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GENOME: MORAL CHOICES AND THE POLITY

-- Thomas Fitzgerald

Summary

The Human Genome Project, now funded and coordinated by the Department of Energy and National Institutes of Health to identify the entire structure of human genetics, has recognized that in addition to long-range scientific challenges posed by its research, ethical, legal, and social consequences follow from application of the resulting information. The Project therefore raises serious questions for the people of this country, both as individuals and as members of political entities.

HGP and its associated institutions, however, have given relatively little attention to the procedures and settings by which those questions may be deliberated and possibly resolved. That in turn ought to raise other issues: about a growing occlusion of citizen participation in forums which involve professional and technological expertise, about the erosion of foundations upon which moral and ethical issues can be decided, and about the crowding out by scientific orientations of other legitimate forms of knowledge, understanding, and representation.

This very large Project can become the occasion for a significant--and divisive--reprise of debates about the wider implications of biological naturalism, such as were heard about Darwinism over a hundred years ago.

Years ago, when I was young and worked in a shabby industrial city in the midlands, I came across a small notice in the Sunday paper about a local theatrical group holding tryouts for a play. It was a minor revival piece I had not heard of, nor had I ever been on stage, but that afternoon I went downtown, read for them, and to my surprise got one of the leading parts. After the play opened, it ran for only a few nights, but the relationships formed in its doing changed the course of my life. A few months ago, I came across and responded to another small notice, this one inviting people hereabouts to sign up for and participate in a series of evening meetings sponsored by one of the state universities, to examine and discuss moral and ethical implications of the Human Genome Project (HGP).

If there is now less risk of my life changing, these discussions, not yet completed, introduced me to a remarkable new ground of scientific research. Funded through the Department of Energy and the National Institutes of Health, HGP seeks to define all the human genetic material and to construct a complete analysis—known as "maps"—of entire chromosomes with the ultimate goal of discovering and sequencing the approximately 70,000 human genes.

Only six years along, this effort is of interest not only for its ambitious scale, but because it raises important moral and political questions about potential uses of that knowledge. Many of those are as yet not publicly articulated, much less debated or resolved, but they join a central dilemma of our times: how to anticipate the "unanticipated" consequences of advanced, instrumentally effective technologies built upon a mass of abstruse knowledge? Remarkably little interest has been shown, moreover, in subsidiary questions about the relevance of the democratic process and the place of the polity in formulating decisions about bio–technology.

News about this research endeavor has, of course, been reported from time to time, often in the same style of acclaim as missile launches for space exploration. Journalists periodically delivery earnest if misleading accounts of the project's progress when reporting newsworthy items such as the discovery of mutations in the "breast cancer gene" [BRCAl/BRCA2].

Yet the hard questions and choices which await us in genetics have been mostly neglected in the media. Perhaps they are too complex to be translated into the presumptuous, up–or–down disposing of public opinion surveys to which we have become accustomed in other issues of human status...say, assisted suicide, or indeterminate sentencing of felons.

Darwinian Echoes

We need not claim history repeats itself to notice its similar themes and parallel lessons. To take an example at hand, the Human Genome Project, now well underway, presents an instructive comparison with Darwinism in the latter half of the 19th century. In both, a prominent scientific effort comes to serve the School of Naturalism, and in turn evokes ethical and moral conflicts which, since they are beyond resolution, become encysted in the culture.

When Charles Darwin published the theory that bears his name, it received wide attention, and although built upon extensive, well-documented observation, was disturbing to many educated people of his time. Yet he told a story that was by then awaiting the telling: All life began in simple cellular forms that, over millennia, randomly varied (“evolved" was the term) into much more complex organisms whose survival was governed by continual testing in difficult, even hostile environments, and in competitive struggle for existence among other species. Those which acquired favorable traits--the fittest--went on to multiply and proliferate into even more complex forms of life in endless branched diversity. He used an explanatory metaphor that has since become ingrained in our vocabulary: *Natural Selection*. It suggested an intelligent and prudent Nature choosing for continuance those creatures best adapted to conditions wherein they find themselves, while sorting out those less well endowed. Darwin argued that humans are the final stage, the most recent descendants of this immensely complicated sequence of biological development, but clearly are not outside or separate from it.

The idea of competition for survival as a natural process that improved the breed was soon put to use in politics as “social" Darwinism, to justify the ruthless economic system of the times while ignoring those impoverished by it. The concept of natural superiority and ascendance of one species over another was used by imperialist nations to justify their colonialist subjugation of indigenous people. Aside from the circularity of *whatever is, ought to be*, his theories were especially unsettling because they broke with traditional understandings of the status of human persons as particular creations of divinity, with all that implies.

