

Genetic Citizenship:

Knowledge and Empowerment in Personal and Civic Health

A Concept Paper

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Bruce Jennings
Senior Research Scholar
The Hastings Center

For further information contact:

Bruce Jennings

The Hastings Center

Garrison, New York 10524

845-424-4040

Jennings@thehastingscenter.org

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I. The Problem of Genetic Literacy and Citizenship

The Human Genome Project and related genetic research have moved human biology and medicine to a new level. We now can identify genes (sections of the huge DNA molecule found curled in the nucleus of each cell of the body) associated with biochemical abnormalities that are in turn linked to symptomatic disease, dysfunction, and perhaps tendencies toward certain forms of behavior.¹ The mapping and sequencing of the human genome has already begun to transform the practice of medicine, and it promises to improve the health of individuals and societies around the world. It also threatens to create new forms of discrimination and domination both on a global level and within particular societies, including the United States.

Genetic science—and the technologies it spawns—are increasingly important forms of power and domains of public policy.² To be cut off from knowledge and information about the new genetics, and to be voiceless in the development of goals and regulations governing its use, is to be doubly disenfranchised. It is to be disenfranchised both in the political system in one's role as a democratic citizen, and in the health care system in one's role as a consumer of health care and a decision-maker, partner in the physician-patient relationship and increasingly in the future, as a subject or participant in genetic research.

This situation poses daunting challenges in America. Despite our enormous wealth, we have a highly stratified and unequal society.³ Despite our ethnic and cultural diversity, we continue to wrestle with racism and intolerance. Access to and utilization of the health care system is sporadic and limited for more than 50 million Americans. Furthermore, despite the remarkable achievements of our technical elites, we do a poor job overall in the area of basic science and health education. With the possible exception of computers, no area of science has received as much general publicity in the last ten years as genetics. So some level of familiarity with the subject is widespread; but most social research has shown that understanding of genetic science to be limited to broad generalizations and images, and to be concentrated, when it exists at all, on particular diseases or disorders in one's own personal or family health experience.⁴

The challenges posed by the new genetics and biotechnology cannot be met without a greater investment in, and emphasis on, that aspect of broad health literacy that might be called "genetic literacy" and "genetic citizenship."⁵ These terms of art carry a special meaning. Literacy literally refers to the ability to read, and difficulty reading and other linguistic barriers obviously hamper one's access to the information and understanding necessary for effective health decisions and health care. But just as the challenge is broader than this, so too the concept of literacy involves more than the provision of information. Literacy means both the ability to understand one's needs and interests and the power to act to protect and promote those needs and interests. This is true of health literacy generally and for genetic literacy in particular. To be sure, our society is rapidly becoming increasingly demanding in the way it requires individuals to master specialized information and complex technical knowledge. Yet the acquisition of

skills is a necessary but not a sufficient condition of genetic literacy. With genetic literacy, it does little good to equip people with functional skills in an unjust or coercive social milieu that makes it difficult to turn those skills into effective capacities and to engage in action that will promote and protect their health and other interests.

Hence, the critical function of the concept of literacy is not to identify flaws or shortcomings of particular individuals or of particular communities. Individuals and communities that currently lack effective literacy seek access to the skills and information necessary and will attain them if given an opportunity to do so. The critical function of the notion of genetic literacy is to focus on the context or the environment within which individuals and communities share information about genetics, try to understand the meaning of that information in their lives, and deliberate and debate with others how the applications of genetics should be used and for what purposes. In other words, genetic literacy must be understood as a “capacity,” which is a property not of the individual taken in isolation but of the individual in the context of a social environment that provides effective resources, rights, and freedoms. A capacity relies on the possession of effective freedom and rights by the individual and on a surrounding social and educational system that supports the development of that freedom.⁶

Literacy is empowerment, not simply a response to instruction. The absence of genetic literacy among large numbers of Americans bespeaks a systemic and structural flaw in our society, not a personal failure or inability to perform on the part of individuals. Similarly, citizenship is not merely a bundle of rights that may or may not be exercised at the personal discretion of the individual (such as the right to vote). It is a kind of freedom, a capacity that involves a particular set of activities and skills.

Citizenship is not like a commodity or possession one owns and uses (or not); citizenship is a form of life, a kind of social being that one can cultivate and pursue.⁷ In an authoritarian society the opportunities to cultivate that form of life may be non-existent. In a democracy they are open as a matter of right to virtually all adults, and when large numbers choose not to do so, they are not so much expressing a preference as calling into question the health and indeed the very existence of democracy.

In some ways, the problem of genetic literacy and genetic citizenship might be easier to approach if the vast majority were a tabula rasa, a clean slate, when it comes to genetics. But partial and distorting sources of genetic information and pseudo-knowledge abound, and they shape attitudes and beliefs that are difficult to change. These distorted sources of information often crowd out other more reliable, but also necessarily more complex, nuanced information, making the task of the public health educator and the genetic counselor all the more difficult.

For this reason, it may well be that familiar approaches in health education, such as personal instruction and information sharing, will not suffice. Genetic literacy may require the creation of active “publics” that seek out knowledge in the process of engaging in civic action as well as the provision of information to individuals. Genetic literacy may require community organizing and the deliberate creation of enhanced “social capital” or civic renewal no less than it requires the services of trained professionals to provide counseling.⁸ In short, genetic literacy may require, as its complement and supplement, some new forms of genetic citizenship.

There are a number of groups and projects around the country that are working to bolster the social capital and genetic citizenship of ordinary citizens, and particularly of

cultural and ethnic minorities. These efforts include the work of the Genetic Alliance; the joint HRSA/March of Dimes Genetic Literacy collaborative project; the Communities of Color Project of the University of Michigan, Michigan State University, and Tuskegee University; the Oregon Gene Forum; the Fred Friendly/Media and Society Seminars; and American Health Decisions, to name just a few.⁹ The purpose of this paper is not to summarize or describe these initiatives, but rather to explore a conceptual and theoretical framework that both undergirds such community based activities and provides a vision and orientation for them.

The discussion will proceed as follows. Section II presents at least the beginnings of a conceptual and theoretical framework for locating the project of increasing genetic literacy in the United States as a movement of civic renewal and democratic empowerment. Should all attempts to promote genetic literacy be assessed within such a framework? Doesn't this give undue weight to a particular political and ideological agenda whereas educational efforts should steer clear of such value commitments? Projects that attempt to develop genetic literacy and citizenship are not value neutral and cannot be. Such efforts have agendas of their own, and it is important for the sake of both consistency and trust that these agendas not be hidden. Who is served by such projects and what kinds of ethical and social values are furthered by them? Our choice is not to avoid questions of this sort, but to be open and reflective about them.

The Public Health Model. One important value orientation underlying projects of this kind comes from the field of public health. Public health has a very broad mission and covers a wide range of activities, some are functions of the state and others are initiatives of civil society, and are the work of various NGOs and community based

agencies. Public health aims both to protect society against disease and to promote population health. In public health, as with the World Health Organization, health is generally defined very broadly as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.”¹⁰

Clearly, increasing the population’s ability to become informed, prudent consumers of genetic services promotes health and is in keeping with the mission of public health. By the same token, it arguably also serves the mission of public health to empower people to better understand and control the impact that new genetic science and technology may have on the culture, attitudes and beliefs of other members of one’s own community of identification as well as other members of society more generally.

Traditionally public health has been viewed as an arm of the state, authorized to exercise “police powers” under the constitution and the law. This rather authoritarian and top-down conception of public health has recently been supplemented by a greater emphasis on working with affected communities to build their own health promoting and problem solving capacity. Living in a vital, well-functioning community itself seems to have positive health affects and hence helping to build such communities is a proper part of public health.¹¹

This new paradigm for genetics in public health also sees building respect for human rights as part and parcel of the steps needed to improve the health of the population and to achieve greater equity in the ways in which the burdens of disease are distributed across race, class, and ethnic group lines.¹² Hence in the public health paradigm the values of health promotion, respect for rights, equity, social justice, and

enhanced quality of life as an active participant in collective activities are among the most important values served by promoting genetic literacy and genetic citizenship.

The Democratic Model. A second, seemingly disparate perspective also sheds light on the objectives of genetic citizenship. That is the tradition of (small “d”) democratic political theory. The basic principle of democracy is that the moral authority of government rests on the active, informed consent of the governed. Within this seemingly simple precept there are two points of considerable complexity that have separated the various proponents of democracy for centuries. The first has to do with the scope of democratic consent; the second with the motivation behind democratic consent.

