on how deep their roots are in the "Nation's history, legal traditions, and practices."	Automatic fundamental-right status

This approach answers, at least partially, the challenge that Justice Scalia poses in his dissents in both *Romer v. Evans*[107] and *Lawrence v. Texas*[108]—Why the court can take sides in a "culture war" over morality. On the face of *Romer* is the issue of whether anti-discrimination laws on the basis of sexual orientation amount to special treatment. At the

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sponsored formative influence is both desirable and a plausible goal.

[107] 517 U.S. 620 (1996) (invalidating, based on Equal Protection Clause, an amendment to Colorado's state constitution prohibiting localities from taking any action designed to protect homosexual persons).

[108] 123 S. Ct. 2472 (2003) (finding unconstitutional a Texas statute criminalizing homosexual sodomy on the ground that it violated the Due Process Clause).

heart of *Romer*, however, involves a competition between homosexuals and the majority of a population for the use of law to officially endorse certain sexual mores. In response to the development of several municipal ordinances banning discrimination based on sexual orientation, Colorado voters adopted a state constitutional amendment that prohibited localities from taking any action designed to protect homosexual persons. The majority in *Romer*, while disclaiming any effort to give homosexuals "special" right, invalidated the state constitution amendment claiming to guarantee for homosexuals only their "equal" protection.[109] Justice Scalia accused the majority of departing from a position of "state neutrality" and siding with homosexuals in a conflict that is indeed a "Kulturekampf" against their "seemingly tolerant" adversaries.[110] He saw the amendment as a legitimate attempt of the democratic majority in Colorado to "preserve traditional sexual mores against the efforts of a politically powerful minority to revise those mores through use of the laws."[111] Similarly, when the majority of the Court in *Lawrence* struck down a Texas statute criminalizing homosexual sodomy and argued that morality alone is

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[109] The majority considered the constitutional amendment as "a bare…desire to harm a politically unpopular group." *See Romer*, 517 U.S. at 634 (quoting Department of Agric. v. Moreno, 413 U.S. 528, 534 (1973)). The debate over whether anti-discrimination laws confer special rights or equal rights involves the question of how we are to draw the baselines. If, for example, the class of people whom anti-discrimination laws intend to protect is thought to be disadvantaged in comparison to the general public, anti-discrimination laws confer only equal protection. For a discussion of equal rights and special rights, see Peter J. Rubin, *Equal Rights, Special Rights, and the Nature of Antidiscrimination Law*, 97 MICH. L. REV. 564 (1998).

[110] Romer, 517 U.S. at 636 (Scalia, J., dissenting) ("The Court has mistaken a Kulturkampf for a fit of spite.").

[111] Romer, 517 U.S. at 636 (Scalia, J., dissenting).

not a sufficient basis for upholding prohibitive legislation,[112] Justice Scalia denounced the decision as "the product of a Court, which is the product of a law-profession culture, that has largely signed on to the so-called homosexual agenda…directed at eliminating the moral opprobrium that has traditionally attached to homosexual conduct"[113] and scored the majority for "decree[ing] the end of all morals legislation."[114]

Justice Scalia's criticism is valid insofar as "taking sides in a culture war" is concerned. Justice Scalia is at least correct in saying that banning homosexual sex or sounding moral disapproval of homosexuality is about protecting the moral landscape of many "from a lifestyle that they believe to be immoral and destructive" by normal democratic means.[115] The nub is to get enough votes to have one side or the other's view of morality officially sanctioned as the formative source of our identity.[116] But if we are

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[112] Lawrence, 123 S. Ct. at 2483-84 ("[T]he fact that the governing majority in a State has traditionally viewed a particular practice as immoral is not a sufficient reason for upholding a law prohibiting the practice….") (citing Bowers v. Hardwick, 478 U.S. 186, 216 (1986) (Stevens, J., dissenting), *overruled by* Lawrence). *See also* Wilson Huhn, *The Jurisprudential Revolution: Unlocking Human Potential in Grutter and Lawrence*, 12 WM. & MARY BILL RTS. J. 65, 90-93 (2003).

[113] Lawrence, 123 S. Ct. at 2496 (Scalia, J., dissenting).

[114] *Id.* at 2495 (Scalia, J., dissenting).

[115] *Id.* at 2497 (Scalia, J., dissenting). *See also* Romer, 517 U.S. at 636 (Scalia, J., dissenting) ("Whether [opposition to homosexuality is as reprehensible as racial or religious bias] or not is *precisely* the cultural debate that gave rise to the Colorado constitutional amendment…." (emphasis in original)).

