



GENETIC INFORMATION AND GENETIC ESSENTIALISM: WILL WE BETRAY SCIENCE,
THE INDIVIDUAL AND THE COMMUNITY?

by

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This time in human history has been characterized both as an "Age of Information" and as an "Age of Biology."¹ This dual view would suggest that the Human Genome Project, with its font of information, would be the focal point for many of the critical questions of our time. This is indeed the case and I believe that the most significant question to address is that of the metaphor or paradigm which will govern the Human Genome Project and the use of its information. This issue must be addressed because the emerging metaphor is a disturbing one, at least in the United States. In a 1995 book, The DNA Mystique, we are told that for U.S. culture the Gene has become a powerful cultural icon and that the DNA is seen as an "awe-inspiring magical entity, the essence of life and the secular equivalent of the soul."² What is emerging is a "striking picture of the gene as powerful, deterministic, and central to an understanding of both everyday behavior and 'the secret of life.'"³ The operative metaphor or paradigm here is that of "genetic essentialism," which sees the human self as a molecular, genetic entity and the many social roles, behaviors and relationships of that self as having a biological-genetic base. In this view, "we" humans are our genes. ⁴

"Genetic essentialism" as an operating paradigm for the use of genetic information is a troublesome one because it may well accentuate human differences and thus threaten rather than help

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mainstream marginal groups. Thus, for example, a perceived biological-genetic base to homosexuality, rather than leading to tolerance and non-discrimination, might well lead to an emphasis on "individual pathology," and "blaming the victim", which, in turn, seems to absolve society of responsibility for any social aspects of homosexuality or any social problems that may arise from this social phenomenon. Further, "genetic essentialism" tends to medicalize problems, to emphasize reproductive choices, particularly dysgenic ones, and thus to open the door to restrictive and oppressive social practices. A future scenario for homosexuality, then, might well include abortion for fetuses predisposed to being "gay," a case already described in the 1993 Broadway play, "Twilight of the Gods." Gene therapy and manipulation might also be part of the future genetic agenda as foreseen by a spokesperson for a National Gay and Lesbian Task Force when they wrote: there will be "tweaking or zapping of our chromosomes and rearranging of our cells so 'presto', we'd no longer be gay."⁵

Such a paradigm and the resulting actions, in my judgment, betray the individual person, for each human self is so much more than genes. Further, to reduce a person's behavior in this manner is to deny what many believe makes us truly "human," namely, our intentionality, our free action, which also constitutes us as moral and responsible beings. Such a construction of a human behavior as complex as homosexuality also betrays the community for it denies the essential social context of the human self and the responsibility of the community for fostering the development

and fulfillment of its members. Finally, an operating paradigm of "genetic essentialism" is a betrayal of science, for it denies the complex and uncertain nature of the scientific enterprise while, at the same time, it engages in "pseudo-science." Good science teaches us caution, restraint and doubt. Scientists and those who have studied science know that in science "all is provisional." American physicist Richard Feynman put this idea very well when he said, "The scientist has a lot of experience with ignorance and doubt and uncertainty...we take it for granted that it is perfectly consistent to be unsure."⁶ As for pseudo-science, Karl Popper has characterized it as a so-called science which "sees confirmation everywhere" and seeks to "explain everything."⁷ Genetic essentialism also goes against what Patrick Suppes and others see as the essential "plurality of science."⁸

In what follows, I will first describe and document the reality of genetic essentialism and its dangerous implications. In doing so, I shall argue that the seeds for such a paradigm are contained in science and have been planted by many scientists practicing genetics today. Secondly, I shall draw on the work of the geneticists contributing to this seminar to show that the picture painted by the "genetic essentialism" paradigm is not true to the science of genetics as it now stands. Thirdly, I shall argue for a new paradigm based on "shared vulnerability" and a close interconnection between individual and community. In presenting this argument I shall also claim that ethicists have been trapped by their own paradigm of "individualism" and "rights" concepts and thus have not been critical enough of

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the emerging paradigm in the Human Genome Project. Indeed, they have tended to accept the social/institutional status quo and not argued strongly enough for re-formulated and anticipatory social and public policy action. Finally, I shall also come to suggest that health-care professionals have been enticed by the Human Genome paradigm and have not seen the need to forge a new understanding of medicine and of the physician-patient relationship.