The scope of consenting activity gives rise to the distinction between representative democracy and participatory democracy. In the former the activities of consent are mainly limited to electoral rather than governing (policy making) activity. They are limited, that is, to the periodic choosing of representatives who will exercise government authority. In a democracy of the participatory type, the citizens themselves become lawmakers and are more directly involved in the policy making process. New England town meetings in local government, ballot initiatives, and trial juries are examples of this more direct kind of democratic activity. Campaigning, lobbying, and periodic voting in primary and general elections comprise most of the citizenship activities under representative democracy.

Concerning the motivation behind consenting or citizenship activity, the basic distinction in democratic theory is between (1) a form of political and civic behavior that involves deliberation, either in a group setting or as a solitary individual, to orient

oneself to the common good; and (2) a form of political and social behavior that involves the calculation of individual self-interest or group interest and the creation of a strategy to devise the most rational means to protect and fulfill those interests. The first of these may be called citizenship as deliberation, and the second, citizenship as informed and rational consumerism.

Notice further that each of these types of political behavior and motivation can be used in virtually any social setting; they are not limited to the sphere of electoral politics or government activity. They apply equally to the activities of local community life and civil society, which is comprised of various voluntary and community service organizations. They might even be applied to the behavior of economic actors in a marketplace or to the behavior of family members toward one another, insofar as the family is seen as an association of free and equal individuals where consent and participation in decisionmaking have a rightful place. Traditional patriarchal conceptions of the family are out of keeping with this outlook, much in the way the political theory of kingship or monarchy differs from the political theory of democracy.

What these four elements (representation/ participation; common good orientation/ self-or group interest orientation) of democracy have in common are the value of respect for persons and the value of being treated as an equal.¹³ The legitimate exercise of power must rest on the consent of the governed because ultimately no one knows better than the governed what is in their own best interest and in the common good. All voices and all value orientations should be heard. No competent adult should be excluded from the practice of consent if he or she is willing to assume the responsibilities of membership or citizenship; the assumptions of natural superiority and

hierarchy that accompany non-democratic ideologies are absent in democracy.

Horizontal relations are valued over vertical ones. A basic faith in the intelligence and perceptiveness of the common person pervades democratic thinking.

It must be said that while democracy respects and values all groups, not all groups value democracy. The ideals of equality, inclusiveness, and solidarity do not fit well with the traditional beliefs and practices of many religions and cultural groups. So initiatives to promote genetic citizenship, particularly those that are based on a deliberative procedure, may not be readily embraced. The reasons for this reluctance may be insightful and deep. They may go beyond the sheer complexity of the subject matter, and its seeming distance or irrelevance to the community. And they may go beyond historical mistrust and suspicion that some communities feel about something that is perceived to be brought in by outsiders. In addition, there may be a sense that the purpose of these meetings is not only to inform or empower the members of the community, but also to transform them morally and politically. This suspicion is not without foundation.

The stream of contemporary political theory upon which I draw is known as “deliberative” or “discursive” democracy.¹⁴ Its basic notion is that public policies are ethically justified and legitimate to the extent that they emerge from the reasonable deliberation of free and equal citizens who will be significantly affected by them. This approach to democracy is in contrast to alternative approaches that see democracy primarily as a matter of constitutionally established electoral and representational processes, and those that see democracy as a system of interest-group negotiations and bargaining to determine the distribution of various kinds of resources. The first of these

is purely passive and procedural. The second lacks a basis for criticizing existing power structures, focuses the attention of citizens on specific personal and group interests, and drives a wedge between the practice of politics and moral ideas such as justice and the common good.

My thesis is that to understand the concept of genetic citizenship within a democratic framework leads us to draw on both the stream of deliberative democracy and interest-group democracy. Thus I believe we need to consider two forms of citizenship that genetic literacy will enable and empower people in the context of the social uses of the new genetics: deliberative citizenship and informed consumerism.

This hybrid approach enables us to draw conceptual tools from both the democratic and the public health orientations, with the internal richness that each of these orientations currently provides. Eventually the participatory, deliberative elements of democratic theory may converge with the civic elements of public health to produce a rich and conceptually powerful, as well as practically useful, program for action and social change. For the moment, however, a more eclectic approach recommends itself. Efforts at promoting genetic literacy and genetic citizenship can supplement conventional representational, interest group bargaining politics and the informed consumerism of the liberal public health tradition with this more participatory, deliberative and civic orientation.

Next, in Section III, I discuss some aspects of the understanding of genetics that is emerging in the popular culture, or social knowledge base, of Americans.¹⁵ Thus far the promotion of genetic science and research in the media and in numerous public debates and statements by scientific, religious, and other groups have created a kind of

folk wisdom around the topic of genetics. This folklore has several elements and dimensions, but at bottom it is a belief in genetic reductionism and determinism, which promises that advances in understanding of the structure and functions of human DNA will eventually enable us to control large areas of our lives and our health which heretofore has been beyond our ability to manipulate and control. If the link between genotype and phenotype were fully understood, we could predict an individual's health risks and susceptibility to various diseases with tremendous accuracy. Therapeutic interventions at the level of the DNA might reverse or prevent (in the context of in vitro fertilization [IVF]) many diseases, conditions, and disabilities. Various interventions at the genetic level may also bring about significant enhancement of certain biochemical processes, traits, or behaviors.

The flip side of this vision of promise and cure is the darker ability to test for “defective” individuals and those who are genetically determined to become ill later in life. Having identified such individuals by the indicators thought to be contained within their DNA, society may subject them to various kinds of limitations and discrimination, ostensibly for their own good or for the good of the “healthy” members of society who in some way need to be protected from such individuals. Imagine a public health response to infectious disease applied to genetics.

Clearly beliefs of this kind on topics like these have enormous significance for our personal, family, moral, and political discourse. Advances in genetic knowledge are here to stay. We shall have to find a way to incorporate them into the repertoire of common social knowledge, cultural “common sense” that individuals carry around with them. Such knowledge (or as I shall argue pseudo-knowledge) shapes political and

moral attitudes. It colors our deliberations and molds the way we perceive our interests, needs, and rights. No democratic society, no theory of citizenship, and no program of health literacy can afford to ignore this ideology and folklore. In Section III, I try to provide a brief discussion of several key elements that will be sufficient to assess the significance of these views for deliberative citizenship and informed consumerism, and how they should be handled by a genetics literacy program.

Finally, I return in Section IV to the democratic foundations of genetic literacy and genetic citizenship to sketch the dynamics of imaginative transformation through community dialogue, participation, and deliberation. This transformation—education and empowerment, literacy in the full sense of the word—can and must be brought about in the domain of genetics if we are to be successful in counteracting the very real potentiality for distorted understanding of self and society that is inherent in the popular reception of the new genetics.

II. Genetic Literacy and Political Theory

Community organizers, public health practitioners, and educators work directly everyday in neighborhoods and clinics helping individuals and families access health services and make sense of the often bewildering and sometimes seemingly offensive and outrageous messages of the new genetics. They see first hand the affects of a genetic test and a genetic diagnosis. They observe the power of genetics to shape a young person's self-esteem and body image; or to shape family relationships through the solvents of guilt and blame. And those with first hand grassroots experience also appreciate the need for the voiceless upon whom genetics is now practiced, so to speak,

to play a larger role in the ongoing social, cultural, and political conversation about the governance of genetics and biotechnology. The problem, they will tell you, is not a lack of intelligence, or even a lack of interest on the part of ordinary people. The problem more typically is a lack of usable and accurate information, presented in a way people at the grassroots level can understand. The problem is a lack of the resources and institutional capacities necessary to interpret the implications of that information, a lack of community organization to exercise an effective voice, and perhaps an absence of hope or optimism about the possibilities of ever organizing or making a difference on a subject seemingly as powerful and intractable as genetics, with the influence of science, corporations, and big money politics behind it.

Genetic literacy and genetic empowerment are practical, not theoretical endeavors. Conceptual analysis and discussion are useful in this field, nonetheless. The usefulness of theory comes first in naming the various experiments in community involvement and grassroots participation that are being developed, often in a rather seat-of-the-pants fashion, as the projects go forward. Like the man in Molière's play who did not know that he was speaking "prose," there is often a telling connection between what community groups are doing and general values and strategies that many other democratic and civic groups and thinkers have attempted before. To discuss the concept underlying such a strategy or value, therefore, is to place the activity in a historical and cultural context; it is to tie present efforts to those of the past, and it is to point beyond present activities toward future possibilities.