Casting mankind back in with the deep pool of other species was seen moreover to threaten religion and people's faith in a transcendent order. If special creation of mankind were to be disproved, how could they continue to believe the rest of doctrine, or look forward to *eschaton* ? Despite those sensible old worries, and recent theoretical dissent--ironically not by religionists but scientists--the evolutionary perspective has become accepted as the commonplace explanation of how we got to be how we are. Now we find difficulty in thinking about our biological condition--or about ourselves--in any other way, even though Darwinian concepts are inconsistent with certain other beliefs we also carry along.

Early in its development, science made another move, the significance of which is generally unappreciated. Stepping back from its own inclusion in Nature, it mentally separated itself as if observing from an exterior prospect, so that Nature became a passive object for undistorted examination and unwavering intervention. Eventually, that objectifying gaze was turned back on the human person, who became one more object for inspection, utilization and improvement, that is to say, a “thingified" self. In so doing, an essential tension was introduced into the political status of persons, especially in liberal societies. Belief in human freedom, consciousness and agency, it was eventually realized, is radically inconsistent with universal causal determinisms asserted and continually extended by the several sciences. Additional tensions are suggested by psychologistic deconstructions of the concept of the self (Rosenau 1992; Fitzgerald 1996).

Science as Singular Mirror

Science's resolute will to know its objects so as to be able to control and utilize them has long been defended as necessary for progress and human betterment. These have indeed been achieved, but not without erratic distribution of benefits and large subsequent costs. Aside from a few notable exceptions, science closed off debate within its ranks about which ends and for whose purposes its instrumental means should be utilized. Required deference to the guild code--holding facts to be severed from values--seemed to settle such questions (Rabinow 1987). Whatever the cognitive claims of science, it has always been a specific, even peculiar way of knowing the world and its habitant species. We need to remind ourselves from time to time of how much that is important to us is routinely excluded from scientific attention.

The enormous success of technology, so prominent now in everyday life and built upon scientific research, has permitted almost everyone to forget that other kinds of knowledge have been disqualified from its realms. Notably absent is recognition of intrinsic worth in things, actions, or persons. Science is silent on moral goods, values, subjective meanings, and goals. Its work habitually assigns defining numbers (quantities, weights, scales, rankings, magnitudes, velocities, exaction measurement and so forth) to every kind of phenomena, but where it cannot do so, dismisses their significance. It simply looks past the aesthetic qualities and given presence of things all about us to focus instead on their neutral, material substance. And the idea that there may be realities, energies and effects which are inaccessible to laboratory methods, is still discredited, although with less ridicule now than in the past (Smith 1994).

The methods of representing the world which science sees gradually come to encroach upon or simply displace alternative explanations and practical understandings. This process of intrusion into everyday lifeworlds, a sort of colonization by a single orientation to knowing, is both inadvertent *and* intentional. Vast sums of public and private funds are invested in research projects throughout the developed countries, resulting in endless publicity supplied to the media about discoveries in every field, with the legitimating lead, “Science now says..."

A depersonalized and pretentious terminology assembled by the so-called social sciences has been adopted by governmental administration, while that mindset informs the professional and managerial education of those in the welfarist services industry. References there to persons in instrumental metaphors smuggles less conspicuous reductionist outlooks into our thinking. Empiricist attitudes of ordinary science are promoted in the schools from the early grades and its methods praised to the young as the source of knowledge most certain and usable.

At the same time, edification through teaching about ethical values is proscribed. Moreover, science-based technology continually produces and makes available wonderful devices for our comfort, enjoyment and distraction; the constant visibility and facticity of these things become indisputable evidence of science's unique superiority. Less surprising then if its positivist methods of data collection and detached analysis have become what we now consider serious thinking and problem solving to be. The story that science repeats--its portrayal of how the world is and what about that world deserves our attention--in time comes to seem like basic common sense. Bit by bit, other accounts, even those of long and reputable standing, are given up and we find ourselves surrounded by technocratic outlooks and materialist ontology (Borgman, 1992; Stanley 1978; Dupre 1993).

