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**Genes and Justice, Past and Present**

In April 1991, an exposition opened in the hall atop the great arch of La Defense, in Paris, under the title *La Vie en Kit*—Life in a Test Tube—*Éthique et Biologie*. The biological exhibits included displays about molecular genetics and the human genome project. The ethical worries were manifest in a catalogue statement by the writer Monette Vaquin that was also prominently placarded at the genome display.

Today, astounding paradox, the generation following Nazism is giving the world the tools of eugenics beyond the wildest Hitlerian dreams. It is as if the unthinkable of the generation of the fathers haunted the discoveries of the sons. Scientists of tomorrow will have a power that exceeds all the powers known to mankind: that of manipulating the genome. Who can say for sure that it will be used only for the avoidance of hereditary illnesses?

Vaquin's apprehensions, echoed frequently by scientists and social analysts alike, indicate that the shadow of eugenics hangs over any discussion of the social implications of human genetics but particularly over consideration of the potential impact of the human genome project. People wonder whether the eugenic past forms a prologue to the human genetic future.

Eugenic ideas go back to at least to Plato, but in its modern version, eugenics originated with Francis Galton, a younger first cousin of Charles Darwin's and a brilliant scientist in his own right. In the late nineteenth century, Galton proposed that the human race might be improved in the manner of plant and animal breeding—that is, by getting rid of so-called undesirables and multiplying the so-called desirables. It was Galton who named this program of human improvement "eugenics" (he took the word from a Greek root meaning "good in birth" or "noble in heredity"). Through eugenics Galton intended to improve human stock by giving "the more suitable races or strains of blood a better chance of prevailing speedily over the less suitable."

Galton's eugenic ideas took popular hold after the turn of this century, developing a large following in the United States, Britain, Germany, and many other countries. Eugenic organizations were formed, including, in 1923, the American Eugenics Society, which, among other things, annually mounted eugenic exhibits at state fairs. The backbone of the movement was formed of people drawn from the white middle and upper middle classes, especially prominent laymen and scientists, particularly geneticists and often physicians. Eugenicists declared themselves to be concerned with preventing social degeneration, of which they found abundant signs in the social and behavioral discordances of urban industrial society. For example, they took crime, slums, and rampant disease to be symptoms of social pathologies, and they attributed them primarily to biological causes—to "blood," to use the term of inheritable essence popular at the turn of the century.

To eugenically-minded biologists, the causes of social degeneration were understood as matters to be rooted out, which led some of them to pursue research in human heredity related to eugenics. As a result, the human genetics research program of the day included the study of medical disorders—for example, diabetes and epilepsy—not only for their intrinsic interest but because of their social costs. A still more substantial part of the program consisted of the analysis of traits alleged to make for social burdens—traits involving qualities of temperament and behavior that might lie at the bottom of, for example, alcoholism, prostitution, criminality, and poverty. A major object of scrutiny was mental deficiency—then commonly

termed "feeble-mindedness"—which was often identified by intelligence tests and was widely interpreted to be at the root of many varieties of socially deleterious behavior.

In the hope of explaining these pathologies biologically, eugenic researchers resorted to Mendel's laws of heredity, which had been rediscovered in 1900, fastening on the idea that biological characters were determined by single elements—which were later identified with genes. Their research was pervaded by the fundamental assumption that not only could such physical characters as eye color or disease be explained in a Mendelian fashion but that so also could characteristics of mind and behavior. Charles B. Davenport, the prominent American biologist, eugenicist, and head of the biological laboratory that, in 1918, became the Carnegie Institution of Washington's Department of Genetics, located at Cold Spring Harbor, on Long Island, New York, searched for Mendelian patterns of inheritance in many behavioral categories, including the inheritance of what he called "nomadism," "shiftlessness," and "thalassophilia"—the love of the sea that he discerned in naval officers and concluded must be a sex-linked recessive trait because, like color blindness, it was almost always expressed in males. A chart displayed at the Kansas Free Fair in 1929, purporting to illustrate the "laws" of Mendelian inheritance in human beings, declared, "Unfit human traits such as feeble-mindedness, epilepsy, criminality, insanity, alcoholism, pauperism, and many others run in families and are inherited in exactly the same way as color in guinea pigs."