Moreover, analysis and clarification of the conceptual framework implicit in various civic activities make it possible to draw connections between aspects of a

problem that appear to be disparate and unconnected. Civic renewal and health literacy understood as a form of empowerment (not simply as information or instruction) in fact depend upon the capacity to see and to make connections in this sense. The sociologist C. Wright Mills clearly formulated this point when he said that the purpose of sociological inquiry (the “sociological imagination,” he called it) was to enable people to see that what they experience as “private troubles” are actually bound up with “public problems.” Civic engagement feeds on the imaginative capacity to see beyond the limits of one’s own situation and experience. Publics or communities are formed when a significant number of people develop that capacity and orient it in the same direction. To form a public is thus quite different from creating an interest group. A public is constituted by a perception of a shared or common good, not by a strategic alliance based on overlapping private interests.¹⁶

The medium through which this perception of the common good arises may take several forms. It is founded on shared or widespread experiences of a certain kind; such as the experience of struggling to gain recognition and respect for one’s health problems from a stressed and overextended medical care system. Such experiences are then filtered through existing forms and patterns of cultural meaning and collective understanding. This interpretative activity takes place at all levels and fills the interstices of a neighborhood’s or an ethnic community’s life. It is at work in conversations among women shopping at the market, and men on lunch breaks or in social gatherings. It is at work in houses of worship and service clubs. It is at work in political meetings or other kinds of civic assembly.¹⁷

Finally, these shared experiences form the basis for what might be called public judgments by being discussed and shared with other members of the community through a participatory process of deliberation.¹⁸ In deliberation, the ordinary discourse of story telling, and the attempt to make sense of what is happening by assimilating it to familiar cultural paradigms is focused by the exchange of reasons and justifications for one's position and by a concerted attempt to assess the significance of what is going on and, if deemed appropriate, to take some kind of collective action in response to the problem. Judgment and deliberation are activities of democratic citizenship par excellence. They build and exercise the sociological, or as I would prefer to call it, the civic imagination.

If we are to comprehend what is potentially at stake in current and future efforts at genetic literacy, we need to look carefully at several key concepts that traditionally have defined the space of citizenship, particularly participatory democratic citizenship. And it is no less important to examine what in contemporary America is often mistaken for democratic citizenship, namely, informed consumerism. Informed consumerism manifests itself most obviously and directly in our private lives as patients as we interact with health care providers and decide whether and how to make use of the available genetic testing, and genetically based drugs and diagnostic options. However, informed consumerism is part of our political lives as well, and as we interact with government, it is often held out as the proper orientation for us to take when we act as "constituents," as those who are the represented in the form of democracy known as representative, interest group democracy.¹⁹

Citizenship: Deliberation and Consumerism

I have referred to literacy as empowerment and to citizenship as a form of social life. In political theory these conceptions are not unknown, but they have not historically been predominant. More common are the notions associated with the outlook of interest-group liberalism and representative democracy in which literacy and citizenship are more individualistic, personal statuses, the one involving the mastery of knowledge, the other involving political and legal status.²⁰ But, as I mentioned earlier, there is an alternative tradition of democratic political theory, traditionally referred to as participatory democracy or direct democracy, now more commonly called deliberative or discursive democracy.²¹

Genetic literacy and citizenship come into play at two different levels in each person's life. One level is public. Genetic literacy is relevant at the level of public policy, the law, the federal political community and the sub-communities at the state and local levels. This is political citizenship as it is widely understood. In addition, they come into play as a part of the civil society that stands alongside political society in forming the public life of each of us. Civil society is made up of those non-governmental, voluntary organizations that are so prevalent in America, but which may now be declining.²² It includes churches, civic clubs, social groups, service organizations, unions, volunteer fire departments, and the like.

The second level is personal and familial. Genetics impacts the lives of persons and families in a myriad of ways, from family resemblances in outward physical appearances (phenotypes) to shared risk factors and family history for the development of various impairments and diseases. More controversial, but possible, is the notion that

family groups with similar genotypes share certain behavioral characteristics or certain propensities for certain forms of behavior. Increasingly genetics will play a role in the diagnosis and treatment of many types of disease, and not only the relatively rare disorders that have been associated with the practice of genetic medicine in the past.

In the future public health genetics policies and services will increasingly affect larger numbers of individuals and families, will demand increasing financial resources, and will be subject to more intense political pressure than has been the case in the past. State based newborn screening programs provide a pertinent example. In the coming years these programs will be challenged to find effective ways to bring broader grassroots and family input into the policy-making process as new tests arise that might be added to the current newborn screening panel. The policy process in many states now provides for lay or consumer representation on advisory boards, but while this may be effective for bring informed consumerism into the newborn screen policy discussion, does it also provide a vehicle for genetic empowerment and genetic citizenship? This is all the more important in as much as newborn screening is non-voluntary in many states and even where voluntary, meaningful parental consent (or refusal) is hard to obtain.²³

In sum, genetics affects the quality of our public (political and civic) lives and the conditions of our personal lives and health. A ubiquitous presence in contemporary consciousness, fueled by a constant drumbeat from the mass media, the new genetics seems to mold both our public and our private possibilities. And little wonder. Our broader economy is becoming increasingly focused on and dependent upon the commercialization and development of biotechnology in agriculture as well as medicine. It is not only educational opportunities, jobs, and the cost of health care that

are affected by genetics, but also the substance of the health care decisions and choices individuals have. Health care decisions increasingly involve some sort of genetic test, diagnosis, and treatment influenced in some way by genetic research.

Cutting across the fluid boundary between public and private life, the new genetics impinges upon the most basic social and cultural attitudes, beliefs, and practices in our society. Genetics is about inherited traits or conditions, and hence it inevitably touches on the most intimate and sensitive cultural domains—kinship, family, ethnicity, race, and personal identity. Genetics extends deliberate human manipulation into heretofore inaccessible and taboo areas such as human reproduction and gestation. Such experimentation touches upon deeply felt and highly controversial matters of religious teaching and faith.

The intersection of genetic literacy and genetic citizenship—the effect of genetics on the quality of our public lives and our personal lives—is only beginning. In the coming years, the issue of science policy regarding the new genetics will be receiving concerted attention at high levels of our government and the scientific research community. As the next phase of the Human Genome Project is discussed, the regulation of controversial uses of the new genetics is as important as strategies of technology transfer, patent rights, intellectual property, and commercialization. The social distribution of the benefits and burdens of the new genetics—access, priority setting, cost—is as important as the planning for the next generation of research topics—such as proteomics, pharmacogenomics, haplotype mapping, and the like.

These issues pose at least three fundamental questions about literacy and citizenship: (1) what is the nature and effects of genetic knowledge? (2) what constitutes

legitimate social control of genetic knowledge in a democracy? and (3) what are the prerequisites for, and conditions of, social and moral learning about genetics in a diverse, pluralistic society? These are fundamental questions about social knowledge, social learning, and politics. They lie at the heart of grassroots initiatives and public health.

One way to organize our thinking about these types of question is to examine the basic social and psychological orientation that may be taken in genetic citizenship, as it impinges on both public and private life. There are two basic orientations, the deliberative and the consumerist. The basic distinction between the two is that deliberation or deliberative citizenship is essentially a dialogic, collective activity, while consumption is essentially monologic, and solitary. When one deliberates one engages in a dialogue of arguments and counter-arguments, reasons and counter-reasons, with others. This dialogic character of deliberation is obvious when it is done in a town meeting or at some other community gathering; it may not be quite so obvious, but still remains the case even when an individual is alone thinking through a problem. An interior dialogue takes place in the person's mind as he or she imaginatively reconstructs the give and take with fellow citizens in a group setting. A decision reached through the dialogue of deliberation is not a personal or individual decision, strictly speaking, although each individual may share in the decision. It is a collective or common decision in the sense that it grows out of a process that has revealed a common good and a common resolve.

With decisions to consume, by contrast, the individual consults his or her own interior preferences, desires, goals, and personal values and makes a decision based on

the principle of realizing one's own self-interest through the act of consumption. The give and take of reasons does not assume the form of a dialogue in this case because even if others have given you their opinion or their advice about what to decide, those views are treated as external information (advisory opinions) only. The ultimate decision will be an individual decision taken by the individual alone as the final best judge of his or her own values and preferences.

This is true no matter what the object being "consumed." It could be a product or commodity, such as a new car. Or it could be a candidate's platform, character, or views which are made the object of choice and consumption by casting a vote for the candidate at election time, or deciding to donate money to a campaign, or even a decision to actively make phone calls or hand out leaflets. All of these are acts of citizenship as a form of consumption and consumerism, rather than citizenship as a act of deliberation.