Genetic Essentialism, Genetic Pre-dispositions and Betrayal

Genetic essentialism, with its attendant notion of genetic pre-dispositions, has, as I have suggested above, many disturbing consequences including the medicalization of social problems, an ethos of apathy about social injustice and social problems, and an ethos of manipulation. A good example of genetic essentialism applied is behavioral genetics which embodies the notion that human behaviors are reducible to a genetic base. Thus, numerous behavioral traits are being attributed to genetic causes or genetic predispositions, eg. mental illness, addiction, homosexuality, criminality, and even educational success. Genetic grounds for schizophrenia, alcoholism, drug addiction as well as homosexuality have been much discussed, at least in the United States. Thus, for example, Simon LeVay, in his 1993 book, The Sexual Brain, claimed that the biological-genetic explanation for homosexuality was a smaller hypothalamus caused by differences in genetic patterns. 9 LeVay's claims came to be supported by the work of Dean Hammer and his team of geneticists at the National Cancer Institute which seemed to demonstrate a

gene located on the X chromosome which "predisposed some men toward homosexuality."¹⁰ Work on the genetic basis for alcoholism is proceeding as is similar research for schizophrenia and other mental illnesses.¹¹ Such discussions usually are premature and almost always lead to the medicalization of the problem. Mental illness has already been medicalized and treated by drug therapy and brain surgery. The new genetic scenario, already partially realized with severe mental retardation, is the abortion of fetuses with "pre-dispositions to mental illness" and perhaps "tweaking or zapping chromosomes and rearranging cells" so that people will no "longer be mentally ill." Perhaps the same will be true for alcoholism, a scenario suggested by a critic of the work of the Ernst Gallo Clinic and Research Center on the biological causes of alcohol abuse. He writes that such work could "increase the potential market for their product as it locates responsibility for alcoholism in an individual's DNA."¹² The point here is not to deny that there is a genetic aspect of these behavioral manifestations, but to be critical of over-exaggeration of the genetic contribution or over hasty judgment about causes. One also sees that any social aspects of these human problems are ignored and thus social responsibility is also abnegated.

These kinds of dangers inherent in genetic essentialism and genetic pre-dispositionism, especially in the arena of human social behavior, can be poignantly seen in the "genetification" of a behavioral trait such as "educational success." Such a move clearly leads to apathy about social problems and the glorifi-

cation of the status quo. Thus, the book, The Bell Curve, by Herenstein and Murray recently became the center of a great deal of discussion when it promoted the correlation between genetic IQ and social, economic, and educational success. These authors argued that those with the highest IQ are rightly at the top of the societal ladder, while African-Americans, with a lower IQ and "biologically inferior genes," are correctly at the bottom of the economic/social/educational scale. 13 Another disturbing example of the biologizing of educational traits is the classification of certain "learning disabilities", including "expressive writing disorders" as developmental, organic disorders in the Diagnostic and Statistical Manual of Mental Disorders (DSM) published by the American Psychiatric Association. 14 A frightening social policy decision based on such a genetic reduction of educational abilities is that of a Long Island, New York organization who attempted to reduce school taxes for special education classes for learning disabled children on the ground that these disabilities were of genetic origin and therefore were the responsibility of the medical rather than the school system. 15

All of us in the United States have seen the increasing influence of genetics and genetic explanation in the area of law and criminal justice. DNA fingerprinting is already prominent, as the O.J. Simpson case has made clear. The "XYY" "aggressor" or "criminal" gene has already been the topic of research, a suggested defense for criminal action (eg., the Richard Speck case); the theme of several movies (eg. Tainted Blood); the topic of numerous news stories and even of a Calvin and Hobbes cartoon.

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In that cartoon, Calvin, describing a vicious "snow snake," says, I suppose if I had two Y chromosomes I'd feel hostile too." 16 If criminality is indeed genetic, then "rehabilitation" as a concept seems wrong and permanent incarceration or perhaps even an ultimate punishment, eg. the "punitive coma for public health reasons" of the novel, A Philosophical Investigation seems most appropriate. 17

Another deeply disturbing trend in U.S. law is the application of "genetic essentialism" in family law. In the past in custody cases judgments were made on the basis of the "psychological best interests of the child" and to assure that children have continued contact with significant people present in their lives. Today courts in the U.S. feel compelled to address genetic bonds and genetic rights. In June, 1994, a judge in the Illinois Supreme Court ordered three-and-a-half-year-old "Baby Richard" removed from his adoptive parents and returned to his biological father who had never seen him. A similar judgment was made in the "Baby Jessica" case. 18 In 1989 in *Coburn v Coburn* a court dismissed the petition of a divorced father for visitation rights with the daughter he had nurtured for ten years. The basis of the decision was genetics. A test revealed that the child was not his biological daughter. Judge J. Crillo, in a concurring opinion on the case, wrote that "knowledge of one's biological parents and heredity is crucial in ordering one's affairs and making life decisions." 19