Some eugenic investigation into human heredity proved to be meritorious, revealing, for example, that Huntington's chorea results from a dominant gene and albinism from a recessive one. However, much of it was recognized in the end to be worthless. Combining Mendelian theory with incautious speculation, eugenic scientists often neglected polygenic complexities in favor of single-gene explanations. They also paid far too little attention to cultural, economic, and other environmental influences in their accounts of mental abilities such as low scores on IQ tests and social behaviors such as prostitution. Like Davenport's behavioral categories, many of the traits that figured in eugenic research were vague or ludicrous.

Class and race prejudice were pervasive in eugenic science. In northern Europe and the United States, eugenics expressed standards of fitness and social value that were predominantly white, middle class, Protestant—and identified with "Aryans." In the reasoning of eugenicists, lower-income groups were not poor because they had inadequate educational and economic opportunity but because their moral and educational capacities, rooted in their biology, were inadequate. When eugenicists celebrated Aryans they demonstrated nothing more than their own racial biases. Davenport, indulging in unsupportable anthropology, found the Poles "independent and self-reliant though clannish"; the Italians tending to "crimes of personal violence"; and the Hebrews "intermediate between the slovenly Servians and the Greeks and the tidy Swedes, German, and Bohemians" and giving to "thieving" though rarely to "personal violence." He expected that the "great influx of blood from Southeastern Europe" would rapidly make the American population "darker in pigmentation, smaller in stature, more mercurial [...] more given to crimes of larceny, kidnapping, assault, murder, rape, and sex-immorality."

Eugenicists like Davenport urged interference in human propagation so as to increase the frequency of socially good genes in the population and decrease that of bad ones. The interference was to take two forms: One was "positive" eugenics, which meant manipulating human heredity and/or breeding to produce superior people. The other was "negative" eugenics, which meant improving the quality of the human race by eliminating biologically

inferior people from the population. The elimination might be accomplished by discouraging biologically inferior human beings from reproducing or entering one's own population.

In practice, little was done for positive eugenics, though eugenic claims did figure in the advent of family-allowance policies in Britain and Germany during the 1930s, and positive eugenic themes were certainly implied in the so-called "Fitter Family" competitions that were a standard feature of eugenic programs at the 1920s state fairs. These competitions were held at the fairs in the "human stock" section. At the 1924 Kansas Free Fair, winning families in the three categories—small, average, and large—were awarded a Governor's Fitter Family Trophy, which was presented by Governor Jonathan Davis, and "Grade A Individuals" received a medal that portrayed two diaphanously garbed parents, their arms outstretched toward their (presumably) eugenically meritorious infant. It is hard to know what made these families and individuals stand out as fit, but some evidence is supplied by the fact that all entrants had to take an IQ test—and the Wasserman test for syphilis.

Much more was done for negative eugenics, notably the passage of eugenic sterilization laws. By the late 1920, some two dozen American states had enacted such laws. The laws were declared constitutional in the 1927 U.S. Supreme Court decision of *Buck v. Bell*, in which Justice Oliver Wendell Holmes delivered the opinion that three generations of imbeciles were enough. The leading state in this endeavor was California, which as of 1933 had subjected more people to eugenic sterilization than had all other states of the union combined.

The most powerful union of eugenic research and public policy occurred in Nazi Germany. Much of eugenic research in Germany before and even during the Nazi period was similar to that in the United States and Britain, but during the Hitler years, Nazi bureaucrats provided eugenic research institutions with handsome support and their research programs were expanded to complement the goals of Nazi biological policy, exploiting ongoing investigations into the inheritance of disease, intelligence, and behavior to advise the government on its sterilization policy. Fischer's Institute, the staff of which included the prominent geneticist Otmar von Verschuer, trained doctors for the SS in the intricacies of racial hygiene and analyzed data and specimens obtained in the concentration camps. Some of the material—for example, the internal organs of dead children and the skeletons of two murdered Jews—came from Josef Mengele, who had been a graduate student of Verschuer's and was his assistant at the Institute. In 1942, Verschuer succeeded Fischer as head of the Institute (he would serve postwar Germany as professor of human genetics at the University of Muenster). In Germany, where sterilization measures were partly inspired by the California law, the eugenics movement prompted the sterilization of several hundred thousand people and helped lead, of course, to the death camps.