In making personal health care decisions, the orientation of consumption is by far the most typical stance, and it is assumed to be what most patients now want and expect. It is not so clear what difference the model of deliberative citizenship would make in personal or clinical health care decisions, perhaps it suggests a model midway between old-fashioned physician paternalism, on the one hand, and the newer (largely consumerist) "contract" model of the doctor-patient relationship, on the other.²⁴ More in keeping with deliberative citizenship are situations that arise in the context of public health, where an individual may be said to have a civic obligation (and not only—or not even—a personal interest) to conform to certain restrictions on personal choice and freedom for the sake of protecting others from possible infection, or for the sake of

sustaining the entire community in a certain condition of health (so-called “herd immunity”).²⁵ As genetic information and analysis enters into clinical medicine, it will become harder to isolate the decision made by one family member and to say that it is an autonomous consumer choice because it essentially affects only the patient himself. A decision to be tested for a possible genetic condition may require the cooperation and testing of other family members to produce reliable findings. Or the outcome of a test on one sibling will effect, willy nilly, other siblings even if they choose not to be tested themselves. For these reasons, genetic testing often provokes something akin to deliberative citizenship within a particular family.

What conclusion should we draw from these considerations? In both the civic realm and in the personal or family realm there is a place for both deliberation and informed consumerism. The stance of deliberative citizenship sometimes plays a vital role, and justice, equity, and respect often require that a deliberative process and decisions that reflects the common good be made. Individuals should not always be allowed to impose their personal, self-interested consumer choices on others, either in the polity or in the family.

By the same token, the stance of informed consumerism is also legitimate and has its rightful place in genetic citizenship. Autonomy and the freedom to support policies that benefit your interests are longstanding values not only of the liberal representative democratic tradition, but also of the participatory democratic tradition. Democratic revolutions, in France, Russia, and China, that have made a concerted attempt to eliminate consumerism and self-interest from political (and even private) life have ended by betraying democracy and imposing frightful forms of dictatorial and

totalitarian rule. The problem is not the presence of self-interest in politics; the problem arises when only consumerism and self-interest are present. Hence the need to make a place for both the stance of consumerism and deliberation.

This has some practical importance in creating programs for genetic literacy and citizenship at the grassroots level. It is unrealistic to expect that the virtues of deliberation and an orientation toward the common good will be the natural starting point for most of the people who come to meetings and who are interested enough in the project to keep coming and to stay involved. By and large, the consumerist orientation is going to be very strong—if not dominant—at the grassroots level, at least at the outset. People will invest their time in such a process only if they feel that they will benefit from it and that it will serve their interest. This is particularly true of a minority community that may feel especially disenfranchised, marginalized, and alienated from the mainstream political system and civil society. There is no reason why they should feel otherwise. If genetic literacy and genetic citizenship do not serve the ends of self-interested, informed consumerism, then they have not been successful or worth the effort. They should lead to better personal health choices and to public policies that serve these particular interests in return for political support.

The lesson to be drawn for the deliberative side of citizenship is how to create its spark in the first place, and how to develop and reinforce it over time? What are the kinds of institutional settings and structures that will lead a group of people naturally and normally out of the consumerist stance and into a mode of deliberation? Out of monologue and into dialogue? It is hard to get anyone to participate in much of anything these days; significant barriers of time, mistrust, and hopelessness must be

overcome. But it is probably easier to motivate people when you are able reasonably to appeal to their interests than it is to promise them the very hard work of coming to think, see, and imagine in new ways. Yet, if I am correct in thinking that democracy needs a sense of the common good and dialogic interaction, this is precisely what democracy and genetic citizenship ask of us. Without deliberation, personal troubles will remain just that. The new genetics does not simply create personal troubles. It creates public problems.

III. Genetics and Social Ideologies: Dangerous Metaphors

No science or technology, least of all genetics, exists in a social, cultural, or historical vacuum. Like all human activities, science is a social practice, and its direction and application are influenced by social values.²⁶ The image of the scientist as a free floating genius or a detached intellectual is a myth. Even the most creative scientists are influenced by the values, outlooks, and ideologies of their culture and their age. The relationship between science and society is not simple, but it is clear that the influences run both ways. Social forces shape science and technology, but new scientific knowledge and new technological power also shape society and culture. Science shapes us individually, and it shapes us collectively and institutionally. Individuals react to this knowledge and technology and usually follow where it seems to lead—they view their bodies and their health differently, they view nature differently, they may view the rights and freedoms of others differently, and they may even find themselves spiritually affected in their life of religious faith. Families, governments, corporations, and churches also react to genetics and genetic technology—increasingly,

it seems, these institutions are allowing genetics to set their agendas and to define their deepest concerns. The social and cultural reception of genetics then—and not the true, intellectual appropriate understanding of genetics per se—is what is at issue here.

With scientific and clinical advances in genetics come tremendous opportunities for restoring health and alleviating suffering. But genetic science and technology also carry with them considerable ideological, social, and ethical concerns. The danger ultimately is that we, through a careless or ill-informed use of scientific concepts as metaphors, will come to think of ourselves and others in ways that hinder the establishment of right relationships among persons; right relationships, that is, as the American civic and constitutional tradition has come to understand them, including love, caring, service, mutual respect, dignity, protecting and promoting the rights of others, and fulfilling duties of justice.

For example, it is misleading to talk about a “gene for” a particular disease or behavior, or even to talk about a gene “causing” a specific condition. Very few human diseases are like Huntington’s Disease, the manifestation of an autosomal dominant gene, that has virtually 100 percent penetrance (everyone who carries the gene eventually will phenotypically manifest some of the symptoms of Huntington’s Disease). Hence very few genetic tests will reveal an unequivocal forecast that symptomatic disease will definitely occur in the person’s future. Far more common is the situation in which genes and genetic tests warrant only talking about susceptibility, probability, and risk, not causation, determinism, inevitability, or fate. A biochemical formation on one’s genome is neither a necessary nor a sufficient condition of manifesting most serious diseases; sometimes our knowledge is such that a genetic

component to the risk for a particular disease can be identified, but the actual risk or probability that one will experience disease is a function of the interaction between one's genetically guided biochemistry and one's environment. What is manifested at the level of our phenotype—our bodies and our experience—is brought about, almost always, by the interaction of our genes and our environment, whether that be the environment within the cell or the ecosystem outside the body that exposes the body over time to a multitude of biologically significant influences and affects.

Note that this state of affairs does not exist because of the limitations on our current biological knowledge or science. It is not true that if we progress far enough in the science of genetics we will eventually discover the underlying genetic cause for diseases that are now thought to be products of a gene-environment interaction. This caution about genetic reductionism and simplistic accounts of how genes “cause” disease is inherent in the probabilistic nature of genetics as a science and in the very concepts of genetics and biochemistry. The biological, evolutionary function of genes is not to cause disease, or for that matter to cause health. DNA and its component genes are an evolutionary solution to the problem of ensuring phenotypic diversity in a population of organisms over time.²⁷ If some of these traits, some of this diversity, turns out to be deleterious to the health, behavior, or survival of a particular organism, that is not particularly significant from a biological point of view, however significant it might be for the individual.

How we speak about ourselves and one another does shape how we think and how we act. Systems of social ideas, including social judgments, sanctions, stereotypes, and prejudices, breed on science like mold in a forest. During the past century or so the

biological sciences especially have been fertile soil for the development of social ideologies and prejudices that were supposedly the logical implication of the science in question.²⁸ At its earlier (much less rigorous and sophisticated) stages, genetics was one of the most problematic of all scientific sources of ideology, and despite the great advances genetics has made in the last fifty years, and especially the last fifteen years, we still have no reason for complacency.

Genetic science has not been developed primarily to assist in the task of clinical medicine, which is concerned with the health and medical treatment of an individual. It has a broader and different scientific and explanatory purpose. If the knowledge gained by genetic science can be pressed into the service of human clinical medicine—and it surely can—we must nonetheless be careful in the way we import the basic concepts of genetics into our medical vocabularies and ultimately into the vocabularies of our everyday lives.²⁹ In everyday life the broad issues of evolution and organic life overall, what genetics as a life science is primarily about, rarely figure prominently, but the experiences and capabilities of individuals—ourselves, our loved ones, and other members of society—certainly do. This is what tends to make us look to genetics for the answers to the wrong questions, not the biological questions but the social questions, or at least the social meaning of the biological questions. It is essential to remain mindful of this.

It is no less essential to recognize that the cultural and historical context of medicine will also have significant influence on the interpretation and application of genetic information in the clinical setting. Thus we can expect that genetics will reflect the cultural, religious, and historical perspectives and assumptions of those who apply

this information in medical research, prevention, and treatment of disease.³⁰ Because both health care practitioners and the lay public will accept the insights of genetics through their pre-existing intellectual and experiential frameworks of health and illness, it is important to understand the prevailing views of medicine and disease in our society and the ethical tensions that they already embody.