Another clear case of legal decisions justified on a genetic basis was the 1990 California dispute, *Johnson v. Calvert*

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Anna Johnson, a surrogate mother for the Calverts, who had donated their gamete, did not want to relinquish the baby she had nurtured for nine months. The judge in this case awarded the Calverts sole custody and justified his decision in terms of the child's genetic endowment. He did not, as he might have, evoke contract obligations, nor did he talk about the child's best interests or the fact that the biological processes of pregnancy and birth might be a legitimate basis for a motherhood claim or for visitation rights. Rather, he noted the "tremendous need out there for genetic children." He defined the child as a packet of shared genes which are the "essence of identity" and the "basis of human identity." He called Anna Johnson, the surrogate mother, a "genetic hereditary stranger."²⁰

This new genetic emphasis in U.S. family law has lead to a new search for "biological roots" and a stigmatization of adoption. The president of an organization known as the Adoptees Liberty Movement, for example, writes: "The destruction of heredity and the identity of the adopted person is a deprivation for which there is no compensation." ²¹ Elizabeth Bartholet, in a book highly critical of this stigmatization of adoption, argues that adoption is seen as a "debased form of parenting." "Parenting, she writes, is equated with procreation and kinship with blood lines. It is only genetically linked parents who are truly entitled to possess their children." ²²

Under the rubric of "genetic essentialism," the family is being redefined as "molecular family," i.e., a relationship between genetic parent(s) and child. Thus, infertility is seen

as a devastating "disease" to be cured with biological and medical technology. In the U.S. infertility is big business with an increase from 50 IVF clinics in 1987 to 235 in 1992. Reproductive choice becomes more and more dependent on science and technology, and combined with genetic technology, the spectre of eugenics becomes very real. Sociologist Troy Duster, for example, has argued that while the front door to eugenics may be closed, the "back door" has already been opened by contemporary medical care practices such as IVF, genetic counseling, the selective identification of genetic disease and the concept of genetic health. 23

Finally, genetic essentialism and its accompanying notion of genetic pre-dispositions, has already had disturbing implications for health care in the United States. Genetic testing for genetic predispositions may well differentiate individuals on the basis of so-called "natural" categories of risk, which, in turn, may result in discrimination in employment and in insurance. Dr. Robert Blank has addressed this issue in this seminar. At present genetic screening for identifying workers has primarily been argued on the grounds of protection of workers' health, i.e. protecting those with specific traits that may predispose them to certain chemical agents in the workplace. However, this may open the "back door" to identifying vulnerable individuals in order to control compensation claims or to avoid costly changes to the workplace environment. Such actions would deny the "individuality" of persons by categorizing them as "risk groups." It would also blame the "victim" for problems and

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thus exonerate a company of any responsibility to provide safe working conditions. 24

In the area of health care, United States insurance underwriters may, with access to genetic tests for risks, identify "risk" groups, both low-risk groups who will get preferred lower insurance rates because they are expected to incur fewer medical expenses and high-risk groups who will either be denied insurance or be expected to pay exorbitant rates. 25 This insurance issue is the topic of a major report of a Task Force attached to the "Ethics, Legal and Social Issues" arm of NIH's Human Genome Project. 26 The central concern of this report is the "fair use of genetic information" one and it discusses in detail a developing new notion of "fairness," namely, "actuarial fairness," i.e. paying according to risk. 27

Another medical/ethical issue raised by genetic pre-disposition testing is the question of "who is the patient?" and "what is the nature of the physician-patient relationship in this situation?" This issue has been raised by Dr. Shickle in our seminar papers. How does one treat a person who is "not yet ill?" Will "disease" be broadened as a concept to include pre-disposition and, if so, with what consequences?? Will the concern in medicine, then, be with "group health" or with "individual health?" To whom will the physician have a fiduciary responsibility? If health risk becomes the over-riding concern, will this open the door to blurring further the line between research and treatment and between somatic and germline gene therapy? Robert Veatch, in a recent talk in Pasadena, presented

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an argument for germline gene therapy primarily based on compassion for the suffering of children and future generations and on a "moral responsibility" to take risks and to eliminate the deleterious genes which will cause such devastating suffering to future progeny. 28 In this vein, Carl Degler suggests that the new eugenics policies will not be those of the past, namely, of compulsory state intervention, but instead, will rely on perceived economic and social interests and a sense of eugenic responsibility. 29 Richard Neuhaus, in a similar vein, sees the language of eugenics today as "the winsome one of progress, of reason, and above all of compassion." 30

Thus, "genetic essentialism" seems very much a reality, at least in the United States. It bodes great danger for human understanding, for human intentionality, and for human responsibility. It also, as I have indicated earlier, is a betrayal of science and of the state of genetics today. But, first, let me show that science and scientists have sown the seeds of genetic essentialism and thus have some responsibility for its strong presence.