So too with news about successful research on our genetic structures. It not only competes for limited public attention, but subtly erodes the standing of alternative understandings of the character of human life. As its newly identified causal determinants are added to an already long list, the scope of the distinctively human correspondingly narrows, shrinking such valued notions as personal accountability and intention. A quasi-official model of the person is again reshaped to include more that is visible to the trained eye, while displacing sedimented beliefs honoring much that is not. Those who want to argue in civic forums from a quite different orientation to life and the world proceeding from another class of knowledge, start from a defensive position even when they have been granted a ticket of admission. A member of a professional panel can dismiss them *tout court* as anti-science, or as captive of the “extremist religious right." Either ascription provides the trump card to shut down whole sectors of dissent.

Large Questions, Ordinary Citizens

The unusual opportunity to participate in a public review of ethical and legal questions arising from new bio–technology—before everything is decided for us—attracted me to the discussion sessions. The group of between 40 and 50 local residents who turned up regularly (depending on the night) received a briefing on the purposes of the discussions. They were also given a course–pack outlining research on the human genome and how available information about genetic markers in oneself and family members (or even future family *in utero*) raises a variety of questions. Some of these also involve legal or market issues, such as:

Who owns the information about individual genetic readings?
How might it best be utilized and by whom?
How will "private" use of genetic information make demands on public funds?

To focus our discussion, we were offered lists of specific issues and encouraged to talk among ourselves in small groups and in open session about them. No attempt was made by the study grantees to persuade us toward one position or another. Conference leading was even–handed to make sure everyone who wanted to speak could be heard.

The first segments of directed topics revolved around the use by individuals of genetic knowledge about themselves. For example: If I intend to have children, am I morally obligated to know about my own genetic endowment? Should I be expected to tell my spouse, or a prospective one, of a serious genetic impairment? If parents know that a child has a genetic predisposition to a disorder or disability that may develop in later years, can they ethically withhold that information from the child? Questions along this line were not difficult ones for the group; they seemed to regard them as matters of personal inclination and practical judgment, as they might respond to similar low involvement items asked by pollsters. In this segment however, and in those that followed, group comments expressed worry—and the familiar distrust prevalent among citizens these days—of insurance companies and employers being able to get hold of individual genetic records and then use them to deny coverage or jobs. A related concern was whether—after universal national health insurance is eventually passed––government will seek to reduce the costs of care by requiring premarital genetic screening for particular disabilities.

Other segments were more troublesome. As the technology and facilities become available, couples will be able to have prenatal genetic testing to determine if their unborn child is at risk for a serious genetic disorder. This in turn raises questions about moral responsibility to undergo such tests, especially where the child might be expected to inherit a predisposition towards severe disability, such as Tay–Sachs, cystic fibrosis, or Down syndrome, or early onset of schizophrenia, breast cancer, or diabetes. If so, will specialized care and treatment be available for the child? To paraphrase one question, How should the "best interests" of the fetus, other children, the parents, and society be "balanced" or "aligned"? And in that process, what advice or assistance should health professionals give to the parents? Alternatively, should prospective parents be permitted to have prenatal tests of any sort, even to determine the sex of the embryonic child, if this would lead (as many expect) to aborting a less–than–desired child? Will widespread utilization of testing lead to further destabilizing the status of the fetus? Or drift toward alteration of germ lines with selective breeding as a new eugenics-lite...bio-engineering without odious ideology?

Although infant disabilities show a wide range of severity, the worst of which are not of common occurrence, various members (understandably) had difficulty discussing questions like these because they were uncomfortable with the prospect of more abortions. And while discussants were mostly able to make judgments for themselves, with no one declaring "It's all relative!", they were reluctant to claim that their own moral choices ought to be generalized into law, that is, to put behind their own judgment the power of the state to compel or forbid this or that action by millions of others not in the room. May the few bind the many?

Discomfort increased in a later segment when the group began considering screening of embryos fertilized outside a woman's body on laboratory glassware...*in vitro*, as it is called, and it involves numerous ambiguities. In that procedure, several embryos result, still at a quite small stage of only eight cells. From those showing favorable genetic disposition, one or more is "implanted." Remaining, or surplus embryos can be made available to other childless couples, or stored for a time for future use. Or they can be "discarded."

Other discussion segments took up questions concerned with "genetic justice," itself a puzzling concept. Assuming again a "just and caring society" with always limited economic and medical resources, what should be the priorities for making available genetic tests, and for whom? Will excessive emphasis on genetic testing and intervention reduce available funds for other sorts of health improvement? Which "needs" presumably make first claims on public funding? Or what portion of those expenditures (including cost of care for those born severely disabled) should be fairly paid for by insurance companies or individuals? Here especially the rumblings of class discrimination have been heard elsewhere, and can be further anticipated, with partisans asserting new entitlements or seeking to redefine public policies regarding parental responsibilities toward children.