Genetic Determinism and Reductionism

One of the most important components in the social, cultural, and intellectual milieu of the United States is the fact that advances in genetics during the past few years have been presented to the public using metaphors and language that generally convey the idea that DNA determines (determinism) and explains (reductionism) the rest of our biological functioning.³¹ These notions must be called into question and discussed in deliberative forums.

The following considerations may assist in those deliberations. While logically distinct, the notions of genetic determinism and reductionism are often linked in popular thinking and mutually reinforce one another. Determinism is an “ontological” claim, a claim about the nature of reality. Reductionism is an “epistemological” claim, a claim about how reality is to be known. Determinism is the view that each of our choices and ultimately our entire life course is determined by our genes. From this perspective a human life is simply the inexorable playing out of the genes that are found in the fertilized egg. The success of modern scientific and technological progress have encouraged many people to believe that humans ultimately are “nothing but” sophisticated machines constructed from and determined by the laws of bio-chemistry.

A full analysis of these issues cannot be undertaken here, but the outline of an answer is clear enough. One can accept the notion that all organic functions are affected by our genetic constitution, but reject the view that genes determine human health and behavior and the view that the explanation for a person's health and behavior ultimately resides in his or her genes. For its part, reductionism is flawed in two ways. First, it ignores the power of what the biologists call phenotype. From its first instants of existence, the human zygote is interacting with its environment, beginning with the uterus and continuing on after birth through the natural and social environment in which a baby lives. From childhood through old age, biological and psychological development is shaped by the particulars of the surrounding world. Genes continue to matter, but they are not the only determinants of thought and action.

Many large genetic epidemiological studies have shown that genetic differences do indeed influence a wide variety of human traits—physical and physiological traits such as stature, body weight, blood pressure or heart function, and are correlated with a range of behavioral traits. However, it is a grave mistake to assume that genes are the only, or even the greatest, part of the story of human differences.

Moreover, it is one thing to demonstrate that genes and/or environmental effects contribute to particular human differences, but it is quite another to identify the specific genes or environments that create such phenotypic differences. This identification is difficult for several reasons. The number of genes and environmental factors influencing the expression of a disease may be very large, with each contributing only a very small part of the variation we observe. Complex traits are affected by large numbers of individual genetic and environmental factors whose individual effects are

too small to stand out against the noise created by all the others. Although the human genome is now thought to contain only some 30,000 genes, the number of possible combinations of differences exceeds the number of humans who have ever lived. The interaction among genetic differences makes it difficult to predict how combinations of genes behave simply from knowing what each gene does in isolation. Thus merely reading the genetic code of an individual may not allow us to predict much about the person with any degree of certainty. The pathways between the genetic code and any particular human trait are numerous, long and interwoven.

Most importantly, the organism may not simply be the sum of its genetic and environmental influences. Humans are not passive recipients of their genetic code; humans act. Their genes affect their interactions with the physical and social world around them, and those worlds are changed as a result of their actions. The result is a changed environment that affects genetics over time. Science itself is but one of the astonishing ways in which humans interact with one another and the world around them. These human actions are limited or empowered by biological, social and economic forces. They are actions of response given meaning by the way that humans interpret them to themselves and each other. Sorting out the relative power of the various determinants of human action, and the reach of human initiative, is a difficult task; although science has made some progress, the wealth of possible modes of analysis reflect a human person who is richly textured in ways that belie genetic determinism and reductionism, just as they belie older forms of historical, economic, or sociological determinism. Valid knowledge of human behavior need not be—in truth, cannot be—reductionistic in form. Explanation and understanding in the human

sciences must be multi-dimensional and contextual in its logical form, not hierarchical and deductively reductionistic.³²

Genetic determinism and reductionism, therefore, are mistaken because they oversimplify genetics, ignore the power of environmental factors, and fail to take account of the human power to interpret, initiate and act on the basis of purposes and reasons.³³ Everything we do is shaped in some way by our genetic make-up; very few things we do are entirely so determined. We have some choice about how we respond to the genetic features that we and other persons have received. Thus, far from absolving us of responsibility, modern genetics extends the scope of responsibility by expanding the possible terrain of choice.

Eugenics and the Social Construction of Disease

Few elements of social ideology are more powerful than those having to do with human reproduction, intergenerational relations, and the identity of a society over time.³⁴ Indeed, since the domestication of plants and animals many thousands of years ago, human beings have no doubt been attentive to the similarities between the traits of one generation and the next. Long before there was any understanding of the genetic mechanisms of inheritance, the manipulation of inheritance on the basis of phenotypic information through selective breeding and the killing of undesirable offspring is a practice that has been a cornerstone of human civilization. That is eugenics. With the notable exception of some utopian thinkers, such as Plato, however, eugenics has not figured importantly in social theory much until the nineteenth century.

The pervasive intellectual interest in evolutionary theory and Darwinian thought, coupled with important strides in agriculture that would soon lead to the contemporary science of genetics, made the period from roughly 1850 to 1950 a particularly fecund period for eugenic theory. And it is perhaps no accident that the most enthusiastic of the eugenicists during this period, such as Francis Galton, J.B.S. Haldane, and J.D. Bernal were impressed by plant genetics and thought to transfer their findings and techniques from plant and animal populations to human societies.

For such radical reformers with a powerful vision of humanity freed from suffering or liberated to achieve new physical or intellectual heights, the cultural and religious impediments to coercive measures for controlled human breeding, forced sterilization, infanticide, and euthanasia seemed like outmoded prejudices and superstitions standing in the way of progress. This characterization may be something of an exaggeration, but it is important to make the point that the older types of euthanasia were not primarily fueled by racism, sadism, or hate; the contemporary association in our minds of eugenics with Nazi fanaticism tends to make us lose sight of that. The eugenics movement came largely from scientists who were humanists, devotedly religious reformers, or otherwise driven by an aversion toward human suffering, a powerful desire to eliminate it, and a vision of human progress and improvement. In a word, eugenics has been fueled by motivations that most of us would readily embrace or applaud if presented to us in a different guise. That is why it is so dangerous.

Today, voluntary, individualistic and clinical uses of genetics are the watchword, and anything else is rarely even discussed. But with pre-natal genetic testing even now,

and in the future with pre-implantation genetic diagnosis in the context of IVF and with endeavors like pharmacogenomics having to do once more with population genetics (or public health genetics), then if the eugenic temptation enters polite social thinking once more it is unlikely to be wearing a brown shirt or jackboots.³⁵

If any form of eugenics remains socially acceptable, it is negative eugenics, the attempt to cure or eliminate the underlying genetic source of terrible diseases. (Positive eugenics, the attempt to improve or enhance the genetic traits of a population or an individual, is now widely rejected, or is at least considerably more controversial.) But even the goal of negative eugenics is much more complex and problematic than it is in the context of say infectious diseases such as polio or smallpox.

Both the diagnosis of health problems and the definition of appropriate prevention or treatment are based in a complex understanding of normal and abnormal human states and behaviors. Most societies understand health and illness in terms of a spectrum of normal physical forms and functions. However, such norms and deviations from them may be defined differently over time and from one culture to another. While deviation from recognized norms of physical form, bodily functions, and related behaviors are often understood in relation to health, in most societies there is significant overlap between health-related issues and religious, social, political, economic, moral, and even criminal considerations.

By categorizing certain forms of deviance as issues of health or religion or morality, a group implicitly identifies their causes, advocates certain roles and behaviors for affected individuals, and assigns particular experts to have authority over them. For example, the classification of drug addiction, infertility, and violence—all conditions

with one or more potential genetic link—as health problems presupposes a more significant role for medical technologies than social, economic, or religious intervention in addressing them.

The accepted description, diagnosis, and etiology of human afflictions can vary greatly. This diversity is evident in the World Health Organization's (WHO) *International Classification of Diseases* (ICD), the world's authoritative catalogue of human maladies as understood by the medical experts of the world's cultures. Only about half of the ICD's entries are considered "real" diseases in Western medicine. The others, many of which are referred to by medical anthropologists as "culture-bound syndromes," typically reflect nonwestern worldviews that define human health in terms of systems of balance, social harmony, or spiritual purity. Conversely, some uncommon conditions associated with a genetic mutation, such as congenital deafness or extremely short stature, may not be interpreted or experienced as medical conditions by those who are affected by them.

Because the manifestation of disease varies with culture and environment, one of the more difficult issues in diagnosis is determining which signs and symptoms define the presence of disease. In genetic diagnosis this question is particularly difficult. As the ICD reflects, the essential physical components of a disease and the relative importance of particular symptoms may be interpreted radically different ways in different venues, both as a function of cultural and moral values and as a function of anatomical and physiological differences among populations.