Since the opening of the DNA era, observers have wondered whether new genetic knowledge will be deployed for positive eugenics, for attempts to produce a super race or at least to engineer new Einsteins, Mozarts, or athletes like Kareem Abdul-Jabbar (curiously, brilliantly talented women—e.g., Marie Curie or Nadia Boulanger or athletes like Martina Navratilova—are rarely if ever mentioned in the pantheon of superpeople). Conferences on the human genome project almost inevitably produce expressions of fear that the state will seek to foster or enhance a variety of highly valued human qualities or characteristics. The apprehensions are not entirely unfounded. In Singapore in 1984, Prime Minister Lee Kwan Yew deplored the relatively low birth rate among educated women, contending that their intelligence was higher than average and that they were thus allowing the quality of the country's gene pool to diminish. Since then, the government, embracing a crude positive eugenics, has adopted a variety of incentives—for example, preferential school enrollment for offspring—to increase

fecundity among such women and provided similar incentives to their less educated sisters who would have themselves sterilized after the birth of a first or second child.

However, it is doubtful that advances in genetic knowledge will lead to a revival of attempts to produce a super race. While the human genome project will undoubtedly accelerate the identification of genes for physical and medical traits, it is unlikely to reveal with any speed how genes contribute to the formation of those qualities—talent, behavior, personality—that the world admires. Equally important, the engineering of designer human genomes is not possible under current reproductive technologies and is not likely to grow a lot easier in the near future.

Many commentators—for example, the late Nobel laureate biologist Salvador Luria or advocates of rights for the disabled—have cautioned that the human genome project is likely to foster a revival of negative eugenics. Since it will in principle be easy to identify individuals with deleterious genes of a physical (or presumptively anti-social) type, the state may intervene in reproductive behavior so as to discourage the transmission of these genes in the population. Indeed, in 1988, China's Gansu Province adopted a eugenic law that would—so the authorities said—improve "population quality" by banning the marriages of mentally retarded people unless they first submit to sterilization. Since then, such laws have been adopted in other provinces and have been endorsed by Prime Minister Li Peng. The official newspaper *Peasants Daily* explained, "Idiots give birth to idiots."

Negative eugenics appeared to motivate the European Commission when in July 1988 it proposed the creation of a human genome project for the European Community. Called a health measure, the proposal was entitled "Predictive Medicine: Human Genome Analysis." Its rationale rested on a simple syllogism—that many diseases result from interactions of genes and environment; that it would be impossible to remove all the environmental culprits from society; and that, hence, individuals could be better defended against disease by identifying their genetic predispositions to fall ill. According to the summary of the proposal: "Predictive Medicine seeks to protect individuals from the kinds of illnesses to which they are genetically most vulnerable and, where appropriate, to prevent the transmission of the genetic susceptibilities to the next generation."

In the view of the Commission, the genome proposal, which it found consistent with the Community's main objectives for research and development, would enhance the quality of life by decreasing the prevalence of many diseases distressful to families and expensive to European society. Over the long term, it would make Europe more competitive—indirectly, by helping to slow the rate of increase in health expenditures; and directly, by strengthening its scientific and technological base. To the end of fostering European prosperity by creating a "Europe of health," the Commission proposed to establish a modest Community human genome project, providing it with 15 million ECU (about \$17 million) for the three years beginning January 1, 1989.