Advocates for the disabled, moreover, have advanced the odd argument that a decision of parents to forego having a disabled child (based, for example, on tested genetic predisposition) constitutes discrimination against the disabled. They also warn that as genetic technologies come into general and even competitive use, those who are born disabled will be further stigmatized, along with their parents. Others have raised searching questions about the normative bases, the assumed criteria used to designate (or constitute) impairment, disability, disease, dysfunction, or abnormality itself.

I found the meetings instructive and was pleased to be part of a community discussion where veteran activists did not attend to turn it into the sort of contentious, competitive, accusatory exchange which succeeds in driving away ordinary people. Instead, this was public exchange where civility prevailed, in part perhaps because some of those present were willing simply to listen and learn from the talk back and forth, while some others were past child–bearing age and thus felt less emotional involvement with questions the study presented. A consensus of judgments was not finally evident, although results may differ from similar meetings held in six other areas of the State.

An Absent Polity

The declared intention of the convening grant holders is to bring all these collected views into a larger conference of professionals and officials. As the principal investigator said at the project's start, the goal is to provide citizen input "to enable policy makers to make rational choices." Reassuring as that could be if it were achieved, the country's political process in recent years would suggest the outcome is less than likely.

Plain people who present themselves as participants at subsequent occasions of deliberation about implications of genome knowledge—other than in a limited study of participation itself—will simply be overwhelmed. Members of the medical and legal associations, representatives of health insurance and hospital corporations, medical equipment manufacturers, clinical service providers, public health agencies, grant recipients in university departments, planning and consultant groups seeking contracts, certain major foundations and think tanks...they will fill the chairs, set the agenda, and hold the podium. These are the people who are able to make themselves heard and who surely will be heard at venues that count, whether open or restricted. They will also exercise a conclusive influence in shaping and steering legislation, policy formulation, administrative rule–making by agencies, guild publications, training graduate students, and other sorts of leverage the rest of us scarcely know about. Against this array, ordinary citizens can have little impact, even if they slip past the gatekeepers.

How formidable this array of expertise and interests really is can be seen by reviewing the calendar of conferences published by the Human Genome Management Information System. It shows 70 meetings on genome bio–technology scheduled for the first half of 1997, with topics from arcane fields of study expressed in the privatized language of high science inaccessible to a lay public and convened at places like Santa Fe, Lake Tahoe, Maui, and Hilton Head, where the monastic rigors of experimental lab work can be balanced out.

To its credit, HGP has recognized that greatly increased knowledge of human biology and availability of genetic information about ourselves will raise complex questions. Provision was therefore made for allocation of funds from agencies' budgets at something under 5 percent for ELSI ("ethical, legal, and social implications"). Several working groups and task forces have been studying the issues and have made grants for activities to address ELSI concerns. Last year a join NIH/DOE audit committee was established to evaluate the work done so far in ELSI programs; it later called for reorganization and other moves to increase public awareness of the issues and to insure independent critique of those programs (NIH/DOE Audit Committee Report, 12/96).

We can scarcely expect ELSI, whatever its resources, to confront the ongoing devolution of democratic participation or the essential opposition between our two cultures of political decision. One is driven by the engine of technological science, ever confident of systematic research and professional skill to diagnose and solve problems, especially if not encumbered by unqualified locals. The other culture relies on civic virtues sedimented from practiced equality of franchise, long ago declared by freeholders. In a curious anti–dialectic, these distinct orientations grow further opposed. Technical expertise and its elaborate equipment become more inaccessible to lay intervention, and at a time when citizens are less disposed to take on the difficult task of preparing themselves to challenge it. Then there's that "image problem": scientists are dependably prestigious and their findings therefore authoritative, but who ever heard of a prestigious factory hand or shop clerk? Without making it obvious, the latter are routinely left out of occasions of debate and decision by a whole new Estate—a knowledge class of *cognoscenti*– – that has wedged itself between the elected and the electorate. As Michael Walzer notes, "Citizenship is today mostly a passive role: citizens are spectators who vote." (Walzer, 1991).