Conceptually, however, whether the presence (or absence) of a recognized genetic marker constitutes a disease in itself further complicates this issue. The

diagnostic meaning of a genetic mutation or abnormality without accompanying dismorphology or dysfunction is a scientific, as well as ethical, question of real significance. From what is known today, it can easily be concluded that even the healthiest human being has genetic anomalies linked to disease. Thus interpreting genetic anomaly itself as the essence of any disorder, irrespective of other symptoms, makes everyone “sick” or “diseased” all of the time. If society, or the professional agents of society such as physicians and genetic counselors, classify a person as having a disease, then very often the person will begin to behave in socially sanctioned, disease-appropriate ways. To have a disease is not just to have a set of symptoms that is personally limiting, it is also to have a social identity.³⁶

Moreover, while scientific medicine defines the causal mechanisms of disease in biological terms, in American society most people also interpret illness in moral terms.³⁷ In many religious traditions illness is often linked to personal moral transgression, sin, impurity, or a lack of faith. Conceptualizing a problem as medical can be beneficial to individuals and society in that it may reduce or eliminate the shame associated with some forms of deviance that historically have been considered to be moral failings. As we contemplate democratic forum opportunities for the development of genetic literacy and the exercise of citizenship in a pluralistic, multi-cultural society, it is important to be aware of the fact that some of the most basic assumptions built into the cultural narrative we have constructed around genetics will be unacceptable to other cultural and religious perspectives. Genetic information will be assimilated into these perspectives in different ways, and the predictable result, as genetics becomes more widely known and discussed, will be a conflict of interpretations in which there may be

agreement on the scientific facts, but none on the medical, cultural, or moral meaning of those facts.

Many normative concepts related to health and illness vary within and among cultural groups, largely due to both their differing social expectations and their culturally constructed responses to illness. Moreover, the experience and expression of biologically defined disease can differ significantly across cultures, even in industrialized nations that accept a common biomedical science. Today researchers are increasingly attentive to variability in the rates and presentation of many diseases across subgroups of the U.S. population, and the causes of such variability are not well understood. Describing different populations' and subgroups' experience of disease requires biological norms against which to define and measure health and illness. Identifying such norms raises ethical considerations as well as scientific questions.

The next phase of the Human Genome Project will be to systematically investigate the nature and significance of different groupings of genetic morphology in large populations. Haplotype mapping, as it is being called, aims to determine the common patterns of DNA sequence variation in the human genome, by characterizing sequence variation, the frequency of those variations and correlations between them, in DNA samples from populations with ancestry from parts of Africa, Asia and Europe. Already these groups are being referred by some researchers as "races," although seemingly without historical or anthropological awareness of the implications of this choice of term. One reason this type of research is important is that it could assist in the development of a new generation of pharmaceuticals tailored, if not to specific individuals, then at least to members of a genetically similar groups of people.

So understood, the motivation behind this kind of research appears beneficial and benign, although even here there lurk some difficult future issues of distributive justice concerning whose group and what part of the world will receive equitable treatment and which won't. Moreover, within a given culture, groups that may show themselves to be collectively less susceptible to the diseases that the culture considers significant may be set up as the healthy or superior group, and vice versa. History cautions that the best scientific efforts to describe such differences objectively may be undermined by social and religious views of difference and its moral meaning. In describing conditions that we now associate with poverty rather than genetic make-up, older proponents of eugenics in both Europe and North America typically attributed the health and social problems of immigrants and people of color to their supposedly flawed genetic heritage. Today potentially racist perspectives may influence genetic findings and interpretations of difference simply because of their subtle persistence in the theoretical frameworks and methodologies of past generations of researchers.

As a consequence of the effort to understand the meaning of racial difference, the very meaning of race as a category has been called into question. Increasingly, geneticists confirm that the genetic differences among socially constructed racial groups are negligible, and epidemiologists argue that individuals are often assigned arbitrarily to racial categories that are inconsistently defined and interpreted. Nonetheless, geographic and migratory history identification as a social category may be an important marker of health-related behavioral and environmental considerations that affect genetic and other physical characteristics. Replacing racial links to genetic connections, such as high blood pressure and heart disease, will require much more

knowledge about the interaction of genes, behavior, and the environment. It is also likely to require a greater willingness to examine the cultural and environmental origins of health-related behaviors.

The Social Face of Technology

The role of technology in American thought is the story of an enduring love/hate relationship. On the one hand, technology has always been seen as the engine of change and as the principal threat to settled ways of life, a kind of Old World corrupting import into the pristine beauty of the garden of the New World. At the same time, technology is perceived as the vehicle of progress and freedom. There is no period of technological innovation that does not have its prophets of salvation and its prophets of doom. Perhaps the opponents of technological innovation of a particular sort fight so hard to keep a technology from being introduced because they share the general American assumption that technology cannot be reversed. Once the genie is out of the bottle, the typical cliché holds, there is no putting it back. But love it or hate it, technology is never far from our thoughts. And for each technology that will ruin us, there usually an alternative that will save us, and the alternative is rarely to return to a pre-technological condition. The alternative is some other form of technology.³⁸

In addition to its irreversibility, there are several other basic cultural assumptions that Americans tend to make about technology that have a bearing on genetics.

First, there is a kind of pre-reflective belief in the technological imperative. If something can be done, it will be done. There are some looming and interesting counterexamples, if one thinks about it. One is the use of atomic and thermonuclear

nuclear weapons. Another is the rather rapid demise of the space exploration program after the moon landings. Another is the stagnation of the nuclear power industry after initial predictions that hundreds of plants would spring up and replace fossil fuels by now. Nonetheless, the technological imperative does seem to hold up more often than not, and when the social harm is not obvious or hard to define and when there is enough money to be made, it seems to be true. Of course, the fallacy of this notion is that technology is somehow outside the realm of human agency and choice altogether. This may be true at the individual level, but it is not true at the political or collective level.

A second assumption about technology is that it automatically expands choice. After all no one is absolutely forced to use it. You can turn off the computer or the television set. You can live in a compact city and ride a bike, like they do in Amsterdam. But if you do chose to use it, the new technology almost by definition gives you more options that you had before. You don't have to know the gender of your unborn child, but you can find out if you want to. You don't have to know if your fetus has trisomy 21 (Down syndrome), but you can find out before birth or even before it is practically too late to terminate the pregnancy. There are several interesting twists here. One fallacy of this notion is that it takes a very individualistic and unrealistic view of the nature of choice and deliberation and underplays the social and cultural pressures at work inside the mind of the chooser. Another aspect of irony here is that by assuming something to be opened up by technology as a choice, that becomes a self-fulfilling cultural notion because it subsequently is treated by others as a deliberate choice rather than as an unfortunate blow of fate. Before prenatal genetic tests, if you had a child with extreme and special needs, you could count upon some measure of social sympathy and

support. But now, it may seem to some like a deliberate act on the part of the parents (who decided to forgo the test) and therefore somehow, their fault; or at least their responsibility. In this way technology feeds upon a myth of social atomism but then turns that atomism into a lived reality in social practice.

Certainly technology gives humankind the possibility to do things that were never before possible. In the case of the new genetics, it has given us new and expanded biological information about our own bodies; in the future it may even give the new ways to treat, cure, control, and alleviate diseases that are now chronic, incurable, degenerative and devastating. Still, while technology expands choices in some ways, it limits it in others. Sometimes it limits choice directly by forcing decisions on us that we would not have to face if we did not have the information technology provides. Who is really free to forgo the test for Down syndrome or worse except those who have already made up their mind and made their choice.³⁹ For those for whom choice is still an open question and life possibility, the availability of the test offers them no choice but to take it. And sometimes technology limits choice indirectly by setting up social situations, expectations, and pressures that individuals and families find virtually impossible to resist.

Most subtly still, we internalize the imperatives and expectations of technology as we live in modern society, and most of us do this without realizing it. In a medical context, healthy or normal conditions are not tested for. The very existence of the genetic testing technology already rests upon a definition of a particular impairment as a disease or disability. Tests showing susceptibility to certain environmental exposures lead the person to seek certain kinds of employment but not others; tests showing carrier

status lead people to make certain marriage and reproductive choices but not others; the power of the technology to define who you are, what you are, what your life possibilities are, and what limits you should place on yourself is a phenomenon that the social ideology of technology as an expander of choice and freedom obscures.

A third assumption is that technology is simply a tool or a group of tools or machines. In other words, we understand technology in terms of its surface physical instrumentation. A more adequate understanding of technology is as a complex structure of information, scientific and engineering knowledge, instrumentation, authority, and social relations, the totality of which adds up to a structure of power over nature and over other human beings. Understood as mere tools, it is hard to see how technology could not be neutral. “It is not the gun that kills, but the gunman.” But understood as a structure of power and as a particular, selective structure of relationships among persons—a structure that permits some forms of thought, practice, and interaction and impedes others—then it is not so far fetched to ask about the moral valance of technology.⁴⁰

As an illustration of these general points, consider the technologies of genetic testing. With the identification of more genes and markers and the development of multiplex methods, genetic testing is becoming more and more widespread and will continue to grow. Another example is newborn genetic screening mentioned earlier.