Economics may well prove to be a powerful incentive to a new negative eugenics. Undoubtedly, concern for financial costs played a role in the eugenics movement. The social pathologies of the early twentieth century were said to be increasing at a costly rate. At the Sesquicentennial Exposition in Philadelphia, in 1926, the American Eugenics Society exhibit included a board that, in the manner of the population counters of a later day, revealed with flashing lights that every fifteen seconds a hundred dollars of your money went for the care of persons with bad heredity, that every forty-eight seconds a mentally deficient person was born in the United States, and that only every seven and a half minutes did the United States

enjoy the birth of "a high-grade person . . . who will have ability to do creative work and be fit for leadership." Thus it was reasoned, eliminate bad genes from the gene pool and you would reduce what are nowadays called state and local welfare costs, by reducing public expenditures for "feeble-mindedness" in its public institutional settings—that is, state institutions and state hospitals for the mentally deficient and physically disabled or diseased. Perhaps indicative of this reasoning is that, in California and several other state, eugenic sterilization rates increased significantly during the 1930s, when state budgets for the mentally handicapped were squeezed.

In our own day, the more that health care in the United States becomes a public responsibility, payable through the tax system, and the more expensive this care becomes, the greater the possibility that taxpayers will rebel against paying for the care of those whom genetics dooms to severe disease or disability. To be sure, the more that is learned about the human genome, the more will it become obvious that we are all susceptible to one kind of genetic disease or disability; we all carry some genetic load and are likely to fall sick in one way or another. Since everyone is in jeopardy of genetically based illness, then everyone would have an interest in a well-financed public health program—national health insurance—and everyone would have a stake in extending its benefits universally. However, not everyone's genetic load is the same; some are more severe and costly than others. It is likely that, on grounds of cost, even a national health system might seek to discriminate between patients, using the criterion of how expensive their therapy and care might be. Public policy might feel pressure to encourage, or even to compel, people not to bring genetically affected children into the world—not for the sake of the gene pool but in the interest of keeping public health costs down.

All this said, however, a number of factors are likely to offset a scenario of socially controlled reproduction let alone a revival of a broad-based negative eugenics. Analysts of civil liberty know that reproductive freedom is much more easily curtailed in dictatorial governments than in democratic ones. Eugenics profits from authoritarianism—indeed, almost requires it. The institutions of political democracy may not have been robust enough to resist altogether the violations of civil liberties characteristic of the early eugenics movement, but they did contest them effectively in many places. The British government refused to pass eugenic sterilization laws. So did many American states, and where they were enacted, they were often unenforced. It is far-fetched to expect a Nazi-like eugenic program to develop in the contemporary United States so long as political democracy and the Bill of Rights continue in force. If a Nazi-like eugenic program becomes a threatening reality in either the United States or a European country, its people would have a good deal more to be worried about politically than just eugenics.

What makes contemporary political democracies unlikely to embrace eugenics is that they contain powerful anti-eugenic constituencies. Awareness of the barbarities and cruelties of state-sponsored eugenics in the past has tended to set most geneticists and the public at large against such programs. Most geneticists today know better than their early-twentieth-century predecessors that ideas concerning what is "good for the gene pool" are highly problematic. Then, too, handicapped or diseased persons are politically empowered, as are minority groups, to a degree that they were not in the early twentieth century. They may not be sufficiently empowered to counter all quasi-eugenic threats to themselves, but they are politically positioned, with allies in the media, the medical profession, and elsewhere, including the Roman Catholic Church to block or at least to hinder eugenic proposals that might affect them. A staunch opponent of eugenics from the beginning of the movement, the Church took an official stand against it in 1930, in the Papal Encyclical *Casti Connubii*, which

also condemned birth control, sterilization, and free love. The Church's well-known opposition to abortion sets it against the kind of eugenics that spokespeople for the handicapped currently fear, since such a eugenics can be accomplished at the moment only by the abortion of fetuses determined to be "defective" by amniocentesis, ultrasound, or some combination of the two.