SCIENCE, PSEUDO-SCIENCE AND THE SEEDS OF GENETIC ESSENTIALISM

Genetic essentialism is a form of reductionism and science has already within its historical development evidence of a drive for reductionism. Reductionism was, in fact, a pivotal idea of the Unity of Science movement initiated by Rudolf Carnap and other logical empiricists 1938. 31 A more contemporary expression of the reductionist attitude is found in the search

by Nobelist Steven Weinberg for "principles that will explain all the laws of nature. ³² The aim of reductionism is to show that one level of reality, i.e., social behavior, can be explained in terms of a lower and "deeper" level of reality, eg. multicellular organisms. Further, an ultimate lower and deeper level of explanation is envisioned so that multicellular individuals are explained in terms of cell behavior while cell behavior is explained in terms of molecules and molecules in terms of atoms and finally atoms are explained in terms of elementary particles. ³³ The historical perceived elementary level for reductionism was atomic physics. However, given that this is an age of biology, it is not surprising that many of today's advocates for reductionism are biologists. Thus, E.O. Wilson, an entomologist, seeks to explain complex human social behaviors in terms of evolutionary biology and "survival of the fittest." ³⁴ Wilson believes the whole human social order can be explained in biological terms. A clear spokesperson for genetic reductionism is Richard Dawkins who, in his 1976 book, The Selfish Gene, called human beings "survival machines- robot vehicles that are blindly programmed to preserve the selfish molecules known as genes."³⁵

It is clear that many contemporary geneticists, like Dawkins, see human identity in terms of the gene. James Watson, co-discoverer of the DNA Double Helix, has proclaimed that the DNA is that "which makes us human."³⁶ DNA fingerprinting and its widespread use in courts as a unique identifier contributes to the equation of human identity and the gene.³⁷ In fact, Dr. Strohman, in his contribution for this seminar, speaks of the

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linear genetic logic and the "uniqueness equation" which underlies the Human Genome Project. He notes the project's simplistic set of assumptions and goals which include the following three ideas: (1) Genes determine diseases; (2) Genes determine aging; and (3) Genetic analysis provides diagnosis and therapy for disease and aging.³⁸

Geneticists associated with the Human Genome Project, in their public appearances designed to help maintain public support for the long term and costly project, have in fact promoted themes which lend support to reductionism and to the idea of genetic essentialism. Three themes seem to stand out. These are: (1) the gene is the essence of identity; (2) genetic research promises prediction of human health and behavior; and (3) the genome is a text that sets out the natural order, i.e. it is a 'Book of Man.'³⁹ In this vein, geneticist William Gilbert, speaking on gene sequencing, introduces his lecture by pulling out a compact disc and announcing to his audience: "This is you." ⁴⁰ James Watson again has said "our fate is in our genes," ⁴¹ and numerous futurists promise that genetic prediction will enhance control over behavior and disease.

Such claims by scientists certainly support genetic essentialism. These claims, however, often take on an even stronger and, some would say, stranger tone, namely, a religious one. ⁴² Bryan Appleyard, in his book, Understanding the Present Science and the Soul of Man, suggests that science's reductionist tendency to seek an ultimate underlying principle is a kind of religious motivation, an effort to establish a "church

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of science" and to give scientific findings moral and cultural force. 43 Mary Midgley, a British philosopher, has made a similar suggestion in her book, Science as Salvation: A Modern Myth and Its Meaning. 44

These notions of a religious flavor to some contemporary scientific claims receive some credence when Stephen Hawking speaks of the quest for a complete description of the universe we live in and argues that when a satisfactory cosmological theory has emerged,

we shall all--philosophers, scientists and just ordinary people-- will be able to take part in the discussion of the question why it is that we and the universe exist. If we find an answer to that, it would be the ultimate triumph of human reason-- for then we would know the mind of God. 45

Physicist George Smoot makes a point similar to that of Hawking when he compares the big bang theory to "the driving mechanism of the universe" and "isn't that what God is?" 46 Leon Lederman, Nobel physicist, has named the subatomic entity that he believes determines everything the "God particle." 47