[116] Romer, 517 U.S. at 639 (Scalia, J., dissenting). *Cf.* HERBERT L. A. HART, *Between Utility and Rights*, *in* ESSAYS IN JURISPRUDENCE AND PHILOSOPHY 198, 217 (New York: Oxford Univ. Press, 1983) (rejecting the proposition that denials of freedom is equal to denials of equal concern or respect and arguing that "the defeated minority's preferences or votes of the liberty were weighed equally with others and outweighed by numbers").

to maintain the condition necessary to the very possibility of a democratic polity itself, taking sides in a culture war against moral legislation that would constitute less tolerant identity of citizens becomes definitely crucial. We do live in a society where some people's "moral identity demands that if their community begins to tolerate heresy…, then they must emigrate, or foment a revolution…."[117] But if moral identity can be as destructive as it can get to one's willingness to expand the selfhood and the very possibility of social solidarity, educating "the citizenry in the civic virtue of having as few such compelling interests, beliefs, and desires as possible"[118] becomes the only formative project worth pursuing. Consistent with this position is not only *Romer*'s equal protection jurisprudence but also *Lawrence*'s dictum that there is an important element of equal respect or tolerance in the concept of liberty.[119]

The concept of privacy that I just suggest and sketch certainly is not the most conventional one. Such a suggestion is most plausible if not entirely uncontroversial, however, if we are to rehabilitate the concern of the interior domain that is traditionally contained in the understanding of privacy but is now largely curtailed. The implication is twofold. Eschewing such a suggestion and continuing to abide by the fallacious

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[117] Rorty, *supra* note 100, at 120.

[118] *Id.*

[119] 123 S. Ct., at 2482 ("Equality of treatment and the due process right to demand respect for conduct protected by the substantive guarantee of liberty are linked in important respects…."). *Cf.* Post, *supra* note 76, at 98-101 (explaining the reasons why *Lawrence* Court used substantive due process doctrine to protect the value of equal citizenship as preserving for the Court flexibility in deciding how it will enter into the national debate about the status of homosexuality in the future).

personhood thesis only give rise to a variety of ethically hollow libertarian views regarding human genomics. Professor Stock's instrumentalist approach discussed earlier in this chapter and Professor Robertson's thesis of "presumptive primacy of procreative liberty" discussed in Chapter 2 are but two examples of the band that keeps failing to touch upon the deepest moral concern with regard to the consequences of human genomics. By contrast, privacy as the protection of a "freer" interior domain will not only lend a hand in our search for a conceptual apparatus capable of delivering the idea of a richer bioethics that takes into account the normative concern of identity formation. It also serves as a "government interest" compelling enough to counter the seemingly impregnable allegation of freedom of scientific inquiry, thereby carving out a niche for public deliberation on the usefulness of human genomics research.

8/ CONCLUSION

If we could make better humans, why shouldn’t we? This is not as simple a question as it may appear at first glance. The reason that there is no easy answer is not because the pursuit of human perfection could ever become an undesirable goal. It is more because the equally pertinent questions of choosing which means to pursue what kinds of human perfection demand more than just a simple yes or no. The challenge is that the lure that originally prompts one to pose the question and suppose its easy answer, i.e., human genomics, has dazzled us with the power it renders possible and often obscured the possibility that alternative ways of making better humans are indeed also available to us. When human genomics is a hammer, human perfection becomes merely a nail.

This study engaged first in a descriptive investigation of the possible consequences of human genomics. The purpose of the investigation was to give an assessment of the impacts of the increasing power of mastering human nature on human society. Although it has been a familiar topic for ELSI era studies to undergo a similar assessment, the focus has been mostly on now well-explored areas, such as risks of unsafe technologies, risks of psychological and emotional harm or survival guilt, risks of losing informational privacy in a society where both the interest and the ability to collect and store personal genetic information is briskly increasing, risks of uncertainty inherent in many multifactorial conditions, and risks of being adversely treated because of undesirable genetic profiles. Accompanying the conventional understanding of the consequences of human genomics is the voluntarist personhood thesis, which envisages an individual making free choices without accounting for the conditions and contexts in which those choices are formed and made. No substantial attention, however, is paid to the fact that freedom of choice is not invariably the product of self-identity. It subserves the delivery of formative influences of human genomics to individuals. Just as anatomy and pathological medicine fabricated the notion of the individual body in the late eighteenth century, a new body image is forged by the new human genomics.