The practical and ethical uncertainty surrounding genetic test results has been a problem since such tests were first developed. Many of the genetic tests currently available today began being used in clinical settings well before their use was understood in the research setting. This phenomenon is not unique to genetics. Medical

practice in the United States is often shaped by the technological imperative. Diagnostic technologies are particularly appealing to U.S. physicians and patients, and nowhere is the technological imperative and the American love of medical technology more apparent than in the use of diagnostic testing and screening.

Much of the U.S. dedication to medical research, and in particular to genetic research, stems from the belief that medical knowledge gives us power over disease and enhances our ability to control nature and forestall death. Diagnostic tests are appealing because they appear to resolve medical uncertainty about the best course of action in a given situation. However, because diagnostic information is so highly valued by both patients and health professionals new diagnostic technology often diffuses widely before the meaning, ramifications, or appropriate use of its results are clear. Many tests' predictive ability and the certainty that they offer are overestimated. All diagnostic tests are subject to limits of sensitivity and specificity that may create a false sense of certainty, either positive or negative. If a test's sensitivity and specificity are not well defined, it will not be possible to discern the meaning of either positive and negative test results.

This problem has occurred with a number of genetic tests that were linking developed by linking particular mutations to the presence of symptoms among members of high-risk families. Because the link between the mutation and symptoms for members of the general population remains unknown, many tests for the presence of disease-linked genes cannot predict whether an individual who tests positive will ever develop symptoms. This limitation has been a particular issue for the BRCA₁ test,

which was still recommended only for research use when it began to be requested by women thought to be at high risk for breast cancer.

Because diagnostic information typically serves as the basis for medical intervention, the availability of test results may imply a need to take action irrespective of the test's appropriateness. If diagnosis is possible when effective treatment or adequate management are not, diagnostic knowledge can create a sense of helplessness for both patients and practitioners. In some instances test results may actually limit medical options in that the simple availability of diagnostic information may compel patients and clinicians to take active steps to intervene where "watchful waiting" may be safer or more effective.

The availability of diagnostic information, however complete or accurate, and the accompanying threat of diagnostic labeling raise the issue of who should have access to the results of an individual's or family's genetic testing. Genetic diagnostic technology has the potential to change the relationship between spouses and prospective spouses by introducing new information about their individual and joint health risks and those of existing and potential children. Insurance companies have traditionally claimed the right to all of any insured's known health information in order to make a fair assessment of risks and rates. In an effort to rule out costly health risks from genetic disorders, insurers may place more weight on genetic diagnostic tests than the tests deserve because they are interested in reducing their uncertainty and its associated costs whenever possible. Employers, who often fund both health insurance and life insurance for their employees and who have certain duties to protect workers from potentially dangerous environmental exposures, may seek employees' genetic diagnostic

information in hopes of reducing their costs and increasing their productivity. Even after defining legitimate access to an individual's or family's genetic information, the use of computerized medical record systems and databases in the management of such diagnostic information makes possible wider access to confidential information, and poses a variety of ethical questions about personal privacy.

IV. The Process of Moral Learning in Genetic Citizenship

The current situation of genetic literacy presents two competing bodies of information, imagery, and ideology struggling for the attention of the American public. One is largely provided by the scientific elite, various interest groups, and commercial and corporate enterprises that have a vested interest in the promotion and use of genetically based biotechnology. The other takes the form of grassroots, community based, consumer-based, and public health oriented programs of education, counseling, information, focus groups, and community forums.

These two sources of understanding offer very different kinds of genetic literacy. The first, while not always intentional, tends to be uncritical and to traffick in metaphors and simplistic claims that are harmful and misleading. It is, in my judgment, largely a source of genetic illiteracy. The second has the potential to produce a much more critical and thoughtful citizenry and social response to the promise and the danger of the new genetics. Its impact, thus far, has been very limited. It is inherently slower, more labor intensive, and often frustrating. The work of personal empowerment and civic renewal requires patience and staying power, which tend not to be the strong suit of most American institutions or funding sources.

In the American political system overall, power is located within the institutions and practices of representative democracy, not participatory democracy; organized lobbying and fund-raising among the affluent, not grassroots and community based activities; and in the appeal to consumerism and self-interest in the marketing of candidates, policies, and products, not in the appeal to judgments concerning the common good based on shared deliberation. This is somewhat less true at the local level than at the state and federal level, but it is at the state and federal levels that most of the significant policies and regulations affecting genetics and biotechnology are made.

Does this mean that the mass genetic literacy coming from commercial sponsors has the only chance of being effective, or that grassroots projects are pointless?

Not at all, for two reasons. First, although public policy concerning genetics is made through the mechanisms of representative democracy, representative democracy can and sometimes does function on the basis of grassroots democracy. Adequate concern and mobilization at the grassroots level can have a significant impact on decisions made in representative bodies. Hence there is the possibility of a “bubble-up” effect growing out of community based efforts to promote genetic literacy and genetic citizenship.

Second, the biotechnology industry, and government officials who regulate and oversee it, is particularly sensitive to the ethical and cultural aspects of their activities and products and to societal reactions to them. Consider the success that grassroots and environmental groups have had in Europe creating public opposition to genetically modified foods, for example. In the United States, the intersection between genetics and human reproduction has received considerable attention, not based on concerns of

consumerism, but based on deliberative values and religious concerns. This is reflected to some extent in recent debates that have taken place over matters such as human cloning, genetic discrimination, and individual privacy rights concerning genetic and other health related information.

As these debates have suggested, those communities that are well-informed and have shown their concerns to be well-thought out and based on deep and well-established community values, are the ones whose voices have been most effective. And they have been heard. The fact is, the promotion of genetic citizenship is the best hope we have for wisely and prudently using the new genetics. Allowing the marketplace unguided to determine the course of this technology and its transfer into consumer products will promote neither public health nor cultural civility. Outright bans on new scientific research and development are unlikely in the United States, and would in any case forgo important medical advances and the relief of widespread human suffering. The middle ground is the only sensible path, and it is the path of genetic citizenship.

A final question: will the face of genetic citizenship that is consumerism and self-interest be sufficient to take advantage of this possibility? I believe that it will not. This is key for initiatives such as the HRSA/March of Dimes Genetic Literacy project. It is important to move beyond consumerism to a capacity for deliberative judgment and an understanding of citizenship as the discovery and promotion of justice and the common good. The appeal of consumerism may bring people into the process, but exposure to a carefully structured process of deliberation about the effects of genetics on our lives will be what trans-forms (as well as in-forms) people. Deliberation does not occur spontaneously, but it can be built up from the common sense, common

knowledge, and story telling that does occur naturally in virtually all cultural and ethnic communities. People do not have to be scientists to understand what they need to understand about the new genetics. Factual information and basic principles can be conveyed in linguistically and culturally appropriate ways. But it is the meaning and value implications of the new genetics—the interpretation of the genetic facts for the shaping of the civic and moral imagination—that requires the shift from monologue to dialogue and from “I-thinking” to “We-thinking.”

Notes

¹ Cf. Philip Kitcher, *The Lives to Come: The Genetic Revolution and Human Possibilities* (New York: Simon and Schuster, 1996).

² Bruce Jennings, "The Liberalism of Life: Bioethics in the Face of Biopower," *Raritan* 23:4 (Spring 2003), 132-146.

³ Kevin Phillips, *Wealth and Democracy: A Political History of the American Rich* (New York: Broadway Books, 2002), 108-70.

⁴ Celeste Conduit, *The Meanings of the Gene: Public Debates about Human Heredity*, (Madison: University of Wisconsin Press, 1999).

⁵ I am grateful to Rayna Rapp for sharing with me some of her unpublished work in progress on the notion of genetic citizenship. Cf. Deborah Heath, Rayna Rapp, Karen-Sue Taussig, "Genetic Citizenship," in David Nugent and Joan Vincent, eds. *Companion to the Handbook of Political Anthropology* (Oxford: Blackwell, forthcoming). They describe genetic citizenship as "a shifting social terrain on which new embodied disciplines and representations of rights and responsibilities are emerging," and as "activism at the intersection between embodied experience with genetic difference and legislative politics".

⁶ Amartya Sen, *Development as Freedom* (New York: Alfred A. Knopf, 1999); Martha C. Nussbaum, *Women and Human Development: The Capabilities Approach* (Cambridge: Cambridge University Press, 2000).