Many elements of contemporary Genetics also have a seemingly religious twist. The DNA has been labeled the "secret of life," and it is thus seen as representing an essential underlying biological principle. Indeed, an article in Pharos, a medical journal, raises a question similar to that posed by the cosmologists, only this one has a biological cast, namely, "Is DNA God?" "Given (its) essential roles in the origin, evolution and maintenance of life, it is tempting to wonder if this

twisted sugar string of purine and pyrimidine base beads is, in fact, God." 48

The Genome has often been described as a text, as a Book of Man, which, like the Bible, would explain the natural order of things. DNA has, in fact, been called upon to explain human pre-history. The Human Genome Diversity Project, for example, is an international plan to use DNA from 500 populations from around the world in order to explain such events as the Bantu expansion in Africa, the origin of Native Americans and the relationship between linguistic groups. 48 DNA has been used to reconstruct individual history, for example, the project to investigate Lincoln's DNA in order to discover whether he had suffered from Marfan syndrome. Sufferers from this syndrome risk a bursted aorta and thus debate has ensued about whether the disease could have taken Lincoln's life even if assassination hadn't occurred in April, 1865. Some even speculate that Lincoln's condition might have affected his decision making. 50 A similar reconstructive history was reported at a recent Genome conference. David Sidranski, a leading researcher in cancer detection reported a reconstruction of Hubert Humphrey's DNA which suggested that he had a P53 gene and probably already had cancer of the bladder when he was first tested in 1967. 51 The suggestion was made that Humphrey "might" have been saved from death if several of the test interpreters had followed through on their suspicions about the test results. 52 In both these cases there is a quality of resurrecting history and even

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a hint of placing "new" value judgments on past actions.

DNA can persist in fossilized form and thus "resurrection of DNA" became a fictional reality in Michael Creighton's novel, Jurassic Park, and in Steven Spielberg's film in which dinosaurs were reconstituted from bits of DNA preserved in insects who were fossilized in amber. "Resurrection of DNA" has become perhaps a reality in a proposal by Nobel Laureate, Kary Mills, to develop DNA cards and even jewelry containing DNA cloned from musical superstars, athletes and other 'secular saints.' Nelkin and Lindee, in reporting this affair in their DNA Mystique, properly call this phenomenon "Genetic relics." 53 Sacred relics, it will be recalled, include fragments of bone or hair or objects once touched by a saintly person. These, it is believed, "carry the power or saintliness of the person" and "make him or her 'present' once again." 54

It is clear from all of this, I believe, that science itself carries the seed for genetic essentialism, that scientists have, in fact, promoted ideas encompassed in genetic essentialism, and that scientists have also contributed to the "mystique" and perceived "power" of the DNA and the gene. Indeed, in my judgment, in fostering such pretentiousness and exhibiting such arrogance, science has truly betrayed its essential nature. In backing up my judgment, I shall call upon the remarks of the seminar geneticists as well as some other material.

SCIENCE AS CAUTIOUS AND COMPLEX

Science, I believe, does teach "doubt" and "refrain", as

so clearly stated by physicist, Richard Feynman earlier. Both of our geneticists, Pinchiera and Strohman, have clearly argued for such a theme. Both have noted the many complexities of the genetic process, especially the mechanisms by which clear expression of a trait occurs. Strohman quotes Nobel Laureate Barbara McCintock who wrote: "We know about the components of the genome. We know nothing about how the cell senses danger and initiates responses to it that are often truly remarkable."⁵⁵ Pinchiera quotes Nobel Laureate Issac Singer who said: "Our knowledge is a little island in a great ocean of nonknowledge."⁵⁶ Strohman claims that population biology argues against genetic determinism and genetic essentialism and against the notion of predisposition risk analysis used in the Human Genome Project.⁵⁷ Population genetics, says Strohman, "sees complex traits including disease as highly interactive and impossible to reduce to genetic elements alone. ⁵⁸ Other scientists argue that efforts to measure the relative effects of heredity and environment on behavior misconstrues these two factors as independent rather than as interactive forces and thus there is an underestimation of environmental forces on gene expression. ⁵⁹

Strohman's point about a dubious risk and statistical analysis methodology in the Human Genome Project is supported by critics who argue that a statistical construct may have meaning for populations but no simple meaning for individuals.⁶⁰ Stephen Gould has pinpointed the nature/nurture distinction as a false dichotomy which confuses correlation with causation. He writes: "Genes influence many aspects of human behavior but we