However, it is certainly not enough to simply point out that our self-identity is to some extent constituted or constructed by human genomics. If various forces that narrate the body image inevitably influence our self-identity, the only difference that can be made is to constitute a kind of self-identity that can better serve our individual goals in a liberal democracy. In this light, the direst consequences of human genomics are its potential to form inflexible identities and in the end its threats to social solidarity, without which social cooperation would become extremely difficult. We saw people cite fear of discrimination—inequality as the unjust distribution of social goods—as a reason to decline genetic testing because it seems to give them a more socially acceptable reason to decline. Yet, it is indeed the fear of the demolition of social solidarity engendered by inflexible identities that underlies the poorly articulated concern of inequality as exclusionary politics. Such an inadequacy of the discourse of conventional micro-bioethics in characterizing the real harm of human genomics results as much from the lack of a forum for public deliberation as from the dearth of alternative vocabulary that is needed for a well-rounded deliberation on the macro-dimension of bioethics.

In search of alternative vocabulary, the normative exploration of this study finally suggested that the legal doctrine of privacy, with necessary rehabilitation of its capacity to protect a “freer” interior domain, qualified as the best candidate. The concept of privacy has long unfortunately been dominated by the voluntarist personhood thesis. The function of privacy so understood is conceived as securing the necessary condition for the full realization of one’s distinct personhood in the interior domain simply by retaining free choices of behaviors in the exterior world. However, if the necessary condition for independent personality is what privacy really means to defend, we must take seriously the formative nature of self-identity in interpreting the concept of privacy. Privacy must not be understood simply as the synonym of “liberty as license” but as a distinct demand imposed directly upon the symbolic Other to accord “mirror images” that allow more rather than less room for imagination.

I have argued that what ought to concern the society is not the formative influences of human genomics on people’s self-identity per se but its effect of giving rise to a kind of selfhood that is detrimental to social cooperation and solidarity. To the extent that privacy can be understood as protecting a “freer” interior domain of identity formation, right to privacy is a powerful vocabulary that not only adequately describes the undesirable aspect of the development of human genomics, but it also depicts a richer idea of bioethics. More importantly, it is an existing and effective legal parlance—a compelling “government interest”—to counter the seemingly impregnable allegation of freedom of scientific inquiry, generating the space for public deliberation on the usefulness of human genomics research that has been crowded out for so long.

More and more people now realize the importance of public participation in the making of science.[1] In this respect, the experience of other, especially European, countries certainly provides invaluable guidance as to how to set up forums such as a consensus conference to take discussion about contentious, or potentially contentious, areas of science and technology beyond the traditional debate among experts and special interest groups so as to include more diversified points of view.[2] Moreover, as early as in 1988, the European Parliament in its Resolution on the Ethical and Legal Problems of Genetic Engineering also explicitly advocated that "there should be an assessment of the concepts of illness and of genetic defect to deal with the danger of defining as a medical disorder or genetic defect conditions which are merely deviations from the genetic norm."[3] Yet, if we want to ensure that any such deliberation does not unwittingly fall into a one-sided monologue even in the form of public participation, furnishing alternative language is as important, if not more, as securing the membership of a loyal dissent in the procedure.

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[1] *See*, *e.g.*, JONATHAN D. MORENO, DECIDING TOGETHER: BIOETHICS AND THE MORAL CONSENSUS 85 (New York: Oxford Univ. Press, 1995); Erik Parens & Lori P. Knowles, *Reprogenetics and Public Policy: Reflections and Recommendations*, HASTINGS CENTER REP., July-Aug. 2003, at S3, S18-S20.

[2] *See* PUBLIC PARTICIPATION IN SCIENCE: THE ROLE OF CONSENSUS CONFERENCES IN EUROPE 9 (Simon Joss & John Durant eds., London, UK: Science Museum with the support of the European Commission Directorate General, 1995).

[3] Resolution on the Ethical and Legal Problems of Genetic Engineering A2-327/88, 1989 O.J. (C 96) 165, 169.

Even with the vigilance of the formative influence of human genomics and of its potential danger of constituting inflexible identities, we still need more conversation in practicing and familiarizing our newly learned vocabulary in different contexts. Admittedly, human genomics has the capacity to reduce pain and suffering. Few people could imagine not submitting to the power of life-saving technology when life is at stake. But when we are in a time in which even the concepts of pain and suffering are largely colonized by biomedical science, learning an alternative vocabulary is probably the only step left for us to secure the benefits of Prometheus's new contrivance while keeping ourselves from its concomitant perils and to imagine varied possibilities of making *better humans*.

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