While journalists have amply reported dishonest electoral campaign practices, they look away from the frame-by–frame occlusion of popular sovereignty by ascendant expertise, and from changes within the electorate itself. Intellectuals on the Left especially have been puzzling in print about The People. While progressives' own platform and programs are in disarray, their hopes have also been lost that the working class, with or without immiseration or a vanguard, will finally leap from the wings to take history's center stage. How to mobilize them now for liberation--or any cause? (Gorz, 1993; Narr,1985). Multitudes sit day after day before the Box, consuming without complaint the corporate manna of fantasy, distraction and deception. These pacified proles become even more of an embarrassment than Marxist *lumpen*. In countless sitcoms and audience fun shows run by celebrity ringmasters, they allow themselves to be made out as buffoons, even colluding in those circus-like performances. Worse, the People have been dependably portrayed by *berühm*t academics as mere aggregations, moved about by remote forces and material factors which one or another version of false consciousness conceals from them—but not, of course, from wise sociologists.

We keep hearing declarations from the nation's capitol that we need a "national debate" about this or that important question, and we will hear this call again as the difficult issues arising out of genome research find their way to public attention. But we know we won't get to have such a debate. As usual, some of our presumptive stewards will appoint themselves to speak in our stead. Or TV networks will offer us "town hall" shows, stage–managed Potemkin villages with dressed up peasants chosen to read their few lines. Or we can listen for hours to fragmented, self-congratulatory issue–chats on National Public Radio to which screened callers are briefly admitted. Or we will get acres of desiccated, decontextualized numbers from the nodding and wagging of "opinion" polls, the invited show of hands that suggests the truncated democracy of plebiscites.

In our present circumstances, can anything be said for participation by the lower ranks? Do they still have relevance in forums of the larger society whose affairs are increasingly directed from a distance and informed by nameless expertise? From the opposed pole, and in contrast to classic, "oversocializing" structural-functionalist theory, those who comprise the biggest part of the polity can at least be respected as purposeful, capable agents, aware of what they are about. They have their own solid sense of being–in–the world and a healthy recalcitrance, informed by practical experience in particular milieus in which they are immersed (Geertz, 1983; Giddens, 1979; Bauman, 1989). At their best (and without sentimentalizing them), they may be guided by immanent moral understandings and intuitions of their own transcendent nature. Their ideas about, say, democratic governance or meanings of the Good, will often be articulated in vernacular speech, unedited, dispersed, and often hesitant, styles that do not play well in media or other quasi–official venues. To assert that members of the polity deserve equal time to be heard, of course, invites dismissal as populism or as nostalgia for democracy. Even if not deliberately excluded by overclass networks, citizens notice how they are passed–over and ignored. The extent and effects of this fencing-out need not be overemphasized, anymore than other strains on democracy: the corrupting influence of large campaign contributors, the plague of insider lobbyists, or the usurpation of legislative authority by the courts. In concert, however, they cannot but undermine the legitimacy of the state.

Ambiguities and Worries

Over 40 years ago, Francis Crick and James Watson discovered the double helix structure of DNA and provided among much else a frame for systematic exploration of human genetics. Less than a decade later, Thomas Kuhn published his tract on historic paradigm shifts in science. In it he tried to explain that more is involved with a shift in a scientific paradigm than reinterpretation of sets of data: "...though the world does not change...the scientist afterward works in a different world." (Kuhn, 1962, p. 121). Which is to say, he or she will see the same things as before <u>differently</u>, as in a gestalt switch that cannot be reversed. Later Kuhn admits that the classic question—"what must the world be like in order that man may know it?"—remains unanswered (ibid., p.173).

Those speculative thoughts point to epistemic consequences of biotechnology's explorations, not only for scientists, but for the populace, whose own views about themselves eventually shift with dissemination of scientific perspectives. Although reductionism is a familiar social misuse of scientific knowledge, reducing people to their genes and chromosomes has not yet become a serious issue, despite idle references in the press about a "queer" gene or alcoholic gene. Those who speak for HGP deny any intent to reduce people to their chromosomes or to ascribe their doings to molecular-biological propensities. Other misuses run deeper, and are less apparent. One effect might be called crowding out. With substantial causal determinants being added to an already long list, the scope of what is assumed to be a distinctively human agency correspondingly narrows. The publicly held cognitive model of the person is again reshaped to include more that has been made visible, while encroaching on older models honoring so much that is not. News about successful applications of new genetic knowledge not only competes for limited public attention, but adds weight to the side arguing against a transcendent understanding of life and its circumbient reality. Empiricist reconfigurations of *humanus*, going back to dissections by anatomist Andreas Vesalius in the 16th century, continue down to our own time, notably by researchers experimenting on electro–chemical brain functioning. With genome mapping the latest methodological tool, we witness a further hollowing out—however unintended—of the unitary and distinct character of human persons.