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cannot say that such behavior is caused by genes in any direct way. We cannot even claim that a given behavior is, say, 40% genetic and 60% environmental...Genes and environment interact in nonadditive ways." 61

Strohman adds another kind of argument against genetic essentialism, namely, he presents convincing evidence that our most feared diseases, eg. cancer and heart disease, are primarily "diseases of civilization." The message, he claims, is that prevention and therapy for these diseases will also be associated with environmental changes. 62

Another element of genetics seems to go against a paradigm of genetic essentialism, namely, the fundamental nature of a "map." Maps, as we well know, are selective, i.e., they focus on and link certain features of the world. It is misleading then to focus on the neutrality of the Genome map to suggest that once a gene is located, its interpretation will be objective and independent of context. Christopher Willis, in his book, Exons, Introns, and Talking Genes: The Science Behind the Human Genome Project, observes that "simply determining the sequence of all this DNA will not mean we have learned everything there is to know about human beings, any more than looking up the sequences of notes in a Beethoven sonata gives us the capacity to play it." 63 Genes, if indeed they are like words, are dependent on context and are open to more than one interpretation and thus we should not be misled to think that a mapped gene is merely a straight forward detail. 64

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The message, then, about genetics and about the DNA and about genes is one of complexity and uncertainty and of mutual interaction with environmental factors. This is the message that scientists, health care practitioners and philosophers should be carrying to the public and to public policy makers. Let us police those who would practice "pseudo-science" by claiming to explain everything. If a metaphor is needed for genetics, rather than genetic essentialism, let it be one of "shared vulnerability" and not one of "we and "they" but one of "we are all together in the same boat" with the same risks and the same responsibilities. Each person has at least 5-10 genetic malfunctions and thus each one of us has our own vulnerability and our own risk. We all, then, take our chances with the environmental and triggering conditions. And we are beings with intentionality and are capable of action. Thus, we have corrected myopia with glasses and we can control allergic rhinitis by avoidance of allergens. Further, if many diseases are those of "civilization" then we are responsible to change social conditions that may be responsible for the onset of these phenomenon. Above all, let us not reduce our selves to one aspect; we are all too complex and rich creatures for that. Finally, in addition, to forging a new paradigm for the use of genetic information, I wish also to suggest new directions for ethical and legal analysis as well as medical practice.

GENUINE INDIVIDUALS AND GENUINE COMMUNITIES: A CRUCIAL PAIR

Science, itself, we have claimed, contains the seeds and has, through individual scientists, fostered the operating paradigm of genetic essentialism. Another fertile ground for this genetic metaphor, particularly in the United States, is the strong individualism which founds much of American ethical, social and political thought. Such an individualism places emphasis on the self-made, self-reliant, self-interested human subject, the autonomous individual who enters into contractual arrangements and who becomes the focus for rights, political, legal and moral. ⁶⁵ Indeed, in the context of this view, the individual is seen to have primacy over the state in two senses: (1) the individual has priority over the state in time because the origin of the state, its legitimation is based on a contract of self-interested individuals; and (2) the individual has moral authority over the state because reason, on which the morality of the good will is based, is an inherent endowment of each individual. Further, the primary value to be protected by the state is liberty or freedom, which is interpreted in the negative sense of non-interference in the individual pursuit of life, property and happiness. ⁶⁶ This individualism, in all its ramifications, is based on a fundamental notion of atomistic, individual entities as the focus of value and as essential reality. Further, this view tends to ignore the role of the community and of the social group. Community and group, in fact, are seen as nothing more than a collection of individual persons. ⁶⁷ In the social sciences and the philosophy of science, this view of community is viewed as a reductionistic

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position and is called "methodological individualism." ⁶⁸ The reductionist aspects of this view is clear when it posits that human social behavior is ultimately to be explained at the level of individual persons. Societal action, in essence, is only actions of individuals. Such a view, of course, fits well with the reductionistic drive of genetic essentialism.