⁷ Rogers Smith, *Civic Ideals: Conflicting Visions of Citizenship in U.S. History* (New Haven: Yale University Press, 1997); Ronald Beiner, ed. *Theorizing Citizenship* (Albany: State University of New York Press, 1995); Michael Schudson, *The Good Citizen: A History of American Civic Life* (Cambridge, MA: Harvard University Press, 1998).

⁸ Robert D. Putnam, *Bowling Alone: The Collapse and Revival of American Community* (New York: Simon and Schuster, 2000); and Stephen Baron, John Field, and Tom Schuller, eds. *Social Capital: Critical Perspectives* (New York: Oxford University Press, 2000).

⁹ For an overview of civic renewal projects nationwide, focusing on healthcare and other issues, see Carmen Sirianni and Lewis Friedland, *Civic Innovation in America* (Berkeley: University of California Press, 2001). See also J.L. Forster, "A Communitarian Ethical Model for Public Health Interventions: An Alternation to Individual Behavior Change Strategies," *Journal of Public Health Policy* 1982; S. R. Arnstein, "A Ladder of Citizen Participation," *Journal of the American Institute of Planners* 35 (4) 1969; Michael Garland, "Experts and the Public: A Needed Partnership

for Genetic Policy, *Public Understanding of Science* 8: 3 (1999), 241-254. Also important in discussing the application of deliberative democratic theory to health policy are several articles by Leonard Fleck, including: "Just Health care Rationing: A Democratic Decisionmaking Approach," *University of Pennsylvania Law Review* 140 (May 1992); 1597-1636; "Just Caring: Oregon, Health Care Rationing, and Informed Democratic Deliberation," *Journal of Medicine and Philosophy* 19 (1994); 367-88; *Genome Technology and Reproduction: Values and Public Policy. A Report on the Fall Community Dialogues*, (East Lansing: Michigan State University, 1996); and *Genome Technology and Reproduction: Values and Public Policy. A Report on the Spring Community Dialogues*, (East Lansing: Michigan State University, 1997).

¹⁰ Cf. Committee for the Study of the Future of Public Health, Institute of Medicine, *The Future of Public Health* (Washington, DC: National Academy Press, 1988).

¹¹ Michael Marmot and Richard G. Wilkinson, eds. *Social Determinants of Health* (Oxford: Oxford University Press, 1999); Ichiro Kawachi, Bruce P. Kennedy, and R.G. Wilkinson, eds., *The Society and Population Health Reader*, Vol. 1 *Income Inequality and Health* (New York: New Press, 1999); Adam Wagstaff and Eddy van Doorslaer, "Income Inequality and Health: What Does the Literature Tell Us?" *21 Annual Review of Public Health*, (2000), 543-567; and Norman Daniels, Bruce P. Kennedy, and Ichiro Kawachi, "Why Justice is Good for Our Health: The Social Determinants of Health Inequalities," *Daedalus* 128: 4 (Fall 1999): 215-251.

¹² Jonathan Mann, "Medicine and Public Health, Ethics and Human Rights," *Hastings Center Report* (May-June 1997), 6-13.; Richard G. Wilkinson, *Unhealthy Societies: The Afflictions of Inequality* (London: Routledge, 1996).

¹³ J. Roland Pennock, *Democratic Political Theory* (Princeton: Princeton University Press, 1979).

¹⁴ John Dryzek, *Deliberative Democracy and Beyond* (New York: Oxford, 2000). For additional works on deliberative democracy see below note 19.

¹⁵ Some material in this section is drawn from Bruce Jennings and Elizabeth Heitman, "Genetics and Genetic Technology in Social Context," in David H. Smith and Cynthia B. Cohen, eds. *A Christian Response to the New Genetics* (Landover, MD: Roman and Littlefield, 2003), pp. 131-146.

¹⁶ C. W. Mills, *The Sociological Imagination* (New York: Oxford University Press, 1959).

¹⁷ David Matthews, *Politics for People: Finding a Responsible Public Voice* (Urbana: University of Illinois Press, 1994).

¹⁸ Daniel Yankelovich, *The Magic of Dialogue* (New York: Simon and Schuster, 1999).

¹⁹ For a broad contrast between representative and participatory or deliberative democracy see Benjamin Barber, *Strong Democracy: Participatory Politics for a New Age* (Berkeley: University of California Press, 1994).

²⁰ Rogers Smith, *Civic Ideals*, pp. 13-40; 470-506.

²¹ John Dryzek, *Deliberative Democracy and Beyond*; James Bohman, *Public Deliberation: Pluralism, Complexity and Democracy* (Cambridge: MIT Press, 1996); John Dryzek, *Discursive Democracy: Politics, Policy and Political Science* (New York: Cambridge University press, 1990); James Fishkin, *Democracy and Deliberation: New Directions for Democratic Reforms* (New Haven: Yale University Press, 1991) and *The Voice of the People: Public Opinion and Democracy* (New Haven: Yale University Press, 1995); Amy Gutmann and Dennis Thompson, *Democracy and Disagreement* (Cambridge: Harvard University Press, 1996). Jon Elster, ed. *Deliberative Democracy* (New York: Cambridge University Press, 1998).

²² Robert Putnam, *Bowling Alone*, passim..

²³ I am currently collaborating with Andrea Bonnicksen of Northern Illinois University on a study of newborn screening policy making in relation to genetic citizenship and deliberative democracy. This work is being done in conjunction with The Hastings Center Project on Decision-making for Newborn Genetic Screening 2003-2004 funded by the National Human Genome Research Institute, ELSI Program.

²⁴ Cf. Robert Veatch, *A Theory of Medical Ethics* (New York: Basic Books, 1981); William F. May, *The Physician's Covenant: Images of the Healer in Medical Ethics* 2nd ed. (Lexington, KY: Westminster John Know Press, 2000.); and Eric Cassell, *The Healer's Art* (1976) Cambridge, MA: MIT Press, 1985.

²⁵ For examples and issues of personal freedom and justified coercion in public health contexts see Lawrence O. Gostin, *Public Health Law: Power, Duty, Restraint* (Berkeley: University of California Press, 2001).

²⁶ William W. Lowrance, *Modern Science and Human Values*. (NY: Oxford University Press, 1985).

²⁷ Stephen Jay Gould, *The Structure of Evolutionary Theory* (Cambridge, Mass: Harvard University Press, 2002).

²⁸ Daniel J. Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity* (Cambridge, MA: Harvard University Press, 1995).

²⁹ Dorothy Nelkin and M. Susan Lindee, *The DNA Mystique: The Gene as a Cultural Icon* (New York: W.H. Freeman, 1995); Celeste Condit, *The Meanings of the Gene: Public Debates about Human Heredity*.

³⁰ Jon Turney, *Frankenstein's Footsteps: Science, Genetics, and Popular Culture* (New Haven: Yale University Press, 1998).

³¹ Cf. Nelkin and Lindee, *The DNA Mystique*.

³² This way of thinking owes much, I believe, to the work of George Herbert Mead, L.S. Vygotski, and Ludwig Wittgenstein. I have been particularly influenced in my own thinking by the more recent work in this tradition. See, Rom Harré, *The Singular Self*, (London: Sage Publications, 1998) and Rom Harré and Grant Gillett, *The Discursive Mind*, (Thousand Oakes, CA: Sage Publications, 1994).

³³ Compare the discussion in Allan Buchanan, Dan Brock, Norman Daniels, and Daniel Wikler, *From Chance to Choice* (Cambridge: Cambridge University Press, 2000), pp. 24-27; 347-370.

³⁴ See generally, Kevles, *In the Name of Eugenics* and Troy Duster, *Backdoor to Eugenics* (London: Routledge, 1990).

³⁵ Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth* (Boston: Beacon Press, 1999).

³⁶ Barbara K. Rothman, *The Book of Life: A Personal and Ethical Guide to Race, Normality, and the Implications of the Human Genome Project* (Boston: Beacon Press, 2001).

³⁷ James A. Morone, *Hellfire Nation: The Politics of Sin in American History* (New Haven: Yale University Press, 2003).

³⁸ Landon Winner, *Autonomous Technology* (Cambridge, Mass: MIT Press, 1977).

³⁹ See the various perspectives on this question represented in Erik Parens and Adrienne Asch, eds. *Prenatal Testing and Disability Rights* (Washington, DC: Georgetown University Press, 2000). The perspective offered in this section are drawn from my own contribution to this volume, "Technology and the Genetic Imaginary: Prenatal Testing and the Construction of Disability," pp. 124-144.

⁴⁰ Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America* (NY: Routledge, 1999). Compare, John Robertson, *Children of Choice: Freedom and the New Reproductive Technologies* (Princeton: Princeton University Press, 1994).