Related changes are subtle, unannounced to consciousness, unarticulated but felt nonetheless. For example: as genetic testing of infants, both pre- and post-natally, becomes available for a wide spectrum of identifiable susceptibilities, a new calculative orientation is inserted into child bearing because genetic valences, like other consequential knowledge, once learned, cannot easily be put aside. Ambitions by those couples intent on having a "better" child, or aspirations by others to have a defect-free one, can invite hesitation about initiating conception, or perhaps later worries about ending a questionable pregnancy, as others of their acquaintance may do. In this manner, an unremarked shift in perspectives occurs from which the child is seen as *project* instead of *humanus*, valid and worthy in itself. That in turn tends to distance and displace the immediacy, the natural acceptance and embracing of the new life given and granted to the parental pair, the novel creature who enters and joins their lives. Put another way, the marketing economist's concept of "buyer's remorse" now impinges on, and can taint the spontaneous satisfaction of generativity known over the centuries [Meilaender, 1996]. Jürgen Habermas, we might recall, has been warning from a larger conceptual framework, of a central theme of our times: the expansion and migration of rationalizing, objectifying logic appropriate for institutional systems to encroach upon and colonize everyday life worlds.

Put another way, the cognitive practices of authoritative, molecular level genetic research, by expanding certain dimensions of that which is seen and recognized as significant reality, inconspicuously strengthens notions of physicalist naturalism. When combined with certain conceptual trends in late modernity (Sass, 1992), that extensive work contributes to diminishing confidence in the integrity of self, to the "erasure of the subject" and to a further thingification of persons. *Regard!* researchers seem to say, we have now reached into every far corner of this apparatus, examined and emptied every receptacle, and find no homunculus in charge there, no mind or will, no spiritual essence. Look at our maps; see for yourself!

Is it unfair to say that such a cognitive shift anticipates an ideology serviceable for future totalitarians? After all, geneticists and their entourage, chatting over drinks at a conference reception, look so nice, hardly like ontological subversives. But as debris piles up from objecification's endless scrutiny, it buries arguments once easily summoned for defending the singularity of human nature. Very many small compromises and the familiarity of intrusive interventions over the years wear down local traditions and alter commonsense understanding. Already, revised attitudes toward humanity are evident in certain quasi-medical practices: the disgraceful transplanting of a baboon heart into a human chest, the storage and sale of the seed of anonymous men, the hurrying along of the dying so their organs can be "harvested." In psychiatric hospitals, invasive procedures----"ice-pick" cranial surgery, overdosing with psychotropic drugs, and repeated convulsive treatments--become accepted both by reference to remote authority, and with the remarkably persuasive process of routinization and habituation. One cannot fail to notice how various new procedures, such as fertilizing eggs outside the womb by whomever followed by implantation in whoever, represent a turning away from the continuity of ancient accounts of special creation:

> *YHWH, God, formed the human of dust from the soil, he blew into*
> *his nostrils the breath of life, and the human became a living being.*

* * *

Ethical Codes and Transient Guidance

Ordinary understanding recognizes hazard entwined in everyday life; it will always move among us. Prudence alone cannot separate us from happenings unannounced: novelty and surprise, meetings by chance, disturbances to routine that unwind later, the missed sign, random intersecting on the street, or in the blood. Uncertainty continues if only because the joining of two lives in conception remains beyond prediction in the momentary instance. Even the encounter and conjunction of man and woman, first in love, then in marriage, is, in itself, a mysterious business. People in medieval times, down to Machiavelli's Prince, could refer to *Fortuna* as a way of confirming turns of fate, sudden disaster or arrival of unexpected riches. Enlightenment rationality offered emancipation from such superstition by disclosing the workings of causality in things great and small, but with epistemic methods that left out much of what previously counted and reduced variety to fit constrained models. Its formulations were eventually translated into numerical calculations, including statistical probability theory and risk profiles, welcomed as an administrative tool for control, and for assessing uncertainty where it cannot be eliminated. (Giddens, 1991).