Although this individualism has been very beneficial in its advocacy of freedom, rights, and autonomy for persons, it does, in its one-sidedness, present difficulties for ethical analysis of the many complex situations encountered in medical and bioethical situations. Its strong emphasis on autonomy and individual informed consent, though of enormous benefit, has led ethicists and others to ignore or discount to different degrees the fact that individuals makes decisions as social beings, i.e. as persons with many characteristics closely tied to their social, cultural, ethnic, family contexts and that these social aspects of the person impact relevantly and often crucially on their actions and certainly on their beliefs. Further, individualism, operating on a belief that social groups and institutions are merely collections of individuals and of their interests, leads ethicists and others, operating from this philosophical base, to pay less attention to the social contexts of decisions-making and to the profound importance of institutional values and beliefs in any decision and action situation. ⁶⁹ Reproductive choices , analyzed from the perspective of an individualistic ethic or political/public policy individualistic view, are illustrative of some of the

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problems encountered in making sense of such decisions which are more than just individual choices, though, of course, a single person, the mother usually ultimately makes the choice. These choices, however, do profoundly impact on others and are always in a social context which sets significant parameters to the decision. These choices often lead to a conflict of the principles of autonomy and beneficence and to a conflict of rights. Such choices also often lead to severely conflicting black and white analyses of the choice such as is the case in the abortion debate in the United States.

Similar troublesome aspects arise in attempting to provide ethical and legal guidance to parental custody decisions and to issues arising out of genetic testing and counseling. For example, what is an ethical and fair resolution of the conflict between the right of privacy of an individual and the duty to inform others in cases where genetic information impacts profoundly on the lives of other individuals who also have a right to make autonomous decisions, which depend on having full information. A strictly individualistic approach to these situations does not, in my judgment, allow us to give adequate analysis of the decision-making process for "community" and "social" aspects are important parts of the decision process, eg. "family" "truth-telling" and "trust."

What is needed is a new philosophical view, a new paradigm, which sees individual and community relationships differently, namely, by recognizing that the task of building authentic individuality and that of developing fulfilling moral communities

supportive of authentic persons are tasks inextricably bound together. Genuine individuality and genuine community arise out of mutual interaction in a creative, ongoing process. 70 In such a view, further, "person" is not seen in terms of an atomistic entity with certain basic inalienable, pre-determined endowments, whether they be rights or genetic predispositions, but rather the person is understood in relational and developmental and contextual terms. The self is a complex process having public, physical aspects -- material, neural, genetic, behavioral, social, cultural, political -- and private, inner aspects -- sensual, intentional, emotional, mental and these aspects are seen as all interacting with and influencing each other in complex and multiple ways. In this view, a necessary condition of one's being a person is being-with-others, for the ascriptions of "personhood" , of "rights" are, in a most fundamental way, ascriptions by others and even one's ability to know oneself is heavily dependent on interaction with others. This is not to suggest that self-contribution is not essential, for it is. Meaning is also self-ascribed; intentionality and autonomy are rightful and crucial aspects of a "person." However, again, the development of individuality and autonomy is also dependent on social circumstances and on the actions of others. Rights, after all, are ascribed and recognized by the community; rights bestow duties on others and thus rights make sense only in the context of community.

I have developed in detail this perspective on the interactive relationships of individual and community and also the

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notion of personhood as process, relational and contextual. 70 Such a view, I believe, fits more appropriately with the complexity, the relational, and interactive nature of the genetic processes as described by Pinchiera and Strohman and others. I cannot develop in this context the nature of this appropriateness, but rather I wish to suggest how this different view of the individual and her community might illuminate two areas particularly threatened by genetic essentialism, namely the family and medicine.

We recall the notion presented earlier of the molecular genetic family and the way in which law courts in the United States have moved to a genetic basis for parental custody decisions. An alternative view, based on our new individual-community paradigm, is to see the "family" as a "formative community." Such a view defines "family" in terms of the quality of relationship and the commitment to that relationship. Such a view does have some legal precedence in United States law. In July 1989, the high court of the State of New York expanded the legal definition of family in order to recognize "domestic partnerships." The court decision included this statement: "It is the totality of the relationship as evidenced by dedication, caring, and self-sacrifice of the parties which should, in the final analysis, control the definition of the family." 71 To make even clearer the definition being proclaimed by the court, Judge Vito Titone provided four "judicial" criteria for determining what constitutes a family. They were (1) the exclusivity and longevity of the relationship; (2) the level

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of emotional and financial commitment; (3) how a couple has "conducted their everyday lives and held themselves out to society;" and (4) the reliance on one another for daily family services." ⁷² This definition of family has within it several important elements. First, it affirms the idea that individuals and their community need each other. Stable, unique selves develop out of a genuine communal context which seeks to provide the conditions which initiate and foster the development of unique, fulfilled selves, conditions, incidentally, which are complex and delicate and need more study and commitment just as do the conditions for genetic and general physical health. And by the way, knowing and dealing with the genetic conditions of persons -- both children and the adult members of the family-- is an important part of this enabling of growth. Sarah Ruddick states our point about family very well when she writes: "We must create institutions and practices where men or women, whatever their personal coupling and connections, might join together in a collective commitment to nurture and cherish the procreative promise of their children." ⁷³