A typically anti-eugenic coalition rose up in response to the European Commission's proposal for a human genome project for predictive medicine after it went to the European Parliament for consideration. In the Parliament, primary responsibility for evaluating the genome proposal was given, on September 12, 1988, to the Committee on Energy, Research and Technology, which considered it in several meetings and, by late January 1989, was ready to vote on a report concerning the matter. The drafting of committee reports in the Parliament is guided by a member—a rapporteur—who is designated for the purpose and who can exercise enormous influence over the position that the committee eventually adopts. The rapporteur appointed for the genome proposal was Benedikt Härlin, a Green Party member from West Germany. Opposition to genetic engineering has been widespread there, and it has been especially sharp among the Greens, a disparate coalition united mainly by a common interest in environmental protection. The Greens' desire to preserve nature has been suffused with distrust of technology and suspicions of human genetic manipulations. The Greens had helped impose severe restrictions on biotechnology in West Germany and raised objections to human genome research on grounds that it might lead to a recrudescence of Nazi biological policies. As James Burn, a Scottish expert on biotechnology and a longtime resident of West Germany, once told a reporter, "Germans have an abiding and understandable fear of anything to do with genetic research. It is the one science that reminds them all of everything they want to forget."

The Härlin report, insisting that the European Community remember, raised a red flag against the genome project as an enterprise in preventive medicine. It reminded the Community that in the past eugenic ideas had had "horrific consequences" and declared that "clear pointers to eugenic tendencies and goals" inhered in the intention of protecting people from contracting and transmitting genetic diseases. The application of human genetic information for such purposes would almost always involve decisions—fundamentally eugenic ones—about what are "normal and abnormal, acceptable and unacceptable, viable and non-viable forms of the genetic make-up of individual human beings before and after birth." The Härlin report also warned that the new biological and reproductive technologies could make for a "modern test tube eugenics, "a eugenics all the more insidious because it could disguise more easily than its cruder ancestors "an even more radical and totalitarian form of 'biopolitics.'" Holding that the primary function of a European health and research policy must be "to block any eugenic trends in relation to human genome research," the report judged the proposed program in predictive medicine "unacceptable" as it stood.

Härlin actually wished to make it acceptable, not to reject it. ("You can't keep Germany out of the future," he later said about his own country's involvement in genome research.) On January 25, 1989, the energy committee voted twenty to one to adopt the Härlin report. It thus urged Parliament's endorsement of the European Commission's proposal as it would be modified by thirty-eight amendments contained in the report, including the complete excision of the phrase "predictive medicine" from the text. Collectively, the modifications were mainly designed to exclude a eugenically oriented health policy; to prohibit research seeking to modify the human germ line; to protect the privacy and anonymity of individual genetic data; and to ensure ongoing debate into the social, ethical, and legal dimensions of human genetic research.

In mid-February, 1989, the Härlin report whisked through a first reading in the European Parliament, drawing support not only from the Greens but also from conservatives on both sides of the English Channel, including German Catholics. The Parliament's action prompted Filip Maria Pandolfi, the new European Commissioner for Research and Development, in early April 1989 to freeze indefinitely Community human genome monies. The move was believed to be the first by a commissioner to block one of Brussels' own technological initiatives. Pandolfi explained that time for reflection was needed, since "when you have British conservatives agreeing with German Greens, you know it's a matter of concern."

The reflection produced, in mid-November, a Modified Proposal from the European Commission that accepted the thrust of the amendments and even the language of a number of them. The new proposal called for a three-year program of human genome analysis as such, without regard to predictive medicine, and committed the Community in a variety of ways—most notably, by prohibiting human germ line research and genetic intervention with human embryos—to avoid eugenic practices, prevent ethical missteps, and protect individual rights and privacy. It also promised to keep the Parliament and the public fully informed via annual reports on the moral and legal basis of human genome research. On December 15, 1989, The Modified Proposal was adopted by the European Community Council of Ministers as its common position on the genome project. On June 29, 1990—the Parliament having raised no objection—the common position was promulgated by the Council as the human genome program of the Community, authorized for three years at a total cost of 15 million ECU, seven percent of which was designated for ethical studies.