The literature on application of emerging genetic knowledge to situated individual lives frequently notes the need for "counseling" to "deal with" the anxiety that will accompany client decisions in reaction to uncertain findings and ambiguous forecasts of genetic tests. The degree of future genetic risk, e.g., can be difficult to calculate because it involves interpretation of records of incidence, not always known, of related disability for family members shown on a generational tree. Without question, help will be needed for people to clarify and make sense of the information received and its possible implications. Some of this will be similar to the straightforward advice and question–answering already common in medical practice such as elective surgery.

The situation of HGP is becoming reminiscent of nuclear power, once celebrated as a triumph of science, but which brought widespread insecurity. As genetic research proceeds, more reports will be published showing statistically stated predisposition or lack of it toward numerous disorders and disabilities of greater or less severity connected to variability of inherited genetic material. Eventually, people will be able to obtain, at a price, diagnostic printouts of their own arbitrarily given genetic valences, inscribed in numerical arrays. In many instances, estimates of early or late symptomatic appearance in the individual will be inexact, hence a source of either worry or hope. Moreover, gene mutations--more often harmful than favorable--occur spontaneously or from environmental insult, as well as from combinings and interactions of genes of biological parents in the first instance. People who learn they have inherited a genetic pair indicating a statistical probability of (n) chances to develop to develop a severe, perhaps fatal disability, may feel alarm or panic or grief, without assurance that medical correction is possible or accessible. Other clinical situations will present ethical and moral dilemmas, the resolution of which must be attempted within the context of a particular, not abstract family. As Reason looks away from fates most unreasonable and irrational, perhaps genetic counselors will occupy themselves with the work, once thought religious, of resignation and reconciliation.

Here one might wonder about the kind of counseling that institutional planners expect, not only in regard to its quality and extent, but its foundations, especially now that new strains are being felt between the public health model of intervention as against the classic physician/patient model of care. Experience over the past half century is hardly encouraging: expansion and proliferation of the therapy industry (with courts routinely mandating its intrusions), guided by the airy rational–individualist mentality of many of its counselors. After federally funded health insurance is established, we can foresee individuals and families being sent to a ministerial–like civil therapeutics that will supplement the civil religion now widely practiced. As Alan Wolfe puts it in <u>Whose Keeper?</u> modern welfare states have become moral agents, "engaged in the business of regulating moral obligation, even in the absence of a moral language to do so." (Wolfe, 1989, p.129). In journal articles, a recurring vocabulary sounds the *Stimmung* of medical ethics: reproductive liberty, personal autonomy, privacy and confidentiality, equity, felt needs, individual rights, social interests or harms, access to resources. These user–friendly terms can distract us from noticing not only their mutual tensions, but that Utilitarian costs-*vs.* benefits consequentialism still rules professional domains.

If such an ethic is to inform the training of institutionally employed advisors,it deserves public attention. An unstable target, however, since it continues to shift in its actual practices, as one barrier after another is breached. In secular ethics, a seamless course moves from many small steps, each of which seems to follow logically from the preceding one by easy glissades of relativizing and equivalence. Will not successful cloning of humans (perhaps in another country) then be used to justify experiments in cloning human-simian hybrids? Such back-tracking of Darwin's evolutionary sequence would inevitably produce brutish anomalies or monstrosities. Less surprising then, if people these days feel threatened by late modernity's constant challenge of, "Well, *why not!*"

Are we not entitled to inquire about the moral principles upon which ethical, legal, social--and personal decisions are to be based? Yet when we look for a foundational basis for deliberating and deciding in whatever venues we might convene, we will find less guidance is available than might once have been expected. Contemporary epistemology has become divided by fundamental disagreements. In philosophy, or at least its most active branch housed in the universities, a mood of resignation has settled in, after some of its more persuasive figures, here and on the Continent, pronounced the end of metaphysics. What remains are contingent linguistic constructions and pluralistic perspectivist enclaves to shuffle between, with no authority left standing for adjudicating rival versions. (Rorty, 1991; Bernstein 1992; Solomon 1996).

After nominalism's rout of validity and truth, ethics finds itself something of an orphan left behind on the field. The theoretical foundations of physical science are also in disarray. (Berlinski, 1995, 1996; Horgan 1996). Quantum and high energy physics has continued to name obscure particles, and to multiply contradictions of locality, identity, and causality, thereby undermining the predictive, deterministic model which had supported normal science for three centuries.