Again, much more could be said about a new view of "family" and I have developed this concept more extensively in another context. ⁷⁴ However, for this context, it probably has been sufficient to indicate that there is an alternative philosophical context for dealing with the problems of family in a genetic and biological age that does not lead to the troublesome implications that the molecular family of genetic essentialism brings with it. Now, I shall turn briefly to comment on "medicine" as it en-

counters this new genetic age. For more extensive comments on medicine I refer readers to other contexts in which I have dealt with this important insitution. 74

Medicine needs to be seen, I believe, as a mediating and interpeting practice, i.e. as engaged in an educational and interpetative role for patients, helping them make informed decisions in complex situations where so many items of information and knowledge are required, including genetic information. In fact, physician and patient(s) need to work together as interpreters in order to build a common community of meaning in which to act. This means that both physician and patient(s) bring their values, beliefs, social and professional contexts to the decision-making process, i.e. there is a recognition that each of the participants in the decision has a view which is important and valuable to coming to a resolution of the problem. This view would, of course, argue against genetic counselors, for example, functioning as "neutral preveyors of information."

In such an interpretation of the physician-patient(s) relationship there must be respect and regard for each self and idea involved. The patient's experiences and perspectives, as well as those of significant others, are assumed to be valid contributions to understanding the problem, its impact and its meaning. Likewise, the views and perspectives of health care providers, physician and others, are important components of the process. All must act as "mutual interpreters", so that, by team effort, the "best informed" -- relying on as many different kinds of information as possible in the situation --

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decision is made and actions taken.

This perspective see both patient(s) and physicians and others involved as morally responsible persons, bringing with them virtues such as "humility," "hope," "courage," "patience," "tolerance" and "compassion." "Courage" is an important virtue in health care situations today because "risks" must be taken and often one must question "old" and "new" practices which may inhibit a "good" decision. McCullough and Chervenak, in their illuminating discussion of physician/patient relationships, make the point that a physician must have the courage to use their professional and institutional power to enhance the ability of patients to make decisions and deal adequately with problems.⁷⁵ Above all, as Dr. Hans-Martin Sass, in his seminar paper has argued, physicians and other health care providers must educate patients to their roles, responsibilities and powers.

Patients too need virtues. Karen Lebacz has, in fact, provided us with a very nice piece on the "virtuous patient." ⁷⁶ She argues, I believe correctly, that virtue is not simply character traits but "appropriate" responses to situations. ⁷⁷ Lebacz sees "being a patient" as a role and virtues of a patient as having to do with "excellence in the role as well as responses to pain and personal change." ⁷⁸ An essential virtue for the patient, in Lebacz's view, is "fortitude" which she primarily interprets as follows: "To accept limitation, to endure in the face of the unchangeable, to quiet the heart..." ⁷⁹ However, as part of fortitude, she also includes the ability to "reassert

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autonomy" and to seek control.⁸⁰ I would add to this the courage to interpret and to demand meaning. The other two virtues identified by Lebacz are those we also would highlight as part of the role of interpreter, namely, "prudence" and "hope." "Hope" involves "perfecting the will to trust in the attainment of the end" and to believe that meaning will "emerge out of the chaos, pain and sense of injustice."⁸¹ "Prudence" is the ability to perceive the reality of the situation, to discern what is required as a "fitting response" as well as the willingness to act on what one perceives."⁸²

These concepts of patient and physician roles, which would be roles also for other health care providers and significant others involved in the decision making process, seem to me to be significant new understandings for medical practice and decision-making in the context of genetic information and the present uncertain, complex, interactive nature of genetic processes. This kind of interpretation foresees medicine moving in the direction of team-effort and decision-making and as a much more educational and proactive process. Such a view of law and public policy might also be appropriate.

The argument has been that "genetic essentialism" is a present and very real threat as we move forward with the Human Genome Project and the use of genetic information. It has also been claimed that those of us in science, ethics, medicine, law and public policy have, in appropriating a paradigm friendly to genetic essentialism, are partly responsible for the threats that this view poses. This means, then, that we must seek

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together to forge a new metaphor or paradigm that can guide the use of genetic information that fosters human freedom in the context of community and that respects and works for rectifying social and environmental conditions that will allow genetic health, physical health and individual and communal growth, fulfillment and well-being.

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NOTES

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