The eugenic past is a prologue to the human genetic future in only a strictly temporal sense—that is, it came before. Of course, the imagined prospects and possibilities of human genetic engineering remain tantalizing, even if they are still the stuff of science fiction, and they will continue to elicit both fearful condemnation and enthusiastic speculation. However, the near-term ethical challenges of the human genome project lie neither in private forays into human genetic improvement nor in some state-mandated program of eugenics. They lie in the grit of what the project will produce in abundance: genetic information. They center on the control, diffusion, and use of that information within the context of a market economy, and they are deeply troubling.

The advance of human genetics and biotechnology has created the capacity for a kind of "homemade eugenics," to use the insightful term of the analyst Robert Wright—"individual families deciding what kinds of kids they want to have." At the moment, the kinds they can select are those without certain disabilities or diseases, such as Down's syndrome or Tay-Sachs. Most parents would probably prefer just a healthy baby, if they are inclined to choose at all. But in the future, some might have the opportunity—for example, via genetic analysis of embryos—to have improved babies, children who are likely to be more intelligent or more athletic or better looking (whatever those comparative terms mean).

Will people pursue such opportunities? Quite possibly, given the interest that some parents have shown in choosing the sex of their child or that others have pursued in the administration of growth hormone to offspring who they think will grow up too short. Benedikt Härlin's report to the European Parliament on the human genome project noted that the increasing availability of genetic tests was generating increasingly widespread pressure from families for "individual eugenic choice in order to give one's own child the best possible start in a society in which heredity traits become a criterion of social hierarchy." A 1989 editorial in *Trends in Biotechnology* recognized a major source of the pressure: "'Human improvement' is a fact of

life, not because of the state eugenics committee, but because of consumer demand. How can we expect to deal responsibly with human genetic information in such a culture?"

The increasing availability of human genetic information challenges individuals with wrenching decisions. Purely for personal reasons, people may not wish to obtain their genetic profiles, particularly if they are at risk for an inheritable disease for which no treatment is known. Still, genetic testing, prenatal or otherwise, can be liberating if it reveals to individuals that either they or their newly conceived children are free from some specific genetic doom. A young woman tested and found to be without the gene for Huntington's declared, "After 28 years of not knowing, it's like being released from prison. To have hope for the future . . . to be able to see my grandchildren."

The problems and opportunities of individual choices aside, the torrent of new human genetic information will undoubtedly pose challenges to systems and values of social decency. Much of the discussion on this point has rightly emphasized that employers may seek to deny jobs to applicants with a susceptibility—or an alleged susceptibility—to disorders such as manic depression or illnesses arising from features of the workplace. Life and medical insurance companies may well wish to know the genomic signatures of their clients, their profile of risk for disease and death. Even national health systems might choose to ration the provision of care on the basis of genetic propensity for disease, especially to families at risk for bearing diseased children.

Many analysts have contended that individual genomic information should be protected as strictly private. However, a great deal more thought needs to be given to the rights of individuals to withhold and the rights of insurers to demand such information. Insurance, and insurance premiums, depend on assessments of risk. If degree of risk can be concealed, it is not insurance companies as such that will bear the costs but other policy holders. In short, it could be that classes of people with low risk will be compelled to subsidize classes of others at higher risk. Thus, insisting on a right to privacy in genetic information could well lead—at least under the system of insurance that now prevails in the United States—to inequitable consequences. However, that prospect seems unlikely in most of Europe, where a strong sense of social solidarity undergirds universal health insurance.

The eugenic past has much to teach about how to avoid repeating its mistakes—not to mention its sins. But what bedeviled our forebears will not necessarily vex us, certainly not in the same ways. In human genetics as in so many others areas of life, the flow of history compels us to think and act anew. It is important not to become absorbed with exaggerated fears that the human genome project will foster a drive for the production of superbabies or the callous elimination of the unfit. It is essential to focus on the genuine social, ethical, and policy issues—some of them already evident—that the human genome project raises, and to respond to them by creating codes of law and/or regulation for the use of human genetic information by geneticists, the media, insurers, employers, and governments themselves.