Organized religion of Abrahamic faiths, which has long provided clear ethical and moral guidance and instruction, is also in quiet crisis. In some major denominations, traditional certitude about doctrinal fundamentals and resolute strictures have faded into comfortable relativism. Others are torn by dissent and by conflict between laity and clergy, and clergy and hierarchy, with apostasy, new schism, and heresy reminiscent of an earlier age. Although we hear praise for contemporary theological pluralism, ecumenical solidarity seems further off than ever, in turn limiting a consistent and united response to moral conflicts inherent in the new genetics (and much else). A further difficulty is that the language of moral reasoning, once prominent in religious institutions, has fallen into disuse; its style and vocabulary now sound archaic, even to those who remain congregated (Bellah, 1991). Its decline, a serious loss elsewhere, will also be felt in deliberating complex questions about reproductive interventions, which require not clamorous marching on clinics, but sustained ethical reflection.

Prospects, Principles

In professional discussions directed toward the numerous and very serious questions about application of new genetic knowledge and technology, less interest has been shown about how and where practical, day-to-day decisions will be made. Not yet clear are the frames of respective decision roles among the various parties with interests, expectations, and responsibilities in an on-going process: individual medical practitioners, hospital and clinical corporations, research facilities, health insurers, third party payors, and of course, individual persons and families as clients. Conflict and differences there surely will be. Not surprising then if government is legislated into those wide-ranging relationships for rule-making, conciliation, financial subsidizing, and evaluatory roles. That prospect, however, is not without problems of its own. Experience suggests we will see creation of new agencies and staffs, official review procedures to approve or deny assistance, required reports that must be reviewed somewhere, compliance inspection schedules, provision of appeals and exemptions along with their adjudication, codification of precedents and case law, in turn implying attorneys who specialize in such matters, contests over competing utilities and rights in the courts, and judicial construction of further administrative rules to fill out *lacunae*. That seems to imply a new instrumentality taking on a bureaucratic character and set of interests of its own, an apparatus for producing impersonal decisions, also remote and inaccessible to citizen complaint.

Studies sponsored by the National Institutes of Health and the Department of Energy, and many of those done by related research, academic, and clinical organizations on implications of HGP have been weighted in favor of a particular, if loose configuration of quasi-official outlooks, assumptions, and cognitive orientations, not without disagreement between them. At the same time, we can note a turning away from certain other understandings of and concerns for our collective situation. The argument made here is about those other important, often neglected aspects which also demand our attention. Research dedicated to deciphering our deeply inscribed genetic codes leads to questions of application of that knowledge, and inevitably to profound questions around the meaning and worth of human life itself. Once again, as with Darwinism of a century ago, we find ourselves asking what we can believe about human personhood, and if civilization's long-standing trust in that distinct status can be sustained, especially against the encroachment of empiricism's objectification and relativizing. Those matters cannot be settled by the market, or by a governmental commission, however well intended or credentialled. New legislation, administrative agencies, or judicial regulation will not resolve them. They must be taken to the country. Inclusive public deliberations can be designed and established, so that those who want to participate will be able to do so; innovative communicative procedures have been recently tried out in practice, and ought to be given further attention (Dahl 1997).

My own view is that among our people--how many I could not suppose--an idea survives and prevails about spirit immanent in each of us, and our essential dignity as humans. That spirit, that dignity, are not chosen *values*, but intrinsic to us; are not rented costumes, but a permanent condition of our being that goes all the way down. A human nature is no less present because inward, it is simply known in other ways than our bodies are known. Neither excludes the reality of the other. As genetic nets are traced out in cells and delineated on imposing charts, they join ample evidence of our authentic physicality, regularities and difference already located by numerous earlier investigators, but are no more a complete account of us than our primal teeth, hide, and hair. To be encompassed is not to be fully defined.

We are well along into late modernity, some say in the end stage of a great epoch, perhaps at the threshold of another age for which we have yet no name. Notwithstanding all that implies for beliefs and believing, doing what is right is as real as a color; wrongs cannot be talked away or wished away. We may still strive with diligence and modesty to seek and advocate the Good, to realize it in choices moral and just. One prospect, then, from which to think about those newly decoded inscriptions written within ourselves. And what we ought to do, and ought not.

Biographical note:

After earning a graduate degree from a major university in economic and social theory and research, Thomas Fitzgerald worked in both government and industry, with special interest in examining and promoting organizational effectiveness and efficiency, and was an early promoter and initiator of participative practices among employee groups. He has been a co-founder of an agency that provides residential care for troubled youth, and has served on several public advisory boards, most notably, for institutionally structured health resources. At last count, he has published some 20 articles in educational, management and literary journals, most recently "The Future of Belief" in *First Things*.

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